

*A Family-Directed Approach to Brain Injury in
Community Settings: The Development of a Positive Behaviour
Support (PBS) Program*

By

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A Family-Directed Approach to Brain Injury in Community Settings:
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ABSTRACT

Background and Aims: Family members often become the primary caregiver for individuals following an acquired brain injury (ABI), and have reported behavioural support as the highest unmet need. Behaviours of concern (BOC) are a leading concern in brain injury rehabilitation, with service providers unable to meet the neurobehavioural support demands in community settings. As such, there is a need to develop and evaluate supports that can be successfully implemented by everyday support people.

The overarching aim of this thesis was to examine how to enhance the capability of family caregivers to manage BOC presented by relatives with ABI in community settings. Family members are ideally positioned to be active members of the rehabilitation team as they are emotionally invested in the individual's progress, and can provide important insight to optimise outcomes. Families have also reported a desire for further practical hands-on collaboration with healthcare professionals.

Methods: A multi-phase mixed methods design was utilised, comprising four research studies. Study one was a systematic review, which examined the evidence supporting family involvement within behavioural interventions for relatives with ABI in community settings. In study two, a Delphi was conducted, which sought feedback from key stakeholders (n=11) regarding current and best practices, and key intervention components considered important in a program aimed at supporting

family caregivers to manage BOC in relatives with ABI. Results from study one and two informed the design of a Family-Directed Behaviour Management (FDBM) program. The FDBM program, which is based on a Positive Behaviour Support framework, was developed to support family caregivers manage BOC following ABI in community settings. In study three, a pre-test post-test pilot (n=2) examined the (a) feasibility and (b) acceptability of the FDBM program and outcome measures utilised for further development. Multiple assessments were conducted pre and post intervention, including a three-month follow up, to collect information about the BOC, levels of support needs and psychosocial functioning of family caregivers, and levels of caregiver burden experienced. Quantitative measures utilised included the Overt Behaviour Scale (OBS), the Sydney Psychosocial Reintegration Scale (SPRS), the Care and Needs Scale (CANS) and the Caregiver Appraisal Scale (CAS). A purpose-designed survey was also used to collect data regarding the family members perceived confidence in managing BOC, and a frequency measure to record the occurrence of BOC. The acceptability of the FDBM program was evaluated using questionnaires and semi-structured interviews directly following the education phase and individualised sessions, and at follow-up. In the final study, a survey was conducted, in which an additional six caregivers were recruited to review the FDBM Education Workbook and provide feedback regarding its accessibility and helpfulness.

Results: The systematic review supported family involvement in behavioural interventions for relatives with ABI, however, it did not reveal any validated management approaches with an emphasis on family involvement, or specific recommendations to guide family caregivers in this process. Findings of the Delphi study suggested that families are not using commonly recommended strategies to

manage BOC. In addition, consensus was reached that there were only two service types in South Australia that were specific to supporting family caregivers with this issue.

Two participants completed the full FDBM pilot, during which they were trained to collect and analyse observation data, and implement and monitor strategies. Outcomes were measured over seven time points (pre, post and follow-up). Participants reported a reduction in frequency and intensity of BOC, high satisfaction with the program, and increased confidence in identifying strategies and responding to BOC. No meaningful changes in levels of caregiver burden were reported. The survey responses were positive, with a majority of families reporting the workbook as clearly presented, engaging and helpful.

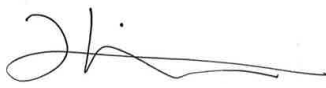
Conclusion: Results suggest that despite the significant time commitment, the FDBM program may be a feasible and acceptable approach to increasing the capability of family caregivers in managing BOC following ABI. Larger scale studies are now required to examine the program's effectiveness.

This multi-phase project has informed the development of a Family-Directed Approach to Brain injury (FAB) model, which provides a theoretical framework for supporting family caregivers as facilitators of change. The FAB model is based on principles of hope, family expertise, education/skill building, and family-directed intervention. With the current shift towards greater family collaboration, the FAB model defines potential active ingredients and provides a theoretical framework to guide treatment implementation. This model emphasises a focus on promoting family competence in supporting behavioural changes following ABI, rather than dependency on service systems.

Declaration

*A Family-Directed Approach to Brain Injury in Community Settings: The
Development of a Positive Behaviour Support (PBS) Program*

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university, and that to the best of my knowledge and belief it does not contain any material previously published or written by another person, except where due reference is made in the text.

Signed 

Ms. Alinka Fisher

Friday, 30th June 2017

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List of publications:

Fisher, A., Lennon, S, Bellon, M., & Lawn, S. (2015). Family involvement in behaviour management following acquired brain injury (ABI) in community settings: A systematic review. *Brain Injury, 29(6), 661-675.*

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Translation and Impact

Research grant:

- Based on the findings of this thesis, funding for a two-year research study (October 2017- September 2019) has been granted by the Lifetime Support Authority, Government of South Australia to examine the feasibility of the intervention program with a larger sample size (Bellon, Fisher, Lawn, Sohlberg & Douglas).

Resources under Development:

- The intervention workbook developed in this thesis is currently under development as an interactive online App to educate and support family members to understand behaviour change following ABI, and promote positive behaviours in relatives with ABI.
- The intervention workbook has also been translated into an educational pamphlet for nonspecialised support workers, titled 'Positive Behaviour Support (PBS) following Brain Injury: A Four-Step Beginner's Guide'. This educational resource is soon to be available online via the Department of Communities and Social Inclusion, Government of South Australia.

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List of Abbreviations

ABA	Applied Behaviour Analysis
ABC	Antecedent-Behaviour-Consequence
ABI	Acquired Brain Injury
AIHW	Australian Institute of Health and Welfare
BIRCH	Brain Injury Rehabilitation Community and Home
BIRU	Brain Injury Rehabilitation Unit
BOC	Behaviours of concern
DR	Differential Reinforcement
FDBM	Family-Directed Behaviour Management
NDIS	National Disability Insurance Scheme
NHMRC	National Health Medical Research Council
PBS	Positive Behaviour Support
PBIS	Positive Behaviour Intervention & Support
PBST	Positive Behaviour Support Team
RCT	Randomised Control Trial
SCED	Single-case experimental design
SSED	Single-subject experimental design
SABIRS	South Australian Brain Injury Rehabilitation Services
TBI	Traumatic Brain Injury

CHAPTER ONE

INTRODUCTION

...As the families introduced themselves... there was a sense of lost hope, isolation and fear. One mum said that she was constantly walking on eggshells, scared that the behaviour would trigger at any moment... and another feared going to bed at night. There was also an overwhelming sense that help could not be found... that no one had the time, and that there was nowhere to go.

An excerpt from the researcher's PhD journal, 2013

1.1 Introduction

Family members often become the primary caregiver for individuals following acquired brain injury (ABI), and have reported behaviours of concern displayed by relatives with ABI as the leading cause of distress for their family members (Anderson, Parmenter & Mok, 2002). In particular, information on how to manage behavioural changes has been identified as family caregivers' highest unmet need (Murray, Maslany, & Jeffery, 2006). The overarching aim of this thesis was to examine how to enhance the capability of family caregivers to manage behaviours of concern (BOC) presented by relatives with ABI in community settings. This chapter provides an introduction to this topic, including the significance and aims of this research, and the methods utilised. Each study in the multi-phase mixed-methods design are presented, together with the research questions they address.

1.2 Defining 'family caregivers'

A working definition of *caregiving* is the “unpaid provision of care to [an individual], including his or her self-care, activities of daily living, transportation and overall emotional support” (Klonoff, 2014, p. 1). Although this care is often provided by family members, others including friends and significant others may also function as caregivers (Collins & Swartz, 2011). Therefore, for the purpose of this thesis, ‘family caregivers’ and ‘family’ also relate to significant others who assume this role. Indeed, the meaning of ‘family’ has changed significantly over the past few decades, with increasing variations to the previously considered nuclear family, and

far greater diversity in the expectations of people's roles within a family (Prince, 2017).

1.3 Background and significance

The life of an individual and his or her family may change dramatically following an ABI (Braine, 2011; Turner et al., 2007), with families often forced to revise their philosophy and reorganise their everyday life (Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005). Family members often become the primary caregiver (Jumisko, Lexell, & Soederberg, 2007; McDermott & McDonnell, 2014), and in addition to coming to terms with the ABI, are left to face the challenges associated with behaviour changes with limited support (Braine, 2011; Murray et al., 2006; Turner et al., 2007). Indeed, family caregivers have reported behavioural issues to be the leading cause of distress, (Anderson et al., 2002; Marsh, Kersel, Havill, & Sleigh, 1998), and information on how to manage behavioural changes as their highest unmet need (Murray et al., 2006).

Research has identified a high occurrence (54%-60%) of behaviours of concern (BOC) among individuals with ABI (Ponsford et al., 2014; Sabaz et al., 2014). These changes will vary for each individual (Gelber & Callahan, 2010) and for many, will persist over time (Ponsford et al., 2014). These behaviours can manifest in a variety of ways, from physical and verbal aggression (Dyer, Bell, McCann, & Rauch, 2006; Tateno, Jorge, & Robinson, 2003) and sexually inappropriate behaviours (Simpson, Sabaz, & Daher, 2013), through to symptoms of mood disorders (Gould, Ponsford, & Spitz, 2014; Mathias & Coats, 1999), apathy

(Kant, Duffy, & Pivovarnik, 1998), and reduced social skills (Kersel, Marsh, Havill, & Sleigh, 2001). As a specific definition of behavioural issues remains elusive, the term ‘Behaviours of Concern (BOC)’ will be adopted throughout this thesis to refer to these conventional types of challenging behaviours, but also these cognitive changes and behavioural sequelae.

In addition to the significant impact BOC present for families, they are also a leading concern for service providers in brain injury rehabilitation (Lombard & Zafonte, 2005). The need for more community-based neurobehavioural support services is widely acknowledged (de Koning, Spikman, Coers, Schoenherr, & van der Naalt, 2015; Fisher, Bellon, Lawn, & Lennon, 2017a; Kitter & Sharman, 2015; Munce, Laan, Levy, Parsons, & Jaglal, 2014; Turner, Fleming, Ownsworth, & Cornwell, 2011). Furthermore, within the current financial climate, where resources are limited and length of inpatient stays are becoming shorter, there is a need to develop and evaluate supports that can be implemented by persons other than rehabilitation professionals (Braga, da Paz Júnior, & Ylvisaker, 2005; Sohlberg, Glang, & Todis, 1998; Sohlberg & Turkstra, 2011).

Increasing the capability of family members in this behavioural support role is a possible response; they are emotionally invested in the individual’s outcomes, and can provide important insight into his or her potential, and relevant supports to optimise outcomes (Degeneffe & Lee, 2015; Foster et al., 2012; also see Gagnon, Lin, & Stergiou-Kita, 2016). The importance of acknowledging and utilising family expertise in brain injury rehabilitation is widely recognised (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007; Gan, Gargaro, Brandys, Gerber, & Boschen, 2010). Furthermore, families have reported the importance of further practical hands-on

collaboration with health care professionals (Coco, Tossavainen, Jääskeläinen, & Turunen, 2011; Kuipers et al., 2014; Lefebvre & Levert, 2012).

Increasing families' capability to manage behavioural changes in relatives with ABI may be one way of addressing unmet support needs, and reducing dependency on the limited specialised services available. This is the focus of this thesis, which explores best practices in supporting family caregivers in this behavioural support role.

This issue has particular relevance in South Australia (SA), where it has been acknowledged that service providers are unable to meet the number of neurobehavioural support needs in community settings (Department of Health, 2012). In 2003, SA was reported to have the second highest prevalence of ABI within Australia, with 2.2% of the population (31,000) living with an ABI compared to 1.8% of the average Australian population (AIHW, 2007). Considering the high occurrence of BOC reported in individuals with ABI (Ponsford et al., 2014; Sabaz et al., 2014) and the impact of behavioural issues on the person's community reintegration and family wellbeing (Anderson et al., 2002; Anderson, Simpson, & Morey, 2013; Kelly & Parry, 2008), this presents a significant issue for many families within South Australian communities.

This thesis seeks to contribute to our understanding of this area by: examining best practices in supporting family caregivers to manage behavioural changes in relatives with ABI; shedding light on the current systems in South Australian community settings that support families with this issue, and identifying the service gaps; and, developing an informed behaviour support approach with an emphasis on family involvement. This research has implications for policy makers,

service managers, providers, and service users globally, who might make comparisons and establish the needs and opportunities for their own system of community supports for family caregivers following ABI.

1.4 Aims

The overarching aim of this thesis was to examine how to enhance the capability of family caregivers to manage BOC presented by relatives with ABI in community settings, and develop and evaluate a pilot intervention program that supports family caregivers in this role. In order to achieve this, four studies were conducted in a multi-phase mixed-methods research design, consisting of: (1) a systematic review; (2) a Delphi study; (3) a pilot; and (4) a survey study.

1.5 Multi-phase mixed-methods approach

This research adopted a multiphase mixed-methods design, consisting of a number of sequential ‘phases’ (or studies) which all advanced towards the core objective (Creswell & Plano Clark, 2011). These studies utilised a mixed-methods approach, in which elements of qualitative and quantitative approaches were combined (Johnson, Onwuegbuzie, & Turner, 2007). This approach emerged partially out of literature on triangulation (Johnson et al., 2007; Teddlie & Tashakkori, 2010), with the purpose of achieving breadth and corroboration across the research topic (Johnson et al., 2007).

Quantitative methods are concerned with establishing cause-effect relationships, which can be analysed using statistical procedures (Minichiello, Sullivan, Greenwood, & Axford, 2004). In contrast, qualitative methods are concerned with studying people's perceptions, views, intentions and logic of thinking (Patton, 2015). These research methods provide different perspectives, and were both seen as integral in this thesis, with the combination of both quantitative and qualitative data providing greater insight and a more complete understanding (analysis) of the research questions (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2010).

1.5.1 Paradigm worldview

There are philosophical assumptions that operate at a broad, abstract level which, in mixed methods, consist of a basic set of beliefs that guide inquiries. These assumptions may be described as 'world views', such as: (post)positivism; constructivism; participatory worldviews; and pragmatism. These worldviews differ in ontology (the nature of reality), epistemology (how we gain knowledge), axiology (the role values play in research), methodology (research protocol), and rhetorically (the language of research) (Creswell & Plano Clark, 2011).

This PhD project was influenced by pragmatism, which is generally considered the philosophical partner for the mixed methods approach (Denscombe, 2008). Pragmatism offers an epistemological justification and logic (a set of assumptions about knowledge and inquiry) that underpins the mixed methods approach (Johnson et al., 2007). It is a well-developed philosophy for integrating perspectives and approaches, distinguishing the approach from purely quantitative

approaches that are based on (post)positivism and from purely qualitative approaches that are based on interpretivism or constructivism (Creswell & Plano Clark, 2011; Johnson et al., 2007).

The current research project adopted a pragmatic stance, as it employed methods considered ‘best fit’ to the research objectives (Creswell & Plano Clark, 2011; Hanson, 2008), and valued the use of both objective and subjective knowledge (Tashakkori & Teddlie, 2003) in solving practical problems in the “real world” (Feilzer, 2010). Pragmatism ultimately brushes aside the quantitative/qualitative divide (Hanson, 2008) by placing the research question as the primary focus (rather than the method or underlying philosophical worldview) (Tashakkori & Teddlie, 2003).

According to O’Cathain, Murphy and Nicholl (2008), a ‘mixed methods’ approach may be utilised with the following intentions:

- a) Complementary – to reveal different perspectives contributing to a broader ‘picture’ of a particular issue.
- b) Development – where methods are aided by preceding studies, such as focus groups aiding the development of questionnaire items.
- c) Triangulation – when the findings of different methods are compared and consensus is reached.

While all three principles can be linked to this research project, the major reasons for adopting a mixed methods approach was to complement a broader understanding of the topic and to contribute to the development of the Family-Directed Behaviour Management (FDBM) program and recommendations for best

practice. The quantitative and qualitative methodologies utilised in this process will be outlined in the chapters presenting each study within the multi-phase design.

1.6 Research Questions

This thesis addressed the following research questions:

1. What is the evidence supporting family involvement within behavioural interventions for relatives with ABI in community settings?
2. What are the key features in the delivery of a program aimed at supporting family caregivers to manage behavioural changes in their relative with ABI?
3. What intervention components should be included in a program aimed to support families to manage behavioural changes in relatives with ABI?
4. What strategies are families currently using to manage BOC in relatives with ABI?
5. What South Australian services and supports are available to family caregivers that address the management of behavioural changes in relatives with ABI?

The findings of these research questions informed the development of a Family-Directed Behaviour Management (FDBM) program, which then addressed the following additional research question:

6. Is the FDBM program a (a) feasible and (b) acceptable intervention in supporting family caregivers to manage BOC following ABI in community settings?

These research questions were addressed by four studies within a multi-phase research design. An overview of the research methodology is briefly summarised below, specifying which research questions were addressed within the four studies.

1.7 Overview of Methodology

A pictorial presentation of the study sequence and their interrelationship is shown in Figure 1.1. Study one, a systematic review, examined family involvement in behavioural interventions for individuals with ABI (Fisher et al, 2015), and informed the preliminary development of the FDBM program. In study two, a Delphi process was utilised to (a) identify current and best practices in supporting family caregivers to manage BOC in community settings, and (b) gain feedback regarding best practices, content and delivery of the FDBM program. In study three, a pre-test post-test pilot study was conducted to examine the feasibility and acceptability of the FDBM program within community settings. In study four, family caregivers who did not participate in the FDBM pilot were independently recruited to complete a survey questionnaire regarding the accessibility and helpfulness of the purpose-developed

FDBM family education workbook, also designed as a stand-alone resource. The findings from all four studies then contributed to recommendations for best practice. Each study and the research questions they address are presented in Table 1.1.

Figure 1.1. PhD program flow chart

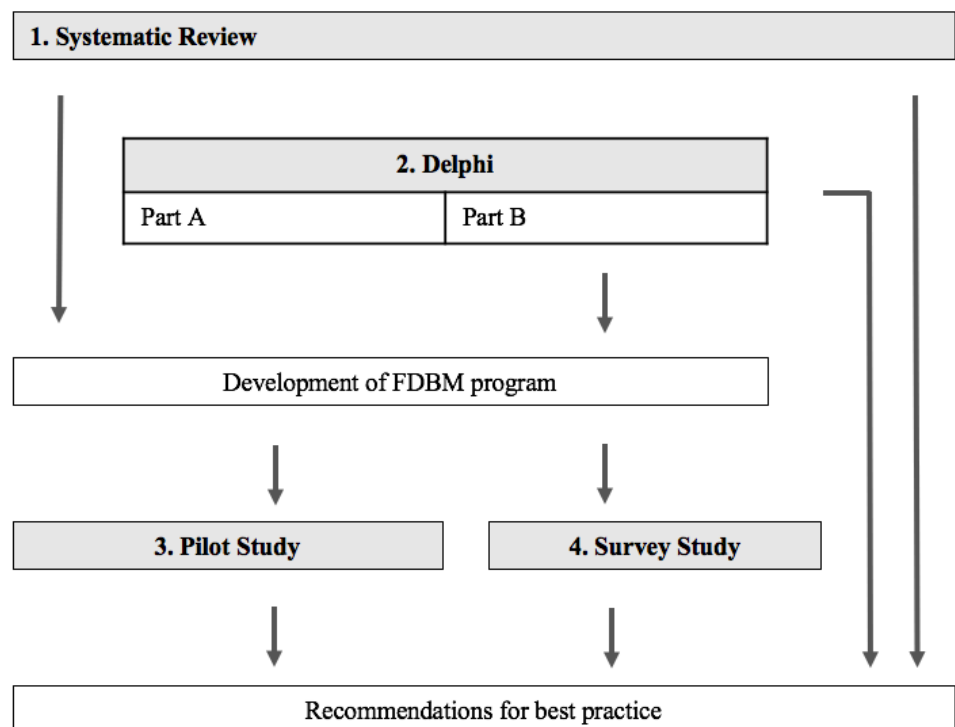


Table 1.1. *Research questions addressed in each study*

Individual Research Questions	Studies addressing these questions
What is the evidence supporting family involvement within behavioural interventions for relatives with ABI?	Systematic Review (Chapter Three)
What are the key features in the delivery of a program aimed at supporting family caregivers to manage behavioural changes in their relative with ABI?	Systematic Review (Chapter Three) Delphi Study Part B (Chapter Four)
What intervention components should be included in a program aimed to support families to manage behavioural changes in relatives with ABI?	Systematic Review (Chapter Three) Delphi Study Part B (Chapter Four)
What strategies are families currently using to manage behaviours of concern in relatives with ABI?	Delphi Study Part A (Chapter Four)
What South Australian services and supports are available to family caregivers that address the management of behavioural changes in relatives with ABI?	Delphi Study Part A (Chapter Four)
<p>Is the Family-Directed Behaviour Management (FDBM) program a (a) feasible and (b) acceptable intervention in supporting family caregivers to manage BOC presented by relatives with ABI in community settings?</p> <p><i>Feasibility:</i></p> <ul style="list-style-type: none"> • Does the FDBM program have an impact on: <ul style="list-style-type: none"> ○ Frequency and severity of targeted BOC 	<p>FDBM Pilot Study (Chapter Six)</p> <p>Survey Study (Chapter Seven)</p>

<ul style="list-style-type: none">○ Family caregiver's level of confidence in managing BOC○ Family caregiver's levels of burden• Are the outcome measures used appropriate for capturing any changes using a pre-post design? <p><i>Acceptability:</i></p> <ul style="list-style-type: none">• Do family caregivers find the FDBM program satisfactory in supporting them to manage BOC in relatives with ABI?• Do family caregivers find the information and strategies provided to be appropriate and helpful in supporting them to manage BOC in relatives with ABI?• How do family caregivers think the FDBM program could be improved to better support them in managing BOC in relatives with ABI?	
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1.8 Structure of Thesis

Chapter Two presents current knowledge regarding the topic, defining and describing brain injury, behavioural changes and support approaches following ABI in community settings. Family experiences and involvement in rehabilitation are also discussed, with a South Australian perspective of family support provided.

Chapter Three presents the first study, a systematic review examining family involvement in behavioural interventions for individuals with ABI. The methods in identifying relevant studies are outlined, followed by the results and discussion according to study characteristics, methodological assessment, interventions and outcomes, and methodological limitations. The limitations of this study are then identified, followed by conclusions regarding the evidence presented.

In Chapter Four, the Delphi study is then presented. The Delphi design and methodology are outlined, followed by the results and discussions relating to behaviour management strategies used by family caregivers, services available and key components to be included in a program aimed at supporting family caregivers with this issue.

The FDBM program is outlined in Chapter Five, including a definition of family-directed versus clinician-lead interventions, and the theoretical lens underpinning its development. The refined FDBM program according to the Delphi process is then presented.

Chapter Six presents the FDBM pilot study, including the pre-test post-test design and methods utilised. The results are then presented in case study format, including participant involvement in the FDBM program and outcomes. This is

followed by discussion relating to the feasibility and acceptability of the program in supporting family caregivers, and feedback for the future development of the program.

In Chapter Seven, the survey study examines whether the FDBM Education Workbook is accessible and helpful for family caregivers with varying levels of education. The methods of recruitment and analysis are outlined, followed by results and discussions regarding feedback and suggestions for its future development.

Finally, in Chapter Eight, the implications of this thesis are presented. Findings from all four studies are synthesised to inform the development of a new theoretical framework for facilitating a Family-directed Approach to Brain injury (FAB). Recommendations for future practice and research are presented, followed by the strengths and limitations of this thesis, and concluding statements.

CHAPTER TWO

CURRENT KNOWLEDGE

Related publication:

Fisher, A., Bellon, M., Lawn, S., & Lennon, S. (2017). Brain Injury, Behaviour Support and Family Involvement: Putting the Pieces Together and Looking Forward. *Brain Injury, Under Review.*

2.1 Introduction

This chapter provides a current perspective on brain injury, family caregivers and behavioural support. Firstly, brain injury will be defined, followed by a brief overview of coma and rehabilitation, and common cognitive and behavioural sequelae following an ABI. This overview of current knowledge aims to: (1) provide a current perspective regarding behavioural support approaches for individuals with ABI in community settings; (2) explore the impact of behavioural changes on family caregivers and support needs; and, (3) provide a current indication of the supports available in South Australia that address this issue.

2.2 Defining brain injury

Acquired Brain Injury (ABI) is the all-encompassing term used for any cerebral damage that occurs after birth (Ponsford, Sloan, & Snow, 2013). ABI can be caused by “an accident or trauma, by a stroke, a brain infection, by alcohol or other drugs or by diseases of the brain like Parkinson’s disease” (Brain Injury Australia, 2016). ABI can be broadly characterised as ‘traumatic’ and ‘non-traumatic’. *Traumatic* brain injury (TBI) refers to damage to the brain from an external mechanical force, whereas *non-traumatic* brain injury is caused by an illness or disease of the brain. The leading cause of ABI death and disability worldwide is TBI and stroke (AIHW, 2007). The leading cause of TBI is motor vehicle accidents (MVA), followed by falls (Ponsford, Sloan, & Snow, Kraus & McArthur, 1999; Myburgh et al., 2008; 2013). TBI predominates in young men (Myburgh et al., 2008)

and the highest overall incidence is within the age-group from 15-24 years (Ponsford et al., 2013). TBI may result in altered states of consciousness, permanent brain damage, functional disability, and generally severe psychosocial and cognitive impairment (Entwistle & Newby, 2013; Rees, 2005).

A stroke (or cerebrovascular accident: CVA) is the result of a disruption of blood flow to the brain. Ischemic stroke, which is the most common, results from an occlusion (blockage) of an artery; others occur when an artery ruptures, and the bleeding causes swelling and pressure in the brain (Dvorak & Mansfield, 2013). When this occurs, the cells around the vessel do not receive sufficient oxygen and die, and depending on where this occurs, different functions can be impaired (Grader & Bateman, 2017).

TBIs are commonly associated with behaviour changes due to the vulnerability of the frontal lobe and frequency of diffuse axonal injuries seen in these types of injuries (Rao & Vaishnavi, 2015; Silver, McAllister, & Yudofsky, 2011). However, brain injury acquired through stroke may also impact speech, movement and memory, and many of the post-trauma symptoms and behaviours following stroke can be similar to brain injuries caused by an external force (Rees, 2005). Hence, this thesis will be inclusive of individuals with non-traumatic brain injury. As suggested by Carnevale and colleagues, individuals with both TBI and other forms of ABI exhibit behaviour problems and effective interventions need to be developed for both (Carnevale, Anselmi, Johnston, Busichio, & Walsh, 2006).

Mild traumatic brain injury (mTBI), also known as concussion, has also recently emerged as a major public health concern (Buck, 2011), with an estimated 80% of TBIs representing mild injuries (Bazarian et al., 2005; Ponsford et al., 2013).

Individuals who sustain mTBI may also experience ongoing cognitive, physical, emotional and social difficulties (Buck, 2011).

2.2.1 Coma and brain injury

Following blunt trauma to the head, individuals often experience immediate loss or impairment of consciousness; when an individual experiences this prolonged unconscious state, they are said to be comatose (McGee, Alekseeva, Chernyshev, & Minagar, 2016). The nature and duration of coma is of significance in indicating the extent of injury (McGee et al., 2016). The depth of coma is indicated by measuring a person's responsiveness to verbal commands and nature of orientation, which is rated using scales such as the Glasgow Coma Scale (GCS) (Jennett & Bond, 1975) and the Rancho Los Amigos Scale of Cognitive Level and Expected Behaviour (Hagen, Malkmus, Durham, & Bowman, 1979). For example, the GCS is used to grade TBI as mild (GCS 13-15), moderate (GCS 9-13) and severe (GCS 3-8) (Jennett & Bond, 1975). Although these scales produce a score that represents an initial guide to the degree of injury (mild, moderate or severe), these scores are not a definite indication of how a person responds to instruction and learns in the long term. As reported by Khan and colleagues, these scales give a prognosis for survival rather than functional outcomes (Khan, Baguley, & Cameron, 2003; Sherer, Struchen, Yablon, Wang, & Nick, 2008). For example, some individuals may have a GCS score indicating mild injury and an abnormal CT or MRI, with outcomes then resembling those of a person with moderate brain injury; in these cases, the neurological and neurobehavioural support needs require considerable attention despite GCS scores being in the mild range (Arciniegas & McAllister, 2008).

When an individual emerges from a coma, they often remain confused and disoriented, with impairments in memory and perception; this period, from the time of injury until the individuals regain ongoing memory for events in their environment, is termed post-traumatic amnesia (PTA) (Nakase-Thompson, Sherer, Yablon, Nick, & Trzepacz, 2004). The duration of PTA is the best indicator of the extent of cognitive and functional impairment after TBI (Khan et al., 2003) with the most common means of assessing PTA in Australia being the Westmead PTA Scale (Khan et al., 2003; Shores, Marosszeky, Sandanam, & Batchelor, 1986).

2.2.2 Rehabilitation

Rehabilitation following brain injury refers to the process of learning again and developing skills and behaviours that enable an individual to achieve and maintain meaningful participation in their environment (WHO, 2011). The rehabilitation process uses an interdisciplinary approach, including multidisciplinary professionals (i.e. neurologists, rehabilitation clinicians, and allied health professionals), and collaboration with the individual with ABI, their family and carers (Khan, Amatya, Galea, Gonzenbach, & Kesselring, 2017; Khan et al., 2003). The focus may be on retraining the individual in activities of daily living, cognitive and behavioural support, pharmacological management, and pain management (Khan et al., 2017).

Within the critical care setting there is a focus on medical matters, given the potential for loss of life and severe medical or neurological compromise (Arciniegas & McAllister, 2008). However, there is no doubt that the initial management of posttraumatic neurobehavioural issues also begins during this phase. During the

acute injury period, most individuals experience cognitive difficulties in areas of memory and executive functioning (Arciniegas & McAllister, 2008; McGee et al., 2016), and these are frequently accompanied by emotional and behavioural changes (Sherer, Nakase-Thompson, Yablon, & Gontkovsky, 2005; Tittle & Burgess, 2010). However, the rehabilitation of BOC seems to be supplementary to other neuropsychological interventions rather than a core component of rehabilitation programs (Cattelani, Zettin, & Zoccolotti, 2010). Many individuals, particularly those with moderate injuries, have little or no formal rehabilitation phase, being discharged home with limited follow up (Oddy & Herbert, 2003). The implications of this will be discussed later in this chapter.

Following inpatient rehabilitation, post-acute programs target improving participation in community activities, including work and independent living (Sander, Clark, & Pappadis, 2010). Community-based rehabilitation (CBR) aims to enhance the quality of life for individuals with ABI and their families, meet their basic needs, and ensure an individual's inclusion and participation (WHO, 2017). CBR consists of a multisectoral approach, which is implemented through the combined efforts of people with ABI, their families and communities, and relevant government and non-government health, education, vocational, social and other services (WHO, 2017).

2.3 Behavioural changes following brain injury

Many studies have shown significant behavioural changes to be common following brain injury (Gelber & Callahan, 2010; Kelly, Brown, Todd, & Kremer,

2008; Norup & Mortensen, 2015; Ponsford et al., 2014; Sabaz et al., 2014), with research identifying a high occurrence (54-60%) of BOC amongst this population (Ponsford et al., 2014; Sabaz et al., 2014). These can be divided into two main categories: externalising symptoms and internalising symptoms (Cattelani et al., 2010). External symptoms include behaviours such as physical and verbal aggression, oppositional attitude, impulsivity, irritability, excitement, disinhibition, confabulation and sexually inappropriate behaviours; whereas internal symptoms include cognitive changes, such as memory problems, apathy, reduced initiative, reduced self-confidence, frustration, memory problems, difficulty concentrating, slowed thinking, word-finding difficulties, and mood disorders (e.g. depression, posttraumatic stress disorder, anxiety disorders, substance use disorders, psychotic disorders) (Arciniegas & Wortzel, 2014; Nash et al., 2014; Ponsford et al., 2014). These cognitive difficulties have been reported to be far more common than physical changes, and persist over time (Ponsford et al., 2014).

Behaviour change may relate directly to the neurological damage, depending on the nature and location of the brain injury (Arciniegas & McAllister, 2008; Gelber & Callahan, 2010; Ponsford et al., 2013). The biomechanics of a typical brain injury often involve the anterior and ventral aspects of the frontal and temporal lobes, cerebral white matter (myelinated axons), the diencephalon (thalamus and hypothalamus) and midbrain areas (Arciniegas & McAllister, 2008). These are neurobehaviourally salient areas, with injury associated with a constellation of sequelae, including altered arousal, impaired cognition, agitation and reduced impulse control (Arciniegas & McAllister, 2008; Cattelani et al., 2010; Sbordone, 2000; Starkstein & Robinson, 1997). It must also be noted that, due to the heterogeneity of brain structure (Kolb et al., 2011), the consequences of brain injury

will vary greatly between individuals, even within those with clinically similar injuries (Arciniegas & McAllister, 2008; McGee et al., 2016).

Besides the site and nature of the brain damage, a number of other factors contribute to behavioural disorders in individuals with ABI. These include premorbid factors (e.g. pre injury coping style, personality, motivation), cognitive and physical sequelae of the injury (such as pain, dizziness, sleep disturbance, and psychological responses), medications with adverse behavioural effects, and environmental factors (i.e. the physical and social context in which the behaviour occurs) (Alderman, 2001; Kurtz, Putnam, & Stone, 1998; Sherer et al., 2005; Tittle & Burgess, 2010). Furthermore, post-injury learning plays an important role, especially when behaviours serve an avoidance/escape function (Alderman, 2001; Gardner, Bird, Maguire, Carreiro, & Abenaim, 2003). The impact of social responses and the environment understandably adds to the complexity of behavioural disorders and management strategies. Hence, late after injury relatives may report improvement, which can be a reflection of a developed understanding of the relationship between the behaviour and the environment, and responses to the behaviour that may reduce its occurrence (McMillan, 2013).

2.4 Behaviour support

2.4.1 Assessment

The management of BOC should begin with comprehensive assessment (Yody et al., 2000). As reported by Alderman and colleagues (Alderman, Knight, & Brooks, 2013), it first has to be agreed that it is acceptable to intervene and change

the individual's behaviour. This process brings a moral and ethical dimension to the decision making process, and there are many factors to consider. These include family and community expectations (which will influence referrals to specialist services), age, culture, and the context in which the behaviour occurs (Alderman et al., 2013). Once a decision is made to intervene, a diagnostic and neuropsychological assessment should be conducted, as it is important to identify factors that underlie the behaviour or that may be affected by the intervention (i.e. confusion, pain, sleep deprivation) (Bogner & Shannon, 2016). Other relevant information is also collected to assist with identifying factors contributing to the occurrence of behaviour, developing a hypothesis and from this, planning an intervention (Alderman et al., 2013).

In collecting relevant information regarding BOC, observational recording measures are recommended (Alderman et al., 2013; Ponsford et al., 2013), which document standardised variables and provide objective information that can then be used to test assumptions about the behaviour (Alderman et al., 2013). One such measure is the Overt Behaviour Scale (OBS: Kelly, Todd, Simpson, Kremer, & Martin, 2006), which provides a comprehensive measure of common challenging behaviours following ABI, including the following categories: physical and verbal aggression; inappropriate sexual behaviour; perseveration; wandering/absconding; inappropriate social behaviour; and lack of initiation. The OBS is described in further detail in Chapter Six. Another observational measure includes the Overt Aggression Scale - Modified for Neurorehabilitation (OAS-MNR: Alderman, Knight, & Morgan, 1997), which provides a standardised method of reporting aggressive behaviours presented by individuals with brain injury.

These assessments are often incorporated within a Functional Behaviour Assessment (FBA), which is the recommended assessment preceding interventions based on Applied Behaviour Analysis (ABA) (including PBS) (Bogner & Shannon, 2016). ABA refers to the application of behavioural principles from learning theory, which will be discussed later in this chapter. A FBA is conducted to gain an understanding of the factors that influence the BOC (Bogner & Shannon, 2016; Gardner et al., 2003; Ylvisaker, Jacobs, & Feeney, 2003). FBA includes correlational assessment, based on interviews with significant others (i.e. family members, caregivers, teachers) and observations of the individual within natural environments, to determine whether antecedent and consequent events reliably predict and maintain the BOC (Lucyshyn, Dunlap, & Freeman, 2015). A Functional Analysis (FA) is then conducted to empirically validate the hypothesised functions of the behaviour through the systematic manipulation of variables (Ylvisaker et al., 2003). Ylvisaker and colleagues (2003) also discuss the concept of ‘dynamic cognitive assessment’. This is understood as the “creative and flexible process of exploring task modifications, strategy suggestions, cues, and other supports to determine the [individual’s] ‘zone of proximal development’ and the types of supports useful in helping the [individual] achieve at higher levels” (p. 20).

These assessment techniques can help in the development of effective intervention strategies, which are most likely to have the greatest impact on increasing positive behaviours and reducing BOC in individuals with brain injury (Gardner et al., 2003; Ylvisaker et al., 2003). Furthermore, Rahman and colleagues’ examination of a descriptive functional assessment approach for nine individuals with ABI, found that 88% of BOC adhered to a social model of reinforcement, serving demand escape functions or attention maintained function (Rahman, Oliver,

& Alderman, 2010). These results suggest that formal functional assessments may lead to better outcomes for individuals with ABI (Rahman et al., 2010).

2.4.2 Behaviour management approaches

Effective management of BOC requires a multimodal, multidisciplinary and collaborative approach, and often involves a combination of nonpharmacological and pharmacologic interventions (Arciniegast & Wortzel, 2014; Wiart, Luaute, Stefan, Plantier, & Hamonet, 2016). Although pharmacological methods are commonly used to manage BOC following brain injury (Wiart et al., 2016), the focus of this thesis will be on non-pharmacological approaches. These may include cognitive therapies (Wood & Thomas, 2013), mindfulness therapies (e.g. relaxation-based therapies), skills-training programs, exposure-based treatments, behavioural interventions and multicomponent approaches (Alderman, 2003; Demark & Gemeinhardt, 2002).

2.4.2.1 Behavioural interventions

There is increasing evidence to support the use of non-pharmacological interventions for the management of BOC following brain injury, with a number of literature reviews examining the efficacy of behavioural interventions following ABI, including: contingency management procedures and PBS (Ylvisaker et al., 2007); traditional ABA approaches, cognitive-behavioural therapy and comprehensive-holistic approaches (which tend to focus more on developing alternative or compensatory behaviours) (Cattelani et al., 2010); and more broadly, neurobehavioural interventions (Alderman & Wood, 2013; McMillan, 2013).

The major limitation of these reviews is that evidence is based largely on single case designs. For example, of the 65 studies reviewed by Ylvisaker and colleagues (2007), only four consisted of group studies (two RCT and two single group studies). Single-subject experiments are the most common research methodology in behavioural studies (Horner et al., 2005); however, not all such studies are conducted using rigorous methodology, and there is increasing evidence to suggest the need for reporting guidelines to inform good quality single case research (McMillan, 2013; Tate, Perdices, McDonald, Togher, & Rosenkoetter, 2014).

With this in mind, however, the existing and accumulating single-case research findings do support the use of behavioural interventions following ABI. In particular, the aforementioned reviews have highlighted the success of management approaches that are based on ABA. In simple terms, ABA refers to the application of behavioural principles from learning theory (i.e. classical [or *respondent*] conditioning and operant [or *instrumental*] conditioning) that conceptualise behaviour as operating on the environment and maintained by its consequences (Alderman & Wood, 2013; Cattalani et al., 2010). The principles of learning theory will be discussed in detail in Chapter Five when presenting the theoretical lens underpinning the intervention phase of this thesis.

Approaches based on Applied Behaviour Analysis (ABA)

Behaviour management approaches based on learning theory (ABA strategies) have been reported in the literature for more than three decades (Alderman et al., 2013; Lucyshyn et al., 2015). These interventions are typically

individually tailored, and are based on procedures emphasising (but not restricted to) the management of BOC by manipulating antecedents (events prior to the occurrence of BOC) or consequences (the response to the behaviour) (Cattelani et al., 2010; McMillan, 2013). The probability that any specific behaviour will occur again in the future may be dependent upon what contingencies are available, such as: a) whether or not it is rewarded (positively or negatively) or not rewarded; b) if an expected reward (or ‘payoff’) has been withheld (referred to as *extinction*); or c) if the behaviour results in aversive consequences (referred to as *positive punishment*) (Alderman et al., 2013; Alderman & Wood, 2013).

Antecedent strategies play a fundamental role in deeming BOC inefficient and ineffective (Horner, 2000). These strategies are based on the manipulation of antecedent events, such as the modification of the environment, instructional modifications and skill training (Loman & Sanford, 2015). Skill training provides alternative means for individuals to achieve the same outcome served by the BOC (e.g. assertive training for individuals who become angry when they fail to get their needs met) (Arciniegas & Wortzel, 2014).

Another commonly used antecedent strategy is differential reinforcement (DR) scheduling, in which desired behaviours are shaped through reinforcement; however, this strategy is used in combination with negative punishment (extinction: a contingency approach), which at the same time aims to decrease the BOC by withholding the ‘payoff’ (Arciniegas & Wortzel, 2014; Lewis, 2015). For example, when an individual holds out their cup for a drink they are rewarded with a drink and verbal praise; however, when the individual throws his or her cup and demands a drink this behaviour is ignored. Previously the latter behaviour may have resulted in

the individual being given a drink (the ‘payoff’), therefore reinforcing the behaviour (increasing the likelihood of it occurring again in the future). ‘Shaping’ may then be used to teach the individual to get their own drinks, by providing a reinforcer (reward) for closer approximations of the target behaviour (Alberto & Troutman, 2013) (i.e. step 1 - hold out cup; 2 - take cup to sink; 3 - place cup under tap; 4 - fill cup with water). Put simply, differential reinforcement refers to reinforcing (rewarding) desired behaviour whilst not providing payoffs for BOC.

Contingency strategies refer to approaches that manipulate the response to the behaviour in order to promote the increased occurrence of desired behaviour and/or reduce the likelihood of problematic behaviours happening in the future (Borgmeier & Rodriguez, 2015). There are a variety of contingency management strategies with a good evidence base for use with individuals following with brain injury (see Alderman et al., 2013). These include: differential reinforcement (Alderman & Knight, 1997; Wood & Alderman, 2011), which is discussed above; token economies (Wood, 1987), in which desired behaviour is rewarded with tokens that can then be exchanged for other reinforcers (e.g. magazines, concerts, favourite food items); and extinction procedures (Alderman, Fry, & Youngson, 1995; Stewart & Alderman, 2010), in which the payoff (maintaining reinforcer) is removed for BOC. With the substantial move away from interventions based on consequential punishment (McDonnell, 2010), these strategies rather emphasise reinforcing (rewarding) desired behaviours and withholding payoffs for BOC. Furthermore, given the influence of the PBS movement (discussed following), there is an emphasis on actively integrating contingency strategies within more comprehensive plans that incorporate proactive, preventative, and teaching strategies (Borgmeier & Rodriguez, 2015).

There has also been a recent trend towards strategies that successfully manage setting events. Setting events (also known as *distal* antecedents or *establishing operations*), refer to physical, social, and physiological events that change the likelihood of a behaviour occurring at a later point in time (e.g. sleep deprivation and missed medication) (Loman & Sanford, 2015). Behavioural strategies that manage setting events and emphasise lifestyle changes have been advocated in the management of BOC following ABI (e.g. Feeney & Achilich, 2014; Giles, Wilson, & Dailey, 2009; Ylvisaker et al., 2007; Ylvisaker, Turkstra, & Coelho, 2005). The most widely cited term for such approaches is ‘positive behaviour support’ (PBS) (Johnston, Foxx, Jacobson, Green, & Mulick, 2006).

Positive Behaviour Support (PBS)

Positive behaviour support (PBS), also referred to as positive behaviour intervention and supports (PBIS), is the application of the science of applied behaviour analysis (ABA) in the support of individuals with BOC (Carr et al., 2002). The primary goal of PBS is to improve an individual’s QOL through understanding the variables that govern behaviour and using this to (1) teach the individual new skills to achieve goals in a socially acceptable manner and (2) rearrange the environment in a way that supports desirable behaviours (Carr et al., 2002; Janney & Snell, 2008; LaVigna & Willis, 2012). These strategies, which ensure the environment is appropriate, meaningful and functional for the individual, have tremendous implications in the development of behaviour support plans within community settings (Loman & Sanford, 2015). As stated by McIntosh (2014), a key

goal of PBS is not to only reduce/eliminate BOC in the short term, but to implement practices that will improve long-term outcomes.

Although PBS is based on principles of ABA, this approach has evolved with several distinguishing features that are critical when working with individuals following ABI (Carr, 2007). Neuropsychological research has found that trauma resulting in damage to the ventral or dorsal frontal lobe impedes the ability of an individual to learn from the consequences of their behaviour (Damasio, 1994; Rolls, 2000; Schlund, 2002). This has therefore prompted the use of PBS strategies that emphasise antecedent-based strategies (e.g. choice making, meaningful activities, positive routines) (Ylvisaker & Feeney, 1998). The practices of PBS also provide more flexibility compared to the traditional intervention models, which recommend universal, prescriptive and exactly defined strategies (e.g. Alderman & Wood, 2013; Demark & Gemeinhardt, 2002). Transferring these clinical approaches to community settings is incredibly difficult, with the need for flexible interventions that impact an individual's environment, but that are also consistent with the theory and practices of PBS (Feeney & Achilich, 2014).

A core component of PBS is antecedent control (e.g. managing triggers of BOC) (Narevic et al., 2011), however PBS approaches are also focused on: promoting choice and control; meaningful routines; setting realistic expectations; errorless learning (to avoid frustration and optimise skill acquisition); positive communication partners; and increasing cue saliency and anticipation (Alderman et al., 2013; Loman & Sanford, 2015; Ylvisaker & Feeney, 1998). However, it should be noted that, even with this increased emphasis on antecedent strategies, PBS often

form part of a multicomponent intervention which may include contingency procedures as well (Ylvisaker et al., 2007).

Antecedent-focused PBS interventions appear to be gaining increasing momentum, with a number of intervention experiments (i.e. Arco & Bishop, 2009; Feeney & Ylvisaker, 1995; Feeney & Ylvisaker, 2006; Feeney & Achilich, 2014; Feeney & Ylvisaker, 2003; Feeney & Ylvisaker, 2008) demonstrating the effectiveness of the PBS framework for individuals with BOC associated with self-regulatory impairments following frontal lobe injury in community settings. Furthermore, a review conducted by LaVigna and Willis (2012), showed PBS to be: effective for individuals with both severe and high frequency BOC; cost effective; easily trained and widely disseminated; and effective in community settings. However, it should be noted that the majority of behavioural studies have been conducted in institutional or residential environments, with limited community-based studies.

2.4.2.2 Community-based interventions

Whilst the effectiveness of behavioural interventions following ABI have been well reported (see Alderman & Wood, 2013; Cattalani et al., 2010; McMillan, 2013; Ylvisaker et al., 2007), there has been an emphasis on the role of paid staff in community-based approaches (Kelly & Parry, 2008; Kelly & Simpson, 2011). It is only recently that there is a greater focus on the involvement of everyday people in natural environments (e.g. Feeney, 2010a; Feeney & Achilich, 2014), with growing evidence to support the long-term benefits of such interventions (Feeney, 2010a). However, interventions provided by individuals with limited training are rarely

implemented in the manner they have been designed (Feeney & Achilich, 2014); this has prompted the need for more functional and practical approaches for supporting individuals in community settings.

In response to this issue, Feeney (2010a) has proposed the concept of ‘structured flexibility’. This approach encourages caregivers to view BOC as being a result of many possible factors that anyone (with or without disability) may confront on a daily basis, and requires professionals to shift from an impairment oriented approach to behaviour (typically focusing on pathology), to a functional needs orientation. This encourages evaluation of the functions of behaviour in the context of every day routines (Feeney & Achilich, 2014).

It is important to consider that many individuals with brain injury who are years post injury are most often supported by caregivers with limited training and knowledge of mental health, neurology and neuropsychology (Feeney & Achilich, 2014), with family members often becoming the primary caregivers (Jumisko et al., 2007; Lefebvre, Cloutier, & Levert, 2008; McDermott & McDonnell, 2014). In implementing community-based behavioural interventions it is therefore important to consider the impact of brain injury on the family, acknowledging issues of adjustment (see Dillahunt-Aspillaga et al., 2014), and the unique challenges they face. Indeed, families will have varying levels of tolerance and expectations regarding specific behaviours, which may be dependent on cultural factors and personal experiences. With this in mind, the impact of brain injury for families will be briefly discussed following.

2.5 Family experience

The life of an individual and his or her family members may change dramatically following a brain injury (Braine, 2011; Turner et al., 2007), with the family equilibrium disrupted by a multitude of changes in roles and responsibilities (Kratz, Sander, Brickell, Lange, & Carlozzi, 2017; Larøi, 2003) in addition to cognitive and personality changes (Lefebvre, Pelchat, Swaine, Gelinat, & Levert, 2005). Family members are faced with adjustment to the impacts of the brain injury, responding to the challenges associated with caring for the person and the challenge of managing their behaviour changes within the community (Braine, 2011; Degeneffe, 2001; Fleming, Sampson, Cornwell, Turner, & Griffin, 2012).

Many individuals following brain injury require prolonged hospitalisation and inpatient rehabilitation (Gelber & Callahan, 2010). It is understandable then, that for some, the thought of returning home is exciting. However, those anticipating returning to their 'normal' lives are confronted with a life anything but normal after discharge (Turner et al., 2007), being forced to revise their philosophy and reorganise their everyday life (Lefebvre et al., 2005). It is often during this transition phase that individuals and their families first start to comprehend how their life has changed as a result of the brain injury (Turner et al., 2007).

One of the early pioneers in the exploration of the family's experience during the emotional aftermath of their relatives ABI includes Murial Lezak (1978, 1988). In 1988, Lezak wrote a seminal paper entitled "Brain Damage is a Family Affair", which explored the impact of TBI on the family, including emotional distress (i.e. depression and anxiety), family disruptions (i.e. social isolation) and adjustment difficulties (i.e. burden). A number of other researchers have also contributed

formative research regarding family reaction patterns following brain injury (i.e. Bond, 1988; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Oddy, Humphrey, & Uttley, 1978; Romano, 1974; Thomsen, 1974), and the role of family resiliency in adjusting to, and coping with, the changes associated with ABI (Dillahunt-Aspillaga et al., 2014; Frain, Dillahunt-Aspillaga, Frain, & Ehkle, 2014; Simpson & Jones, 2013). Brooks (1984) and Kreutzer and colleagues (Kreutzer, Marwitz, & Kepler, 1992) provided further insight within their coherent overviews of the psychosocial disability associated brain injury, revealing behavioural changes (i.e. changes in temperament, irritability, lability, spontaneity, restlessness and childlike behaviour) to be the most disturbing for families. This is in consensus with research conducted later by Anderson, Parmenter and Mok (2002), who identified three neurobehavioural problems that influence the levels of psychological distress experienced by caregivers following brain injury, including behavioural, communication and social difficulties, with BOC reported as the strongest in predicting high levels of distress (Anderson et al., 2002).

Behavioural difficulties may become particularly apparent following the transition home, when there is a focus on returning to premorbid activities such as employment (Marsh, Kersel, Havill, & Sleigh, 2002). This highlights the importance of community-based behavioural supports, but also the need to educate individuals and their families about the potential long-term consequences following ABI and on what to expect. As suggested by Montgomery and colleagues (Montgomery, Oliver, Reisner, & Fallat, 2002), giving anticipatory guidance to families in the acute care setting may alert them to potential issues including possible behavioural disturbances. However, too much information too early in the rehabilitation process, when the family is still coming to terms with the brain injury (Turner et al., 2007),

will not be retained and may overwhelm families (Montgomery et al., 2002; Oddy & Herbert, 2008). Yet too little information or information given too late may undermine the family's sense of control and even hope (Montgomery et al., 2002), with caregiver needs often relating to their stage of caregiving (Dillahunt-Aspillaga et al., 2013). This highlights the need to deliver information to families in a timely fashion, when they are most likely to be receptive to the information presented.

Considering the extent of responsibility families have in caring for individuals following brain injury (Oddy & Herbert, 2003), one might presume that families would be well informed regarding the brain injury and potential behavioural changes. However, the literature suggests this not to be the case, with families reporting unmet information needs (Hawley, Ward, Magnay, & Long, 2003; Jumisko et al., 2007; Kolakowsky-Hayner, Miner & Kreutzer, 2001; Kratz et al., 2017; Murray et al., 2006; Piccenna, Lannin, Gruen, Pattuwage, & Bragge, 2016; Watanabe, Shiel, McLellan, Kurihara, & Hayashi, 2001), and the level of information provided often not being understood or relevant to the individual or families' situation (Piccenna et al., 2016). In studies conducted by Murray et al. (2006), the item most rated as unmet by families/caregivers related to receiving instruction on how to manage the individual when they are "upset" or acting "strange". This suggests that families/caregivers should have access to education materials regarding behaviour management and instruction specifically relating to their family member with an ABI (Murray et al., 2006) and the environmental contexts in which BOC occur.

2.5.1 Family support programs

There have been a number of support programs developed in attempt to address unmet family needs following brain injury (i.e. Acorn, 1995; Albert, Im, Brenner, Smith, & Waxman, 2002; Brown et al., 1999; Kreutzer et al., 2009; Rivera, Elliott, Berry, & Grant, 2008; Sinnakaruppan, Downey, & Morrison, 2005; Smith & Godfrey, 1995). Of these, the Brain Injury Family Intervention (BIFI) developed by Kreutzer and colleagues (2009) has the stronger evidence base (see Kreutzer, Marwitz, Sima, & Godwin, 2015). There have also been programs developed that specifically support families with behaviour management and problem solving across adult (Carnevale et al., 2006; Rivera et al., 2008) and paediatric populations (Wade, Walz, Carey, & Williams, 2008).

Families benefit from psycho-educational services, such as support groups, with family members reporting value in participating in group discussions with other people in similar situations (Bellon, Sando, Crocker, Farnden, & Duras, 2015; Foster et al., 2012; Sinnakaruppan et al., 2005), or meeting professionals who take the time to listen to them (Jumisko et al., 2007). Families' relationships with physicians and professionals are positive when the families' knowledge and experience are recognised (Lefebvre et al., 2005). Indeed, families are the experts of their experience of everyday life with the individual with brain injury, and benefit from having this expertise acknowledged (Lefebvre et al., 2005). Professionals also benefit from this intimate knowledge (Degeneffe, 2001; Foster et al., 2012; Gagnon et al., 2016), which helps to paint a more complete picture of the individual's situation and support needs.

The importance of family collaboration is now widely acknowledged for both adult and paediatric groups (Boschen et al., 2007; Gan, Gargaro, Kreutzer, Boschen, & Wright, 2010; Turner-Stokes & Wade, 2004; Wade, Walz, Carey, & Williams, 2009; Woods, Catroppa, Eren, Godfrey, & Anderson, 2013), and there is current focus on the increased involvement of families within the rehabilitation process.

2.6 Family involvement in the rehabilitation process

As introduced above, there are a number of forces driving the increased involvement of family members, including economic and therapeutic benefits. The involvement of families, and family wellbeing, has been linked to better rehabilitation outcomes for individuals with ABI (Macaden, Chandler, Chandler, & Berry, 2010; Sander, Maestas, Sherer, Malec, & Nakase-Richardson, 2012). It has also been long argued that families can learn the critical skills to be applied to problems as they develop, rather than placing the responsibility and control of such problems with rehabilitation professionals (Jacobs, 1991).

There is only limited research examining transfer-of-training to family caregivers specific to behavioural supports for adults with brain injury. There have been reports of several single-subject experiments and case studies (i.e. Feeney & Ylvisaker, 1995, Feeney & Ylvisaker, 2003; Ylvisaker & Feeney, 1998; Feeney & Ylvisaker, 2008, 2009; Feeney & Achilich, 2014) in addition to a RCT conducted by Carnevale et al. (2002), which have placed emphasis on training natural everyday support persons. The foundations of family-directed intervention has also been drawn from research supporting the effective training of family members in the rehabilitation process following ABI (Braga et al., 2005) and within behavioural

interventions for children with developmental disabilities (e.g. McIntyre, 2008; Padden, 2016; Quinn, Carr, Carroll, & O'Sullivan, 2007; Webster-Stratton, 1992), intellectual disabilities (e.g. Annette & Rollings, 2009; Gore & Umizawa, 2011; Soresi, Nota, & Ferrari, 2007; Todd et al., 2010) and autism spectrum disorders (e.g. Reynolds, Lynch, & Litman, 2011; Todd et al., 2010). These studies have shown increased family efficacy in implementing strategies and a reduction of BOC.

These findings provide further evidence that family members can be involved in behavioural interventions, and place importance on further investigating a transfer-of-training approach to facilitate this process specific to ABI. However, given the limited research identifying the efficacy of family involvement in behavioural interventions for individuals with ABI, the first step is to examine the evidence underpinning this topic. This will be the focus of the first study in this thesis, a systematic review in Chapter Three.

2.7 Family Support – a South Australian perspective

In South Australia (SA) there are a number of government and non-government organisations that provide rehabilitation services to individuals with ABI and their families; however, there are significant gaps in community support regarding the management of BOC (Department of Health, 2012). Government-funded brain injury rehabilitation services are offered by the South Australian Brain Injury Rehabilitation Service (SABIRS) and Disability SA (a Government case management service). The current state-wide service model includes partnerships between these organisations and other government and non-government organisations, and across government sectors.

SABIRS consists of the Brain Injury Rehabilitation Unit (BIRU, both a hospital and urban facility), and outreach services provided by Brain Injury Rehabilitation Community and Home (BIRCH) services (SA Health, 2015). Individuals with ABI and persistent behaviour difficulties may be referred to BIRCH, which offers a range of multidisciplinary services and expertise relating to behaviour management following ABI. However, support is only available for a limited period of time (a maximum six months), and if an individual exhibits behaviours that are not deemed ‘manageable’ they may not be able to access these services (Department of Health, 2012).

Within Disability SA there is a Positive Behaviour Support Team (PBST), which consists of a team of specialist behaviour support practitioners (social workers, psychologists and developmental educators). However, this time limited support is only provided to adults residing in Disability Services’ accommodation services, and is therefore not accessible to those individuals in need who are living with their families in the community.

So what happens to individuals with ABI who exhibit BOC deemed ‘too difficult to manage’ by service providers? Research suggests that these individuals may be referred to psychiatric wards (Manchester, Hodgkinson, & Casey, 1997) or nursing homes (Winkler, Sloan, & Callaway, 2010), and in other cases may be discharged back to their homes to families who do not have the skills or support to manage BOC (Murray et al., 2006; Willis & LaVigna, 2003). Research has also reported a large proportion of individuals with TBI within prison populations (Perkes, Schofield, Butler, & Hollis, 2011; Schofield et al., 2006) suggesting the

ineffective management of neurobehavioural issues in the community may lead to exposure to the criminal justice system.

Individuals with ABI may be able to access community and lifestyle support and enhancement programs through a number of agencies, such as Brain Injury SA (including their Springboard program) (Brain Injury SA, 2016), the Community Re-entry Program (CRP) at Flinders University (2015), Community Living Project (CLP), Take 5 (Uniting Communities, 2016) and North East Networks. However, these agencies do not offer specialised and community-based consultation regarding behaviour management.

Individuals with ABI and their families are able to access information and attend sessions regarding behaviour management through Families4Families Inc. (2011), a state-based peer support network which provides networking opportunities and education on a range of topics including behaviour management following ABI. However, the network also does not provide specialised individual behaviour consultation to family caregivers.

Public and private (neuro)psychologists and (neuro)psychiatrists also offer support regarding behaviour management following ABI in community settings. These services are invaluable for individuals with brain injury and their families, providing assessment, diagnosis and individualised plans for the management of BOC (Littlefield, Stokes, Bardenhagen, & Collins, 2012). However, individuals with ABI are unable to access the specialist clinical neuropsychological services they need under the current Medicare system (Littlefield et al., 2012). These services are provided under the Department of Veterans' Affairs (DVA) and insurance schemes (including WorkCover, the Motor Accidents Insurance Board [MAIB] & Transport

Accident Commission [TAC]), but many ordinary Australians are not covered by these schemes, resulting in much inequity in provision and access to services (Littlefield et al., 2012). Furthermore, there are long delays in accessing these services in SA (Department of Health, 2012). It should also be noted that even though neuropsychologists specialise in assessment, diagnosis and treatment of psychological disorders (Littlefield et al., 2012), they may have limited experience in working with families and BOC within community settings.

These supports offered to family caregivers regarding behaviour management suggest a fragmented and inconsistent model of care, resulting from: time-limited support offered through SABIRS and Disability SA; the valuable but unspecialised support provided through Brain Injury SA, Families4Families Inc. and other community-based organisations; and the inability for many families to access or be eligible for existing services (available through SABIRS, Disability SA, and Specialists) due to structural and bureaucratic divisions. There are a number of other government and non-government agencies that provide elements of behaviour support. However, on the whole this is a fragmented model of care, with no clear pathways to access specialised support.

Furthermore, individuals who are not eligible for insurance systems mentioned above may be eligible for support under the National Disability Insurance Scheme (NDIS). Individuals between 18 and 64 years in SA will be able to access NDIS from July 2017 (dependent on where they live) (NDIS, 2016). The NDIS promises to ensure the provision of information, referral and linkage for families and caregivers, enabling them to receive the community support systems to assist them in their roles (NDIS, 2016). Within this scheme, people living with a disability have

choice and control over their NDIS plan, giving them the flexibility to choose how to spend their funds. These rapidly changing developments to the disability sector will result in significant changes in service provision, however the extent to which these changes will be inclusive of supporting family caregivers with the management of BOC remains to be established. Considering these upcoming changes to the current model of care, this thesis is timely in identifying the service gaps for family caregivers and in informing best practices in supporting families with the management of BOC following ABI in community settings.

2.8 Summary

Individuals may experience significant behavioural and cognitive sequelae following ABI, resulting from both the neurological damage (including the location and extent of injury) and environmental factors. Environmental factors include the physical and social contexts in which the behaviour occurs, and also more distal setting events (e.g. missed medication, sleep deprivation, pain). Other contributing factors include premorbid characteristics (e.g. pre injury personality and coping style), and medications with adverse behavioural effects.

This overview has described behavioural approaches commonly used to manage BOC following ABI. There is increasing evidence supporting behavioural interventions, particularly those based on learning theory. These ABA approaches typically emphasise strategies that manipulate the antecedent or consequences to the behaviour to promote desired behaviours and reduce the occurrence of BOC. Although these approaches have shown successful outcomes, there is a recent trend

towards using PBS strategies. Positive behaviour support has evolved from ABA and places emphasis on antecedent strategies, including skill-building techniques and the successful management of setting events, and focuses more broadly on increasing the quality of life and wellbeing of individuals with ABI. There is growing evidence to support the effectiveness of PBS interventions for individuals with an ABI in unstructured community settings.

Family members often become the primary caregiver following ABI, and have reported BOC to be the leading cause of distress, and instruction on how to manage BOC as the highest unmet support need. Families have reported the importance of further information support, but also practical hand-on collaboration with healthcare professionals. Furthermore, evidence is supportive of family involvement within brain injury rehabilitation, with families able to provide important insight to optimise rehabilitation outcomes for relative with ABI.

Although there appears to be limited research examining evidence underpinning family involvement specific to behavioural interventions, research does suggest family members can be effectively trained in implementing PBS strategies. Involving family members within behavioural interventions for relatives with ABI is also a priority for health care providers, with the need for more community-based neurobehavioural support services widely acknowledged. Furthermore, within the current financial climate, there is a growing need to develop support approaches that can be implemented by everyday support people. The evidence underpinning family involvement in behaviour management following ABI is examined in a systematic review in the following chapter.

CHAPTER THREE

STUDY ONE – SYSTEMATIC REVIEW

Related publication:

Fisher, A., Lennon, S., Bellon, M., & Lawn, S. (2015). Family involvement in behaviour management following acquired brain injury (ABI) in community settings: A systematic review. *Brain Injury*, 26(9), 661-675. DOI: 10.3109/02699052.2015.1004751

3.1 Introduction

This chapter presents a systematic review examining family involvement within behavioural interventions for relatives with ABI in community settings. The aims will be outlined, followed by the methodology employed, the results, and a discussion of the findings in relation to the relevant research objectives.

3.2 Aims

This systematic review addressed the following research question:

- What is the evidence supporting family involvement within behavioural interventions for relatives with ABI in community settings?

This review is inclusive of studies involving active family participation in the management of BOC; whether exclusively, or in collaboration with paid workers, as opposed to interventions carried out by paid workers only.

3.3 Methods

This systematic review was conducted in accordance with the PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). A search of the literature from 1980 to 2013 was conducted using the following electronic databases: CINAHL (Cumulative Index to Nursing & Allied Health Literature), Informit, OvidSP (ovid Medline and PsycINFO), Cochrane and PEDro.

Subject headings and keyword searches were developed under the following three main themes: behavioural problems/intervention (e.g. Behavioural Disturbances, Behaviour Therapy and Disruptive Behaviour), family involvement (e.g. Family-Centred Care, Home Nursing, and Family Therapy) and Brain Injury (combined using the Boolean operator 'AND'). The associated medical sub-headings (MeSH) were used preferentially; these were expanded upon and further clarified through articles identified through preliminary searches of each database, using mapped subheadings relating to brain injuries, behaviour change and behaviour therapy.

The preliminary searches of each database consisted of the following subject headings: CINAHL; 'Disruptive Behavior', 'Social Behaviour' and 'Behavioural changes', combined using the Boolean operator 'OR', combined with 'Brain Injury' using the Boolean operator 'AND'; Medline; 'Social Behavior Disorders' and 'Behavior Therapy' united by 'OR' and combined with 'Brain Injury' using 'AND'; PsycINFO; 'Behaviour Disorders' and 'Behaviour Therapy' united using 'OR', combined with 'Brain Damage' ('OR') 'Head Injuries' using 'AND'. The subject headings used to classify relevant articles identified through this search were then used to further refine the search strategy for this review (see Appendix 1 for details). MeSH terms varied across the selected databases, which resulted in database being searched separately.

The search strategy for Informit, PEDro and Cochrane consisted of key words, as mapped subject headings were not provided. Key word searches were developed under the same themes: behavioural problems/intervention (e.g. 'Behavioural modification', 'Harmful Behaviour', 'Aggression', and 'Psychiatric'), Family involvement (e.g. 'Home', 'In-home', 'Community', 'Caregiver' and

‘Spouse’) and Brain Injury (e.g. ‘Head Injured’, ‘ABI’ and ‘TBI’), using alternative spellings.

To ensure saturation of relevant literature, further strategies were also utilised. Additional papers were identified using the citation indexes ‘Scopus’ and ‘Web of Knowledge’, and by conducting hand searches of the reference list of relevant articles.

3.3.1 Study selection

The initial inclusion criteria were kept broad during the electronic and manual searches, to prevent the exclusion of potentially relevant articles. Inclusion limits were also not placed on study design, as it was anticipated that the available literature regarding behavioural interventions involving family would use a variety of study designs. Furthermore, studies were not excluded due to methodological weakness given the limited research available.

This review only included studies that were published in English, with a primary population of individuals with ABI who were 16 years or older and sustained an ABI at 15 years or above. The reason for implementing this inclusion criterion was to target families that had a sense of the person before the injury, with their experience of knowing and living with the person then changed dramatically; whereas for ABI in younger relatives or from birth, the accommodation to the change would likely take a different path.

The studies were also required to directly concern the involvement of ‘family members’ (including spouses, friends, and unpaid caregivers [but inclusive of those

receiving government allowances]) in behaviour management within home and community settings. Studies were excluded if they explored the experience of paid support workers exclusively. Studies were also excluded if they did not include the families' involvement in the management of behaviours.

The primary researcher screened titles/abstracts for full-text review. If there was uncertainty regarding the inclusion of articles, a second reviewer was consulted. Articles selected for full-text review were then independently considered by two reviewers. Through consensus, both reviewers then agreed on the final studies to be rated and analysed.

3.3.2 Assessment of methodological quality

Studies that met inclusion criteria were then assessed by the primary researcher using the following critical appraisal tools: McMasters (for quantitative and qualitative studies) (Law et al., 1998; Letts et al., 2007); and PEDro (for RCTs) (Maher, Sherrington, Herbert, Moseley, & Elkins, 2003). These tools are divided into sections corresponding to various aspects of study validity. The McMasters critical review tool for quantitative studies consists of sections regarding study design, sample selection, reliability and validity of outcome measures, data collection, withdrawals and dropouts, the avoidance of contamination (if participants in the control group inadvertently receive treatment) and co-intervention (if participants receive another form of treatment at the same time as the study intervention), the appropriateness of analysis method/s and conclusions made. For each section of the instrument, a rating of 'yes', 'no', 'not addressed', or 'not applicable' was assigned to the study. The PEDro was originally designed for the assessment of RCTs for

physical therapy and has since been used to assess psychological interventions (Tate et al., 2004). The PEDro scale consists of 11 items regarding the random allocation of participants, concealed allocation and blinding of participants and assessors, and the reporting of statistical comparisons and measures of variability. Each item was evaluated and totalled to give a total score out of 10 (scoring items two to 11 according to the PEDro guidelines (Maher et al., 2003). The studies were also rated according to their level of evidence as recommended by the Australian National Health and Medical Research Council (NHMRC) (2009). The NHMRC is the peak funding body for medical research in Australia, and was established to develop and maintain health standards (NHMRC, 2014). The NHMRC provides a medical research grading system used to assess the reliability of medical publications (NHMRC, 2009).

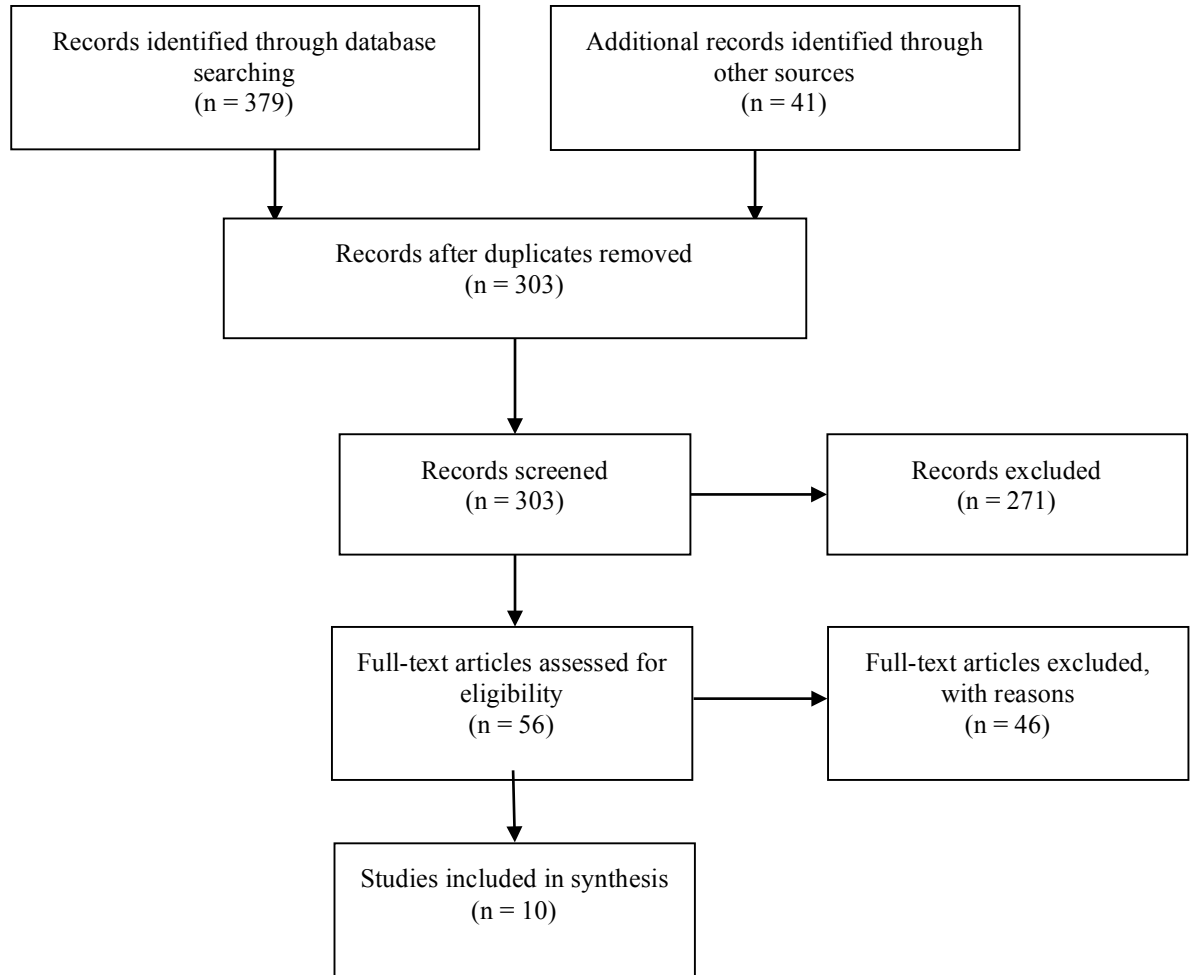
3.3.3 Data extraction and synthesis

The following study details were collected: study design, participant characteristics, sample source, inclusion/exclusion criteria, diagnostic criteria, study design, outcomes and main findings. A qualitative narrative synthesis of the findings was then performed using this information, describing both consistencies and discrepancies between the studies. A meta-analysis was not possible given that studies differed significantly with respect to design and outcomes.

3.4 Results

A total of 303 articles were identified after duplicate removal and screening. An additional 41 articles were identified through the use of citation indexes and hand searching reference lists. Articles were reviewed for inclusion relevant to the content of their title and abstract, resulting in the exclusion of 271 studies. Fifty-six full-text articles were evaluated for inclusion (refer to PRISMA in Figure 3.1). Forty-six articles were excluded for the following reasons: 21 papers did not specifically concern the family members' experience of managing behaviours; nine papers explored the implications of ABI on family members and/or importance of family intervention, but were not specific to behaviour management; eight papers consisted of participants who were not primarily diagnosed with ABI or were not specific to behaviour management; four papers concerned participants who did not fit age criteria (16-64yrs) for this review; and the remaining four papers explored implications of ABI or available support for families, but were also not specific to behaviour management. Nine articles were independently selected by the two reviewers, with consensus achieved regarding the inclusion of a 10th paper.

Figure 3.1 PRISMA flow diagram for articles identified through database searches



3.4.1 Study Characteristics

There were a total of 112 participants included across the 10 studies, including 77 males and 35 females (mean age 31.7yrs), with mild to severe ABI. Sample sizes in the studies were consistently low, ranging from 1-37 participants. The demographic and injury characteristics of participants in each study are presented in Table 3.1

Table 3.1. Participant demographics

Studies	Individuals with ABI	Age (Mean)	Gender	Injury Type ABI/TBI	Time post injury (Mean)	Functional level	Caregiver Relationship (parent/spouse/ children/sibling/other)	Caregiver Age (Mean)	Caregiver Gender
Arco & Bishop (2009)	1	43	M	ABI	8 years	-	Parents	-	M=1 F=1
Carnevale (1996)	11	30.5	M=7 F=4	TBI	10.2 years	Mean coma duration in weeks = 5.8	Family Members/Caregivers	-	-
Carnevale et al. (2006)	37	40.5	M=28 F=9	24=TBI 13=ABI	7.6 years	Duration of unconsciousness <24h = 2 >24h = 34 Never unconscious = 1	Family Members/Caregivers	-	-
Carnevale et al. (2002)	27 (Undisclosed overlapping sample(G. J. Carnevale, Anselmi, V., Johnston, M.V., Busichio, K., Walsh, V., 2006))	38.9	M=18 F=9	TBI = 17 ABI = 10	8.7 years	Duration of unconsciousness <24h = 1 >24h = 26	Family Members/Caregivers	47.5	-
McKinlay & Hickox (1988)	2	40.5	M=1 F=1	Not specified	2.4 years	1.5wks (PTA ^a)	Spouse (F) = 1 Adult Son =1	-	-

Studies	Individuals with ABI	Age (Mean)	Gender	Injury Type ABI/TBI	Time post injury (Mean)	Functional level	Caregiver Relationship (parent/spouse/ children/sibling/other)	Caregiver Age (Mean)	Caregiver Gender
Palmisano & Arco (2007)	3	33	M=3	ABI	3.3 years	DRS ^b Score = 3 (Partial disability) DRS Score = 5 (Moderate disability) DRS Score = 3 (Partial disability)	Spouses	28.3	F
Sander et al. (2009)	15	22	M=10 F=5	TBI	-	Severe = 10 (GCS ^c Score ≤ 8) Moderate = 3 (GCS Score 9-12) Complicated mild = 2 (GCS Score 13-15)	Parent= 11 Spouse=3 Other=1	45	M=3 F=12
Wade et al. (2009)	9	15.04	M=5 F=4	TBI	9.7 months	Severe=2 (GCS Score ≤ 8) Moderate=7 (GCS Score 9-12)	Parents	-	-

Studies	Individuals with ABI	Age (Mean)	Gender	Injury Type ABI/TBI	Time post injury (Mean)	Functional level	Caregiver Relationship (parent/spouse/ children/sibling/other)	Caregiver Age (Mean)	Caregiver Gender
Wade et al. (2008)	9 (Overlapping sample (S. L. Wade, Walz, N. C., Carey, J. C., & Williams, K. M., 2009))	15.04	M=5 F=4	TBI	9.7 months	Severe=2 (GCS Score ≤ 8) Moderate=7 (GCS Score 9-12)	Parents	-	-
Whiting et al. (2012)	7	(between 18-62)	M=4 F=3	PBT ^a	-	-	Spouses = 5 Adult children = 2	45.8	M=4 F=3
Total	112	31.7	M=77 F=35	ABI=24 TBI=95	5.7 years^d		Parents = 21 Spouses = 12 Adult children = 3 Other/not specified = 76	45.4 (n=45)^e	M=8 F=19 (n=26)^d

^a Post Traumatic Amnesia

^b Primary Brain Tumour

^c Disability Rating Scale

^d Glasgow Coma Scale

^e Information not provided in all studies

Three studies specifically concerned participants with TBI (Sander, Clark, Atchison, & Rueda, 2009; Wade, Walz, Carey, & Williams, 2008; Wade, Waltz, Carey, & Williams, 2009), and the remaining studies consisted more broadly of participants with ABI. The cause of brain injury varied significantly, with TBI resulting from motor vehicle accidents (Carnevale, Anselmi, Busichio, & Millis, 2002; Carnevale, Anselmi, Johnston, Busichio, & Walsh, 2006; Palmisano & Arco, 2007), falls, construction-related accidents and assaults (Carnevale et al., 2002; Carnevale et al., 2006), and ABIs resulting from meningitis (Arco & Bishop, 2009), anoxia, stroke, arteriovenous malformations, encephalopathy, electrocution (Carnevale et al., 2006; Carnevale et al., 2002), aneurysm (Carnevale et al., 2006), and brain tumours (Palmisano & Arco, 2007; Whiting et al., 2012). Five articles did not specify the cause of brain injury (Carnevale, 1996; McKinlay & Hickox, 1988; Sander et al., 2009; Wade et al., 2008; Wade et al., 2009).

The presence of a behavioural impairment related to brain injury was required for participant inclusion in three studies (Carnevale, 1996; Carnevale et al., 2006; Carnevale et al., 2002); however, no detail was given regarding the definition of 'behavioural impairment'. Participant inclusion in the study conducted by Arco and Bishop (2009) required that parents rated at least 15/20 in the Head Injury Behaviour Scale (HIBS) and behaviour caused moderate or severe distress for one or both parents, *or* one or both parents reported a high level of burden on the Care Burden Scale (CBS). The remaining six studies did not specify inclusion requirements relating to the presence of behavioural problems. Five of the studies excluded participants with a history of psychiatric disorders, developmental disability, or substance abuse (Carnevale et al., 2006; Carnevale et al., 2002; Carnevale, 1996; McKinlay & Hickox, 1988; Palmisano & Arco, 2007).

The target behaviours varied significantly across the studies, including; aggressive/inappropriate behaviour (damaging property and verbal aggression), elopement, disinhibited and potentially dangerous behaviour while driving (Carnevale et al., 2006), routine behaviours such as maintaining cleanliness of bathroom, independently collecting belongings required for day activity and putting them away on return, communication with spouse regarding payment of bills and telephone messages (Palmisano & Arco, 2007), independence carrying out morning routine (including preparing breakfast, sitting at dining table, and eating breakfast) (Arco & Bishop, 2009), and ‘temper outbursts’ (McKinlay & Hickox, 1988). Six studies did not provide details regarding BOC exhibited by participants (Carnevale, et al., 1996; Carnevale, et al., 2002; Sander et al., 2009; Wade et al., 2009; Wade et al., 2008; Whiting et al., 2012).

Family members involved in studies predominately included parents (Arco & Bishop, 2009; Carnevale, 1996; Sander et al., 2009; Wade et al., 2008; Wade et al., 2009) and spouses (Palmisano & Arco, 2007; Sander et al., 2009; Whiting, et al., 2012), and were also identified as ‘relatives’ (McKinlay & Hickox, 1988), adult children (Whiting, et al., 2012) and ‘other’ (Sander et al., 2009). The remaining two studies did not specify the relationship of the caregiver to the individual with ABI (Carnevale et al., 2006; Carnevale et al., 2002) (See Table 3.1). However, as family members’ were involved within the baseline phase, it was inferred that they were included in the ‘caregiver system’. Although this was not explicitly stated, the families’ involvement was also not ruled out. For this this reason these studies were included within this review. However, the inclusion of these studies should, therefore, be viewed with caution.

These studies included a range of international perspectives: six studies were conducted in the USA, including New Jersey (Carnevale et al., 2006; Carnevale et al., 2002; Carnevale, 1996), West Texas (Sander et al., 2009) and Ohio (Wade et al., 2009; Wade et al., 2008); three studies were conducted in Australia, including Perth (Arco & Bishop, 2009; Palmisano & Arco, 2007) and Sydney (Whiting et al., 2012); and one was conducted in the UK (city unspecified) (McKinlay & Hickox, 1988).

3.4.2 Methodological assessment

Overall, the studies included in this review were of poor quality. The highest quality studies consisted of two level II evidence (NHMRC, 2009) randomized control studies, with a mean score of 7/10 according to the PEDro rating scale (see Table 3.2). All remaining studies consisted of level III-3 evidence studies (NHMRC, 2009), with a mean score of 7/12 according to the McMasters critical appraisal tool (with a maximum of 11 recorded for one study [Palmisano & Arco, 2007]) (see Table 3.3). These studies consisted of six single case designs (Arco & Bishop, 2009; Carnevale, 1996; McKinlay & Hickox, 1988; Palmisano & Arco, 2007; Sander, et al., 2009; Wade et al., 2009), one single case design with a concurrent control group (Wade et al., 2008), and one pre-test post-test mixed-method study (Whiting et al., 2012).

Table 3.2 *PEDro Scale – Critical Appraisal Tool*

Criteria (PEDro Scale) – RCT designs	Carnevale et al. (2006)	Carnevale et al. (2002)
1. Eligibility criteria were specified	Y	Y
1. Subjects were randomly allocated to groups	Y	Y
3. Allocation was concealed	N	Y
4. The groups were similar at baseline regarding the most important prognostic indicators	Y	Y
5. There was blinding of all subjects	N	Y
6. There was blinding of all therapists who administered the therapy	N	N
7. There was blinding of all assessors who measured at least one key outcome	N	N
8. Measures of at least one key outcome were obtained from more than 85% of the subjects initially allocated to groups	Y	Y
9. All subjects for whom outcome measures were available received the treatment or control condition as allocated or, data for at least one key outcome was analysed by “intention to treat”	Y	Y
10. The results of between-group statistical comparisons are reported for at least one key outcome	Y	Y
11. The study provides both point measures and measures of variability for at least one key outcome	Y	Y
TOTAL SCORE	6/10	8/10

Table 3.3 *McMaster University: Critical Review Form – Quantitative Studies*

Criteria (McMaster University – Critical Review Form)	Arco & Bishop (2009)	Carnevale (1996)	McKinlay & Hickox (1988)	Palmisano & Arco (2007)	Sander et al. (2009)	Wade et al. (2009)	Wade et al. (2008)	Whiting et al. (2012)
1. Was the purpose clearly stated?	Y	Y	Y	Y	Y	Y	Y	Y
2. Was relevant background literature reviewed?	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the sample described in detail?	Y	N	Y	Y	Y	N	N	Y
4. Was sample size justified?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
5. Were outcome measures reliable?	N	N	N	N	Y	Y	Y	N
6. Were outcome measures valid?	Y	N	N	N	Y	Y	Y	N
7. Intervention was described in detail?	Y	Y	N	Y	Y	Y	Y	Y
8. Contamination was avoided?	N/A	N	N/A	N/A	N/A	N/A	N/A	N/A
9. Cointervention was avoided?	N	N	N	N	N	N	N	N
10. results were reported in terms of statistical significance?	N	Y	N	Y	Y	Y	Y	N
11. Were the analysis method(s) appropriate?	N	Y	N	Y	Y	Y	Y	Y
12. Clinical importance was reported?	Y	Y	Y	Y	N	Y	Y	N
13. Drop-outs were reported?	Y	Y	N	N/A	Y	Y	Y	Y
14. Conclusions were appropriate given study methods and results?	N	Y	Y	Y	Y	Y	Y	Y
TOTAL SCORE*	8/12	7/12	5/12	8/10	10/12	10/12	10/12	7/12

*Although this tool consists of 14 criteria, not all criteria are relevant to each study design. Where this is the case, the criterion is marked as 'not applicable' (N/A)

3.4.3 Interventions

An overview of studies included is presented in Table 3.4. The two highest evidence studies reviewed (Carnevale et al., 2006; Carnevale et al., 2002), evaluated a Natural Setting Behaviour Management (NSBM) program. A NSBM group (including education and an individualised behaviour program) was compared with an education only group, versus a control group. Although the sample sizes were limited ($n < 40$), and there was an overlap of an undisclosed number between samples (Carnevale et al., 2006), these studies make significant contributions to literature regarding behaviour management in non-specialised community settings.

The NSBM program provides structured education and intervention to individuals with ABI in community settings, including home, work or school environments. The NSBM team in both of these studies consisted of doctoral-level psychologists and behaviour technicians working in collaboration with participants and caregivers (Carnevale et al., 2006; Carnevale et al., 2002). The first phase of the NSBM was consistent across these two studies, consisting of a three-week education phase. Participants and their caregivers in the NSBM (education and intervention) group and education-only group received education regarding common neurobehavioral sequelae of brain injury, with a gradual emphasis on the neurological factors underlying the particular target behaviours and practical behaviour management techniques. The second phase consisted of an individualised NSBM behaviour plan, which was developed in collaboration with participants and caregivers focusing specifically on targeted behaviours. Caregivers were responsible for implementing interventions, with interactive sessions held with staff throughout this process to elicit problem-solving regarding modification of behaviours.

Table 3.4 *Overview of studies included in review*

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Arco & Bishop (2009) (Single Case Design) [III-3(7/12)]	N=1 Individual with ABI and his caregivers (parents) Male, Age: 43yrs	Location: Perth Setting: Home-based Facilitator: Research Assistant	Observation of target behaviours using task analysis checklist	Parents trained to prompt individual with ABI to self- record behaviors and provide verbal & physical prompts throughout morning routine: preparing breakfast (PB), siting at dining room table (SDT), eating breakfast (EB)	Mixed and Inconclusive
Carnevale (1996) (Single Case Design) [III-3(8/12)]	N=11 Individuals with TBI & their families/caregivers M= 7 F=4 Mean age (years): 30.5 Mean age at injury: 20.3	Location: New Jersey Setting: home-based Facilitator: Masters level rehabilitation counselor & behaviour technician	Structured Interviews, Percentage change from baseline data, Attitudinal survey & symptom checklist	Educational module presented in 2 parts: Overview of common neurobehavioral sequelae of TBI, & General principals of behaviour management Frequency of staff contact was gradually decreased Follow-up sessions 1,3,6 & 12 month intervals	82% improvement in target behaviours. Greatest improvement occurring during educational phased. Caregivers felt program information was practical, reasonably paced, & assisted them in coping with daily stressors

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Carnevale, et al. (2006) (RCT) [II(8/10)]	N=37 Individuals with ABI & their caregivers (24=TBI) M=28 F=9 Mean age (years)=40.5 Mean time post- injury=7.6	Location: New Jersey Setting: home & community settings Facilitator: 2 clinical psychologists & a behaviour technician	Observation of target behaviours. Subscale in Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members QRS. Adapted version of Maslach Burnout Inventory (MBI) The Neurobehavioral Functioning Inventory Revised (NFI-R)	Natural Setting Behavior Management (NSBM) Education and individualised behaviour program, versus education only versus control group Data collection at 7 wks, 16wks & 30 wks post baseline	Target behaviours improved more frequently among NSBM participants than education and control group. Statistically significant improvements at 3- months follow-up ($P<.002$) Group differences not significant at first 2 follow-up points, but significant at 30-week follow up ($P=.05$)
Carnevale, et al. (2002) (RCT) [II(6/10)]	N = 27 Individuals with TBI & their families/ caregivers M= 18 F=9 Mean age (years): 38.9 TPI: 8.7 Caregivers mean age: 47.5	Location: New Jersey Setting: home & community settings Facilitator: Clinical psychologist and behaviour technician, supervised by an experienced neuropsychologist	Subscales of the QRS Adapted version of the MBI	Education only & education plus group met with NSBM staff for approx. 2 hrs wkly for 4 weeks. Education regarding common neurobehavioural sequelae of BI and practical behavior management techniques from a standard protocol. Education plus intervention group met with NSBM staff 2 hrs weekly for additional 8 wks & individualised treatment plans developed Data collection at 5wks and 14 wks post baseline	No statistical significance seen for all QRS subscales post intervention. MBI subscales also not statistically significant. In every ANCOVA, the covariate was statistically significant ($P< .05$), except for QRS subscale 11 (Personal Burden and Respondent) at 14 wks post baseline ($P= .052$) Indicates that initial baseline level on these subscales was highly predictive of outcome

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
McKinlay & Hickox (1988) (Single Case Design) [III-3(5/12)]	N=2 Male, Age: 41yrs TPI: 4 yrs PTA: 1 wk Case 4 Female, Age: 40 TPI: 9 months PTA: 2 wks	Location: UK Setting: Community- based Facilitator: not identified	Frequency counts of temper outbursts	Triggers of temper outbursts are identified. The relative prompted and rehearsed management strategies with participant, including anticipating trigger, going through 'temper routine' & recording event. Acceptable assertiveness behaviours are also taught, & relatives provided with info about handling stressful situations & their response to participant's problems Treatment period 19wks	Case 3 revealed no convincing improvements. Case 4 showed no temper outbursts in second half of treatment
Palmisano & Arco (2007) (Single Case Design) [(III-3)8/11]	N=3 (Males) Individuals with BI & their spouses Participant 1 = 44 yrs, caregiver 28yrs. Participant 2: 25yrs, caregiver 28yrs. Participant 3: 30 yrs, caregiver 29yrs	Location: Perth Setting: Home-based Facilitator: Researcher	Observations of task behaviour using task-analysis checklist Questionnaire of Resources and Stress – Short Form (QRS-SF) Purpose-designed questionnaire to measure social validity Length of intervention: 6 weeks	Spouses trained to use checklists to record target behaviours Development of individualised intervention plans reviewed during alternative weekly 1-hr home visits Follow-up 1 month post intervention	Significant improvement of target behaviour (P1 – 60% to 97%)(P2 – 62%-90%)(P3 – 60%-90%) No significant change in caregiver burden

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Sander, Clark, Atchison, & Rueda (2009) (Single Case Design, Feasibility study) [III-3(10/12)]	N=15 Caregivers of individuals with TBI Mean age (years): 22 M = 10 F = 5 Severe TBI = 10 Moderate TBI = 3 Complicated mild TBI = 2 Caregiver mean age: 45 F= 12 M = 3	Location: West Texas Setting: Community-based Facilitator: post-doctoral fellow in neuropsychology, & a master's-level counselor (developed content). Information presented by 2 neuropsychologists	Problem checklist (PCL) from the Head Injury Family Interview (HIFI) Supervision Rating Scale (SRS) Perceived Burden subscale of the Modified Caregiver Appraisal Scale (MCAS) Satisfaction survey Follow-up Interview	6 web-based videoconference sessions using PowerPoint (15-20 mins). Didactic education & interactive problem-solving. Number of sessions attended dependent on caregiver needs Data collection within 2 weeks of discharge from trauma centre 9 caregivers completed follow-up interviews average 18mths post-intervention	For each module participants rated satisfaction as 'very satisfied' or 'somewhat satisfied'. Majority participants reported amount of information presented was 'just right'. Some felt not enough info on general education, awareness, attention & memory

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Wade, Walz, Carey & Williams (2009) (Single Case Design) [III-3(10/12)]	N = 9 Adolescents with TBI and their families M= 5 F=4 Mean age (years): 15.04 (range: 11:8-18: 2) Mean time post injury: 9.7 months (3-21 months) 2= Severe TBI 7= Moderate TBI	Location: Ohio Setting: Home-based videoconferences Facilitator: 3 licensed psychologists	Website Evaluation Questionnaire (WEQ) Adapted version of the Online Satisfaction Survey (OSS, parent and teen versions) Completed by 7 mothers, 5 fathers & 9 adolescents at postintervention follow-up (average 11 days after completing final session [range 0-27 days])	Teen Online Problem Solving intervention (TOPS). Ten core sessions including information about TBI, problem solving, organizational skills, coping with behavioural changes, & planning. 4 additional sessions offered based on skills, therapist recommendations and interest Baseline & postintervention follow up (average 11 days after final session was completed)	All adolescents and parents completed at least 10 sessions. Participants rated the helpfulness and ease of use of website & videoconferences as moderate to high. Both parents and adolescents reported increased knowledge regarding targeted knowledge & skills

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Wade, Walz, Carey, & Williams (2008) (Single Case Design + control group) [III-3(10/12)]	N=9 Adolescents with TBI M= 5 F=4 Mean age (years): 15.04 (range: 11:8-18:2) Mean time post injury: 9.7 months (3-21 months) 2= Severe TBI 7= Moderate TBI	Location: Ohio Setting: Home-based videoconferences Facilitator: 3 doctoral-level clinical psychologists	The child Behavior Checklist (CBCL) Children's Depression Inventory The Global Severity Index of the Symptom Checklist 90-R Short form of Conflict Behavior Questionnaire (CBQ) The issues checklist and Issues Severity Scale	Families randomly assigned to TOPS (web-based problem-solving treatment programs for adolescents with TBI and families) with or without audio 5 families – TOPS-audio 4 Families – TOPS-no-audio TOPS consisted of 16 sessions. Ten session – problem-solving, communication & social skills training Self-assessment completed following ninth session. 4 supplementary sessions offered based on needs & interest	All 9 families completed 10 core sessions, 6 families completed 1 or more supplementary session Parents reported significantly fewer internalizing symptoms at follow up ($P=.03$). Adolescents & parents reported lower levels of depression. Parents reported significant reduction in parent-adolescent conflict ($P=.04$) and problem issues ($P=.01$) Participants in TOPS-audio group had greater outcome in some areas

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Whiting et al. (2012) (Pre – post test Mixed-Methods Design) [III-3(7/12)]	N=7 Caregiver & family member with Primary Brain Tumour (PBT) M = 4 F = 3 (between 18-62 yrs) Caregiver: Spouse=5 Adult children=2	Location: Sydney Setting: Training session based on knowledge of home- based interactions Facilitator: Radiation Oncologist, Neurosurgical clinical Nurse Consultant & Clinical Psychologist	The Strategy Use Measure (SUM) – purpose-developed. 9- item scale to evaluate use & knowledge of compensatory strategies to manage behavioural & cognitive changes Purpose-designed evaluation questionnaire	3.5 hour workshop comprised of 5 sessions, included education & group discussion	Family participants demonstrated significant increase in knowledge postintervention (P<0.05) Participants rated workshop to be ‘good’ and ‘very good’ with open-ended items reflecting increased knowledge

The effectiveness of web-based interventions was evaluated in three studies (Sander et al., 2009; Wade, et al., 2008; Wade, et al., 2009). Two of these studies evaluated the outcome of a Teen Online Problem Solving intervention (TOPS) using the same sample group (Wade et al., 2008; Wade et al., 2009). The TOPS program consisted of 16 sessions, including 10 core sessions providing problem-solving, communication, and social skills training to family members. The remaining six sessions addressed content relating to the stressors and burdens of individual families. After completion of these self-directed exercises, the families met with a therapist via video-conference to review exercises and implement a ‘problem-solving process’ (Wade et al., 2008). The first study examined outcomes for participants with ABI and their parents relating to depression and parent-adolescent conflict (Wade, et al., 2008), and the second study (Wade et al., 2009) evaluated the delivery of the TOPS program. The third web-based intervention (Sander et al., 2009) consisted of six videoconference sessions providing education and interactive problem solving for family members, evaluating their levels of perceived burden and satisfaction ratings.

Six studies involved community-based interventions, where family members were supported by professionals to develop individualised treatment plans in managing behavioural problems in their relatives with ABI (Arco & Bishop, 2009; Carnevale et al., 2006; Carnevale, 1996; Carnevale et al., 2002; McKinlay & Hickox, 1988; Palmisano & Arco, 2007). The remaining study evaluated the outcome of a half-day training workshop for family members of individuals with Primary Brain Tumour (PBT: Whiting et al., 2012). This session was delivered in a group format, consisting of five sections involving education and group discussions relating to behavioural and cognitive change following PBT and management strategies (Whiting et al., 2012).

Interventions were delivered by a range of health professionals, including neuropsychologists, clinical psychologists, behaviour technicians, counsellors, a radiation oncologist and a neurosurgical clinical nurse consultant. Three studies did not identify the profession/experience of the researchers facilitating interventions (Arco & Bishop, 2009; McKinlay & Hickox, 1988; Palmisano & Arco, 2007).

3.4.4 Outcomes

Outcomes measured included: observed change in targeted behaviours; levels of burden; stress and depression experienced by family members; levels of family functioning; improved knowledge regarding ABI and compensatory strategies to manage behavioural/cognitive change following ABI; and satisfaction with interventions among family members/caregivers. The outcome measures varied between studies (see Table 3.4), with those most utilised including: observation of target behaviours using structure checklists (Arco & Bishop, 2009; Carnevale et al., 2006; Carnevale, 1996; McKinlay & Hickox, 1988; Palmisano & Arco, 2007); subscales of the Questionnaire on Resources and Stress for Families with Chronically Ill of Handicapped Members (QRS: Holroyd, 1987) (Carnevale et al., 2006; Carnevale et al., 2002; Palmisano & Arco, 2007); an adapted version of the Maslach Burnout Inventory (MBI: Maslach, Jackson, & Leiter, 1996) (Carnevale et al., 2006; Carnevale et al., 2002); attitudinal and satisfaction surveys (Carnevale, 1996; Sander et al., 2009; Wade et al., 2009); purpose-designed questionnaires (Palmisano & Arco, 2007; Whiting et al., 2012); and interviews (Carnevale, 1996; Sander et al., 2009).

Of the five studies that recorded behaviour change following intervention (Arco & Bishop, 2009; Carnevale et al., 2006; Carnevale, 1996; McKinlay &

Hickox, 1988; Palmisano & Arco, 2007), three reported significant improvements in target behaviours (Carnevale et al., 2006; Carnevale, 1996; Palmisano & Arco, 2007). However, only one of these studies consisted of an evidence class II RCT design (Carnevale et al., 2006) using reliable outcome measures. In this study a significant reduction in frequency of target behaviours was reported ($P < .002$) in the Natural Behaviour Setting Management (NSBM) group (education plus intervention) at three months post-intervention. Research conducted by Carnevale (1996), which also evaluated the NSBM program, revealed 82% improvement of target behaviours among participants, and Palmisano and Arco (2007) reported improvement in independent behaviours in all three cases presented, with behaviours improving from a mean of 61% to 92% of task completion at one month follow-up. However, the reliability of these results is limited due to weak study design and data collection methods.

Interestingly, the two studies measuring caregiver burden (Carnevale et al., 2002; Palmisano & Arco, 2002) revealed no significant changes following behavioural interventions, even though improvements in target behaviours were reported.

Family members who participated in the Teen Online Problem Solving intervention (TOPS) reported significantly fewer internalising symptoms, lower levels of depression, and a reduction in conflict and problem issues with their relative with ABI (Wade, et al., 2008) (see Table 3.4). Across the four studies that evaluated the caregivers' satisfaction with the intervention (Carnevale, 1996; Sander et al., 2009; Wade, et al., 2009; Whiting et al., 2012), results suggested families were

satisfied with content, felt information presented was practical, and reported an increase in knowledge.

3.4.5 Methodological limitations

There were a number of methodological limitations consistently noted. Only 112 participants were included across the ten studies, significantly impacting the generalizability of results. Furthermore, only two studies consisted of a RCT design (Carnevale et al., 2006; Carnevale et al., 2002), with the absence of comparison groups limiting outcome reliability of the remaining studies.

Further clarification was also needed with regard to participant inclusion criteria and family involvement in managing behaviours. The presence of behavioural impairment was required for participant inclusion in three studies (Carnevale, 1996; Carnevale et al., 2006, Carnevale et al., 2002); however, a definition of behavioural impairment was not given, and six studies did not provide details regarding the behaviour problems exhibited by participants (Carnevale, et al., 1996; Carnevale, et al., 2002; Sander et al., 2009; Wade et al., 2009; Wade et al., 2008; Whiting et al., 2012).

The relationship of the caregiver to the individual with ABI was not specified in two studies (Carnevale, et al., 2006; Carnevale, et al., 2002), and in one study no detail was provided regarding the involvement of paid versus unpaid caregivers in the intervention (Carnevale, 1996). In an additional four studies, the extent of family involvement in managing behavioural problems was not clearly outlined (McKinlay & Hickox, 1988; Palmisano & Arco, 2007; Wade et al., 2009; Wade et al., 2008).

There was also a lack of rigorous follow-up data specific to the improvement of target behaviours. The most reliable follow-up data was recorded following the RCT conducted by Carnevale et al. (2006) at 30 weeks post-baseline. Carnevale (1996) also collected follow-up data at 12 months post-baseline, however the validity of these results are limited due to weak study design and data collection methods. Of the remaining four studies that collected follow-up data (Carnevale et al., 2002; Palmisano & Arco, 2007; Sander et al., 2009; Wade et al., 2009), only one study reported on the frequency of target behaviours (Palmisano & Arco, 2007), with data collected at one month post-intervention.

3.5 Discussion

This systematic review examined the evidence base for the efficacy of family involvement in behaviour management following ABI in community settings. While none of the studies provide sufficient evidence for practice guidelines, they did indicate possible benefits of family involvement in behaviour management, and intervention techniques meriting further validation.

3.5.1 Methodological assessment

Among the 10 articles meeting criteria for inclusion in this review, there were no evidence class I studies, and only two evidence class II studies consisting of RCT designs (Carnevale, et al., 2006; Carnevale et al., 2002). This lack of high class research reflects the difficulty faced in selecting rigorous and appropriate research design to evaluate rehabilitation programs for individuals with ABI and their families

(Baddeley, Meade, & Newcombe, 1980). As individuals with ABI are typically heterogeneous, due to the diversity of brain injury (Gelber & Callahan, 2010), it can be difficult to describe a sample due to a lack of (adequate) records (Godfrey & Smith, 1995). This is evident from this review. In general, the studies have not provided adequate information on the population sample characteristics, definition of BOC and methodology to allow for replication.

Furthermore, no studies provided information on the likelihood of the use of co-interventions. As reported by Comper and colleagues (Comper, Bisschop, Carnide, & Tricco, 2005), brain injury often results in a number of complaints, making it possible that individuals were receiving treatment for various symptoms while also taking part in the behavioural interventions. This is an important consideration, as behavioural problems may be present as a result of underlying factors, including memory difficulties, and additional cognitive and physical impairments for which the individuals may be receiving support.

The major limitation of the two evidence class II studies (Carnevale et al., 2006; Carnevale et al, 2002) were the small, and overlapping samples (n=37, n=27), limiting the generalisability of these results. Given the heterogeneity of this population (Ponsford et al., 2013), larger samples are necessary if outcomes are to have sufficient statistical significance in detecting clinically meaningful changes (Smith & Godfrey, 1995). Furthermore, the relationship between the caregiver/family members and participants with ABI were not specified in either of these studies. However, these findings do warrant further investigation of the efficacy of the NSBM program.

There was also a lack of information provided across the studies relating to intervention techniques, participants' demographic and family involvement. Wade et al. (2008) did not provide details regarding the individual 'problem-solving' process and the extent to which the family was involved. Two studies (Wade et al., 2009; Wade et al., 2008) did not provide the specific age of participants (mean age =15.03; range = 11-18 years), so inclusion of these studies within this review should be viewed with caution. The separate roles of family and paid caregivers were also not defined within the intervention conducted by Carnevale (1996). The people involved in the 'caregiver system' were identified for all participants, which included paid caregivers, such as a part-time attendant, private-duty nurses, school personnel, personal care attendants and supported employment personnel, as well as relatives of the participants with ABI. Throughout this article both 'caregivers' and 'family' appear to be referred to separately; however, it was not explicitly stated as to whether the 'caregiver' or 'family' member completed the caregiver attitude survey. Although the family member was included within the 'caregiver system', to what degree they were involved in the intervention was unknown. This limited the reliability of this study according to the inclusion requirements. Furthermore, results were reported in a purely descriptive manner, utilising case studies, and there was no mention of the use of standardised outcome measures or whether decreases in behavioural problems reached statistical significance.

Arco and Bishop (2009) presented three single case designs, with only one fitting the inclusion criteria for this study. The parents were trained to prompt their adult-child with ABI to independently carry out a morning routine (preparing and eating breakfast). However, limited detail was provided regarding the training given to parents, prompts used and at what rate they were withdrawn. These

methodological limitations, as well as the mixed and inconclusive findings of this study, also limit the applicability of results.

Five of the studies excluded participants with a history of psychiatric disorders, developmental disability or substance abuse (Carnevale et al., 2006; Carnevale et al., 2002; Palmisano & Arco, 2007; Carnevale, 1996; McKinlay & Hickox, 1988). While this ensured that behavioural problems related specifically to the brain injury, it could also be argued that excluding these behaviours may have resulted in a non-representative sample. Pre-existing behavioural/psychiatric disorders and substance abuse are reported risk factors for TBI (Drubach, Kelly, Winslow, & Flynn, 1993; Rutter, 1981), adding to the complexity of management and coping for all concerned.

3.5.2 Interventions

All studies included in this review involved either an educational phase or family training relating to the use of checklists and management strategies. Education included information on common neurobehavioural sequelae of brain injury (Carnevale, 1996; Carnevale et al., 2006; Carnevale et al., 2002; Sander et al., 2009; Wade et al., 2009; Wade et al., 2008; Whiting et al., 2012), including discussion relating to possible factors that contribute to the behaviour problem identified by each family (Carnevale, 1996; Carnevale et al., 2006; Carnevale et al., 2002). General principles of behaviour management were also provided, including antecedent and consequence analysis (Carnevale, 1996; Carnevale et al., 2006; Carnevale et al., 2002), identifying triggers and handling 'stressful situations' (McKinlay & Hickox, 1988), and strategies to reinforce appropriate behaviours and

the use of external cueing (Wade et al., 2009), problem-solving (Sander et al., 2009; Wade et al., 2008), and strategies for managing behavioural and cognitive changes after PBT (Whiting et al., 2012). Families were trained in how to use observation checklists (Palmisano & Arco, 2007; Carnevale, 1996; Carnevale et al., 2006; Carnevale et al., 2002), and to prompt an individual with ABI in self-recording behaviours (Arco & Bishop, 2009). Education delivered to families through the web-based interventions also included sessions more broadly relating to ABI, including topics relating to reduced memory and attention, changes in language and social communication, reduced initiation and organization (Wade et al., 2009), and social skills training (Wade et al., 2008).

The educational components included in these studies were not outlined in enough detail to replicate the content. However, the broad categories relating to common neurobehavioural sequelae and general principles of behaviour management were included across a majority of these studies (Carnevale, 1996; Carnevale et al., 2006; Carnevale et al., 2002; Sander et al., 2009; Wade et al., 2009; Wade et al., 2008; Whiting et al., 2009). Carnevale and colleagues (2006) delivered education using a standard protocol, and stated the NSBM training manual could be obtained for further detail. However, the researcher was unsuccessful in making contact with the authors for this information.

There was great disparity in the behaviour problems identified by family members across the studies, including socially inappropriate behaviours (e.g. damaging property and verbal aggression) and apathy (limited independence in routine behaviours and organisation relating to daily activities), which is reflective of the wide range of behavioural issues problems reported following ABI within

community settings (Johnson & Balleny, 1996; Kelly et al., 2008). The broad scope and cause of behaviour problems adds to the complexity of conducting research in this field and further highlights the importance of developing management approaches that are equally varied and individualised to target specific behaviour problems (Yody et al., 2000).

According to Prigatano (1992), behavioural problems are not necessarily related to neurological impairment, but may constitute a reactionary behavioural disturbance. This assertion is based on research conducted by Hinkeldey and Corrigan (1990) that indicates irritability following ABI correlates significantly with forgetfulness, symptoms of fatigue when other people are around and experiencing difficulty following conversation. Anger and irritability can also arise from high levels of noise, specific activities or the demands of therapy (Ponsford et al., 2013). It is, therefore, important that families understand the basis of the behavioural changes and are provided with strategies to identify triggers and antecedents. This is necessary in developing a complete picture of behavioural problems. Families should also be encouraged to focus on the individuals' strengths within a meaningful environment, realising the individuals' potential to replace BOC with more adaptive behaviours (Ponsford et al., 2013; Ylvisaker et al., 2005).

The challenge then is to develop interventions that are specific to individual needs but also are methodologically sound, increasing reliability and allowing for replication. Although this was not achieved adequately by any of the studies reviewed, the RCT designs conducted by Carnevale et al. (2006; 2002) consist of research designs showing most potential towards this goal.

3.5.3 Outcomes

Significant findings were reported in five out of 10 studies (Carnevale et al., 2006; Wade et al., 2008; Palmisano & Arco, 2007; Whiting et al., 2012; Carnevale, 1996), with results revealing significant improvement in target behaviours, caregiver satisfaction and improved knowledge relating to neurobehavioural sequelae following ABI and management strategies.

Findings suggest that education alone may not be sufficient in addressing long-term behavioural problems. Results reveal significant change in behaviour following intervention consisting of both an educational component and the development of individualised behaviour plans (Carnevale et al., 2006). The importance of providing education to family members has also been highlighted by Sander et al. (2009), with participants reporting education sessions relating to the management of emotional and behavioural problems to be the most beneficial. This has also been emphasised in previous research (Murray et al., 2006) in which families reported information on how to manage behavioural changes as the highest unmet need.

The study conducted by Carnevale et al. (2002) evaluated the effects of NSBM in reducing caregiver burden, revealing no significant changes following the intervention in any of the groups. As stated by Carnevale et al. (2002), these results suggested that initial levels of caregivers' burden and distress were highly predictive of these ratings at outcome, regardless of participation in behaviour intervention. These findings are also in consensus with studies conducted by Palmisano and Arco (2007), where there was no correlation between improvement of functional behaviour and reported caregiver burden. It was suggested that possibly a more

general approach to behaviour management (not one that targets specific behaviours) might have a more positive impact on family burden (Palmisano & Arco, 2007).

The studies included in this review support the importance of measuring levels of caregiver burden in conjunction with behaviour improvement following intervention. This will impact the future development of community-based behavioural support most beneficial to overall wellbeing and improved family functioning. These studies also support the need for further research identifying the relationship between behavioural disturbances and caregiver burden, which appears to be a complex and multilayered phenomenon (Wells, Dywan, & Dumas, 2005). As reported by Marsh, Kersel, Havill and Sleigh (1998), emotional difficulties, particularly anger and apathy, cause significant distress for caregivers. However, with regard to the impact that caregiving has on their own lives, caregivers are most distressed by the loss of personal free time (Marsh et al., 1998). This suggests that even with the reduction of behavioural problems, levels of burden will remain high where individuals with ABI are dependent on their caregivers for assistance in daily routine tasks.

The web-based interventions were also supportive of family involvement in behaviour management, reporting positive outcomes relating to functioning and problem-solving skills (Wade et al., 2008), increased knowledge, and satisfaction with intervention delivery (Sander et al., 2009; Wade et al., 2009). The study conducted by Wade et al. (2009) also raised an important issue, with the inclusion of measures relating to families' perceptions of the ease of use and helpfulness of the videoconferences. The importance of the quality of this therapeutic relationship was not measured in any of the other studies reviewed. As reported by Cattelani et al.

(2010), if participants do not trust or respect the therapist they will be unlikely to cooperate and will, therefore, not benefit from the intervention as much as those with a positive attitude towards the working relationship. This issue should be addressed when evaluating the effectiveness of interventions tailored for individuals with behavioural problems following ABI (Cattelani et al., 2010).

Overall, there was a lack of adequate follow-up data recorded across all ten studies relating to the impact the intervention had on target behaviours and burden experienced by the family caregiver specific to behavioural problems. This was particularly evident following web-based interventions, where participants reported increased knowledge following intervention (Sander et al., 2009; Wade et al., 2009), but there was no follow-up examining the application of knowledge acquired by family members in managing behavioural problems.

Similarly, results of the study conducted by Whiting et al. (2012) are limited as no follow-up data was collected to examine if new knowledge gained during the half-day workshop was applicable to the caregivers' daily experiences within community settings. The purpose-designed outcome measure used (SUM) in this study had also not been validated, limiting reliability of results.

3.5.4 Limitations

Although this systematic review used valid methodologies in identifying studies, there are some limitations that should be recognised. Limitations to the search strategy may mean the review is not completely representative of the overall relevant literature. Specific conditions resulting in ABI, such as dementia,

Parkinson's, and stroke, were not included as keyword searches. Specific cognitive and behavioural outcomes following ABI that present challenges, such as apathy and absconding were also not included as search terms. Furthermore, studies were only considered if they were published in English and published in peer-review journals or books. Therefore, studies were not considered if they were published in government documents and conference proceedings.

The author was also unsuccessful in making contact with researchers to acquire missing information and clarify study methodology; therefore, studies that did not sufficiently report on aspects of their methods may have received a low quality score, despite being well-conducted studies.

The critical appraisal tools used to evaluate the quality of the research may have also limited conclusions made, as each section was weighted equally. For example, criteria such as 'validity of outcome measure' and 'justification of sample size' contributed equally to the final overall quality rating.

3.5.5 Implications

The evidence supporting the involvement of family members in behavioural interventions carried out in community settings is promising, with improvements seen in target behaviours and high levels of satisfaction reported by family members. Results were supportive of multi-phase interventions, consisting of education components followed by the development of individualised treatment plans specific to the individuals' behavioural problems. However, due to the paucity of high evidence studies, no conclusions can be drawn regarding their efficacy. There were

only two RCT studies included in this review, and these studies had a limited sample size ($n < 40$), and overlap in their sample group. The relationship between caregivers and participants with ABI were also not defined, limiting the reliability of conclusions drawn from this review regarding the involvement of family members in managing behavioural problems following ABI. More research is required, with larger sample sizes and more rigorous design including proper comparison groups, with RCTs most desirable and well-designed ($n = 1$) trials. Studies should include more explicit detail regarding the relationship of the caregiver, the role of the caregiver within the behavioural intervention, and the specific target behaviours displayed by individuals with ABI. Studies should also examine the impact of family-led behavioural intervention on target behaviours and levels of family burden. It will only be when this is achieved that we can determine the efficacy of family involvement in managing behavioural problems.

3.6 Conclusion

The findings of this systematic review provided important insight relevant to this thesis, presenting evidence to support family involvement in behavioural interventions for individuals with ABI, but also providing foundations to inform the content and delivery of a family-directed behaviour management (FDBM) program. The next step in developing the FDBM program and informing best practices, was to gain feedback from key stakeholders. This was achieved through a Delphi process, which is presented in the following chapter.

CHAPTER FOUR

STUDY TWO: DELPHI STUDY

Related publications:

Fisher, A., Bellon, M., Lawn, S., & Lennon, S. (2017). Identifying Current Practices and Supports in Behaviour Management following ABI in South Australian Community Settings: A Delphi Study. *Brain Impairment, 1-15*. DOI: 10.1017/Brimp.201.36.

Fisher, A., Bellon, M., Lawn, S., & Lennon, S. (2017). The development of a family-directed approach to supporting behaviour changes in individuals with ABI in community settings: A Delphi study. *International Journal of Therapy and Rehabilitation, Under Review*.

4.1 Introduction

This chapter will outline the aims of the Delphi study, followed by the methodology employed and the significant results that emerged. The findings will then be discussed in relation to the relevant research objectives. The contributions this study makes regarding the further development of the FDBM program and the intervention protocol for the pre-test post-test pilot study will then be presented in Chapter Five.

4.2 Aims

The Delphi study consisted of two parts. The aim of Part A was to reach consensus regarding current and best practices in supporting family caregivers in the management of BOC. In particular, it addressed the following research questions:

- What strategies were family caregivers using to manage BOC presented by their relative with ABI in community settings?
- What South Australian services and supports were available to family caregivers that address the management of BOC in relatives with ABI?

Part B of the Delphi process was used to further refine the content of the FDBM program and the delivery protocol for the pilot testing of the final program, which is presented in Chapter Five. In particular, this component of the Delphi study gained feedback on (1) the accessibility of the FDBM program for family members,

and (2) the appropriateness of the program in effectively supporting family involvement in behavioural interventions.

4.3 Design

A Delphi method is an iterative process of obtaining the most reliable consensus of a group of key stakeholders best-suited to addressing the research questions (Okoli & Pawlowski, 2004; Skulmoski, Hartman, & Krahn, 2007). This method is the most effective when the goal is to improve understanding of problems and develop solutions (Skulmoski et al., 2007). The Delphi method has been applied to a wide variety of situations as a tool for expert problem solving; with variations of the method being tailored to specific problems and outcome goals (Okoli & Pawlowski, 2004).

The Delphi method has many benefits compared to the traditional survey approach as a research strategy (Okoli & Pawlowski, 2004), and has been selected for the following reasons:

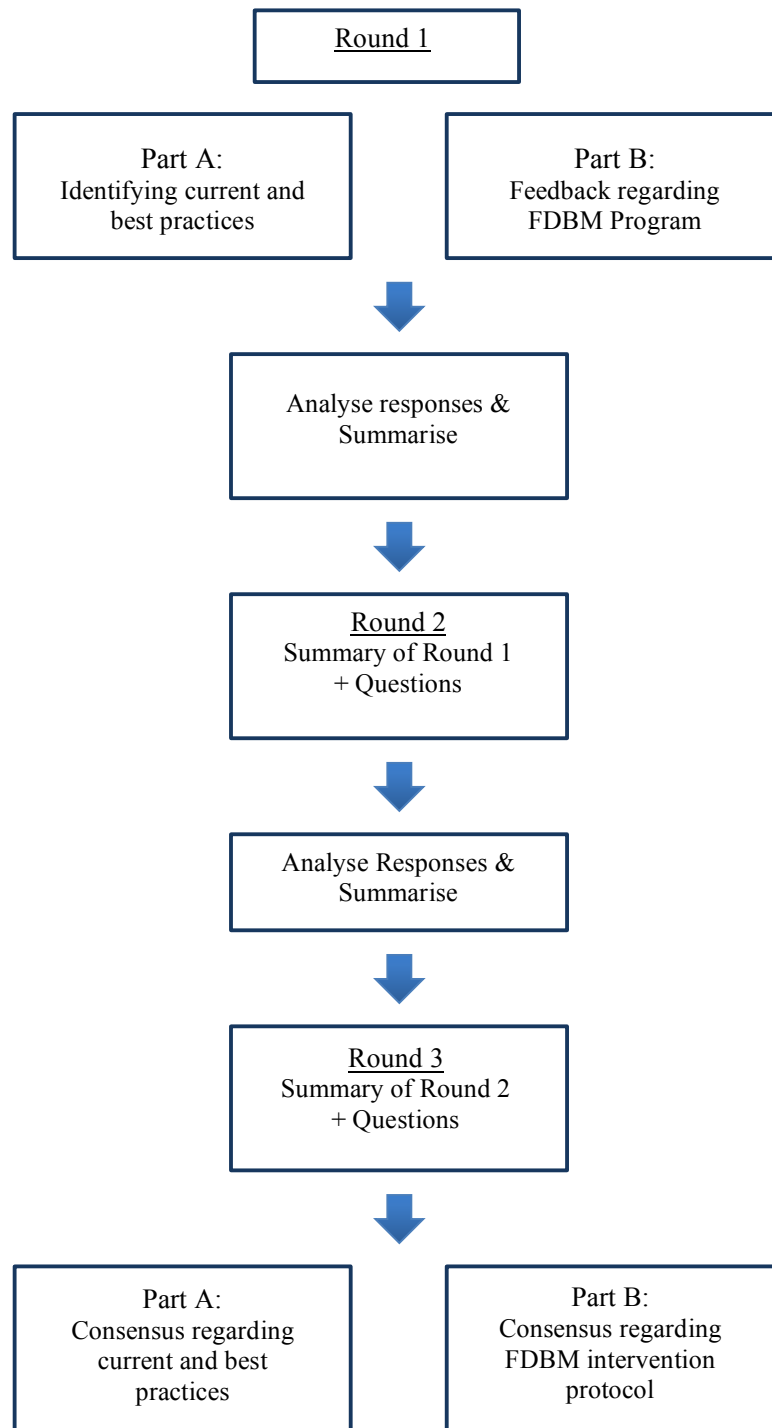
1. This study is dealing with a complex issue requiring knowledge from people who have expertise in this area. Participants must understand the complex nature relating to the cause and presentation of problem behaviours among individuals with ABI, and also have current knowledge of current support services and families' experiences within the community.
2. The research questions will be answered most appropriately by a panel of key stakeholders' responses, rather than any individual key stakeholder's response. Delphi is an appropriate group method, and is desirable in that it

does not require the participants to meet physically, which could be impractical for key stakeholders residing state-wide.

3. The Delphi process is flexible in design, and is amenable to follow-up interviews. This results in richer data that leads to greater insight regarding the fundamental research questions.

A three-round Delphi process was considered appropriate for this study, giving key stakeholders a chance to review feedback, change their answers and to comment on the emerging and collective perspective of the expert panel. The process of the Delphi method is illustrated in Figure 4.1.

Figure 4.1 *Delphi process*



4.4 Ethical Considerations

Ethics approval for this study was obtained from the Royal Adelaide Hospital Human Research Ethics Committee (Protocol No: 140906), and the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University (Project Number: OH-00109). See Appendix 2 for approval letter.

4.5 Methodology

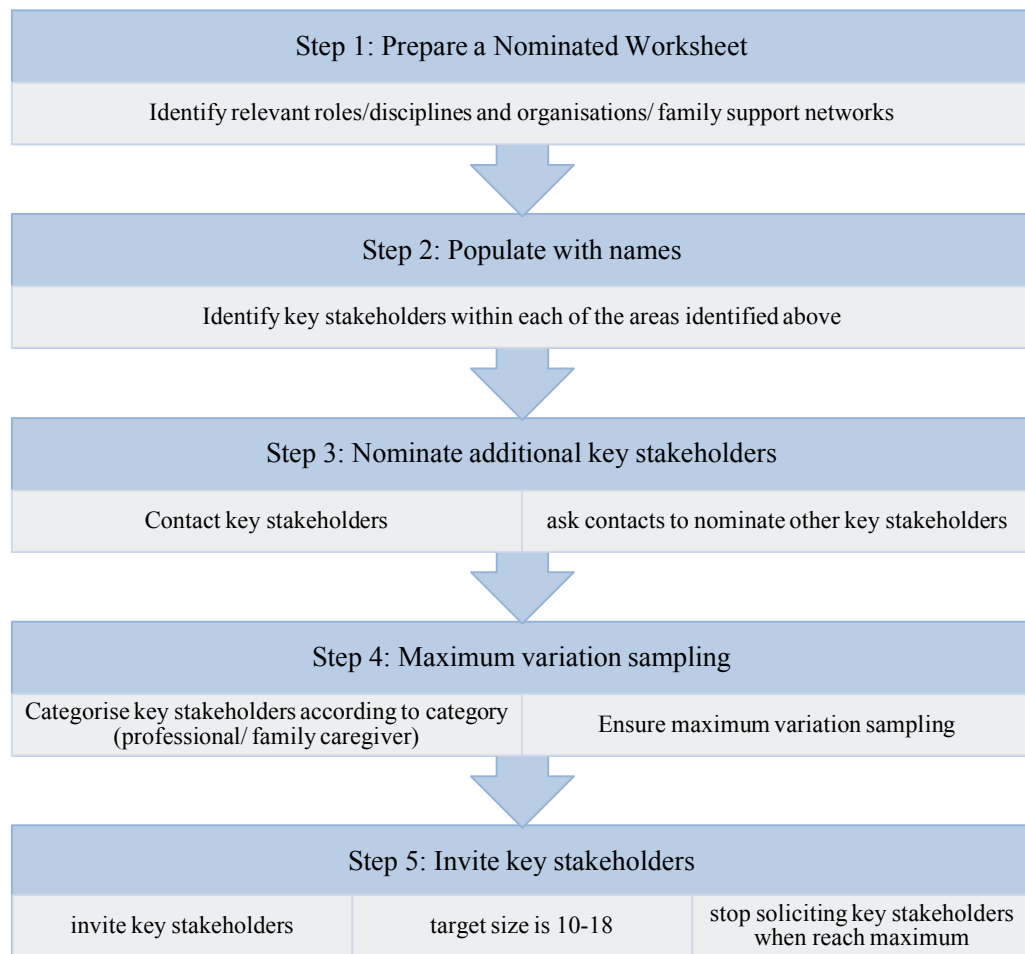
4.5.1 Selecting participants

Since the purpose of a Delphi is not to represent the general population but rather to seek ‘expert’ opinion, a purposive sample is necessary (Fink & Kosecoff, 1985). For the purpose of this study participants consisted of experts by experience (family caregivers) and experts by service delivery for ABI (rehabilitation professionals) from within SA. These combined perspectives were considered important in effectively answering the research questions. As this research specifically examined a South Australian perspective, key stakeholders were recruited from within SA, rather than nationally/internationally. The intention was to recruit key stakeholders that were knowledgeable about the current services available in SA, which was important in effectively answering relevant research questions.

Participant criteria for the Delphi panel required they were rehabilitation professionals/family caregivers, were 18 years or above, and were directly involved (and have been for a minimum of two years) in the management of BOC exhibited by individuals with ABI living in community settings.

An initial list of key stakeholders was identified through professional contacts, with the “snowball” sampling technique then being utilised to generate subsequent participants. This technique is recommended by Fink and Kosecoff (1985) and refers to an outreach strategy, where an individual with the desired characteristics is identified and their social networks are used to recruit similar participants (Denscombe, 2010). Once a list of initial contacts was generated, a letter of invitation was sent to these organisations to identify further possible participants (See Appendix 3). The process used to select participants is outlined in Figure 4.2 (adapted from Okoli & Pawloski, 2004).

Figure 4.2 *Method of participant recruitment for Delphi study*



Step 1. Preparing a nomination worksheet

The purpose of the nomination worksheet was to categorise the key stakeholders before identifying them (Okoli & Pawlowski, 2004). The roles/disciplines and organisations identified to be most fruitful in identifying key stakeholders relevant to the research questions are presented in Table 4.1.

Table 4.1 Roles/disciplines identified for recruiting participants

Roles/ disciplines	Organisations
1. Professionals	<ul style="list-style-type: none">• BIRU/BIRCH• Brain Injury SA• Disability Services S.A• Families4Families Inc.• Community Reentry Program (CRP)
<ul style="list-style-type: none">• Brain Injury Rehabilitation Unit (BIRU)• Brain Injury Rehabilitation Community and Home (BIRCH)• Brain Injury SA• Disability Services SA• Families4Families Inc.• Community Reentry Program (CRP)• Internet sources	
2. Family caregivers	<ul style="list-style-type: none">• Families4Families• Community Reentry Program (CRP)• Professional networks

Step 2. Populating the nomination worksheet with names

Once the nomination worksheet was complete, the categories were populated with names of potential key stakeholders for the Delphi study. Each heading (role/discipline, organisation) represented a different lens for identifying and considering key stakeholders, and it was expected that there would be a high degree of overlap of key stakeholder names between and within headings (Okoli &

Pawlowski, 2004). However, this multi-lens perspective was helpful in identifying as many key stakeholders as possible (Okoli & Pawlowski, 2004). Personal lists were first used to fill as many names as possible into the appropriate categories. This is the baseline procedure. However, as the personal lists were limited and biased to the researcher's personal networks, each list was then further populated according to the category using the following strategies:

Professionals – the first step involved contacting each of the organisations identified, and sending out an invitation for participation. This letter was addressed to key stakeholders identified using personal networks, who were then asked to distribute this letter to other professionals within the organisation who met participation criteria.

Family Caregivers – Family caregivers were identified using personal networks within the identified organisations. Potential participants were contacted by these key contacts within organisations, and those that were interesting in taking part were asked to give consent for the primary researcher to make contact regarding the details of the project.

Organisations - Identified organisations were contacted via the Web, e-mail, and/or phone. The aim was to contact key stakeholders who could then provide additional contacts within and outside their own organisations.

Step 3. First-round contacts – Nominations for additional key stakeholders

At this point, the key stakeholders identified were asked to nominate others for inclusion on the list, resulting in a total 18 letters of invitation being distributed

by the researcher and key contacts combined. A brief description of the Delphi study was provided, explaining that they had been identified as key stakeholders regarding behaviour management following ABI, and inviting them to participate.

Step 4. Maximum variation sampling

At this step, key stakeholders were grouped into two sub-lists: professionals and family caregivers. This occurred in conjunction with step three. For the purpose of this study, the aim was to gather a sample that was as diverse as possible to capture the breadth of the phenomenon of interest (Minichiello et al., 2004). This ensured that both professional and personal experiences were represented on the panel. A minimum of 20% of family caregivers on the panel was considered appropriate for this study.

Step 5. Inviting key stakeholders to the study

Eighteen key stakeholders were invited to participate, which was considered appropriate given that drop-out rates tend to be low when participants have verbally agreed to be involved in the study (Okoli & Pawlowski, 2004).

Participants were contacted and given an explanation of the subject of the study and the procedures required, including the commitment required. For this study, key stakeholders were asked to commit to completing up to six 10-20 minute questionnaires (with exception of the first round questionnaire, which was expected to take 30-40 minutes) and return them within two weeks of receipt. This consisted of a total of two hours involvement over a period of up to three months.

For this study, it was required that participants had access to email for receiving and returning questionnaires. The first round questionnaire was emailed to each participant the same day they confirmed their desire to participate.

4.5.2 Sample size justification

There is no agreed upon group size for a Delphi method, with numbers varying in studies from four to 171 key stakeholders (Okoli & Pawlowski, 2004). There is therefore no “typical” Delphi; rather the method is modified to suit the circumstances and research questions. As stated by Okoli and Pawlowski (2004), the Delphi group sample size is not dependent on statistical analysis, but rather on group dynamics of key stakeholders in arriving at consensus. However, literature recommends 10 to 18 key stakeholders on a Delphi panel (Okoli & Pawlowski, 2004). This number was considered achievable given the specialised nature of this study.

4.5.3 The Delphi Process

The Delphi method utilised was consistent with the four key features outlined by Rowe and Wright (1999):

1. The Delphi participants remained anonymous, allowing participants to express their opinions freely without pressure to conform with others on the Delphi panel. Decisions were therefore evaluated on their merit, not according to who had proposed them.

2. Iteration: allowed the participants' to reflect on the group's responses at each round and refine their views.
3. Controlled feedback: informed the participants of the other participant's perspectives, and provided the opportunity for them to clarify or change their views.
4. Statistical aggregation: allowed for quantitative analysis and interpretation of group responses.

Round 1.

This round consisted of an anonymous open-ended questionnaire regarding the research objectives. Participants were asked to (1) identify strategies that family caregivers use to manage BOC in adults with ABI, and (2) what services and supports are currently available to family caregivers that address the issue of behaviour management following ABI in community settings in SA (see Appendix 4 for Round 1 cover letter and questionnaire). Participants were asked to identify a minimum of five and maximum of 10 items for each question. According to Keeney and colleagues (Keeney, Hasson, & McKenna, 2011) these numbers should safeguard against an unmanageable number of items for the second round and should also ensure a reasonable to good response rate. During this round, demographic information was also collected regarding the participants' role, employment (if applicable), and length of time managing behaviours following ABI in community settings. This information was not made available to other participants, only the researcher.

Round 2.

In the second round, the items from the first round were presented to participants. Participants were asked to rate these items using a Likert-type scale numbered 1 to 5, with 1 indicating very important; 2, important; 3, neither important or not important; 4, less important; and 5, unimportant. Participants were informed that the aim of the exercise was to reach consensus (a minimum of 75% agreed response) regarding research objectives. In Part A of the Delphi, participants were also asked to indicate whether they were aware of each service that was identified as being specific to supporting family caregivers in behaviour management following ABI using a closed yes/no question following each item. The Round 2 cover letter and questionnaire is included in Appendix 5.

Round 3.

In the third round, participants were provided with items that had already reached consensus in Round 2 and items that were close to reaching consensus (>50% consensus in either upper or lower categories). Scores from the upper (e.g. 'very important' and 'important') and lower bands (e.g. 'not important' and 'not at all important') were collapsed to provide a group consensus as either 'important' or 'not important'. Where there was no trend towards consensus (<50% agreement) in either the upper or lower bands, the item was omitted from the Round 3 questionnaire. In this round the participants were provided with the group consensus rate from Round 2 (as a percentage), and were asked to reconsider their original response in the context of the group response. Participants were also informed that they did not have to change their original response if they did not wish to. Following

Round 3, the results from the Delphi process were emailed to participants, who were then invited to make comments on the outcome of the study. See Appendix 6 for Round 3 cover letter and questionnaire.

4.5.4 Administering the questionnaires

The Delphi questionnaires were administered using SurveyMonkey, a web-based survey tool. The advantage of this “rapid” online approach is that it ensured a minimum turnaround time between questionnaires. However, it was estimated that it would take about a month to receive the completed questionnaires for analysis, before the next round could be sent out (Okoli & Pawloski, 2004). These factors were considered when developing an appropriate timeline for this process. Participants were given two weeks to respond to each round, as recommended by Delbecq et al. (1975, cited in Keeney et al., 2011), and were emailed a reminder one week before the set return date.

4.5.5 Analysis

Data analysis of the Delphi process involved both qualitative and quantitative data. Qualitative data was analysed after the first round of the process, which used open-ended questions to collect expert opinions. The responses were analysed thematically, in which responses that were similar in content were grouped together (Green & Thorogood, 2014). Given the small sample size, this was conducted manually. Once similar responses were combined, a group decision making process was used to decide whether items occurring infrequently should be included or

omitted, as it was important to keep the list a manageable size (Keeney, Hasson, & McKenna, 2006). This process therefore had the potential to introduce researcher bias. Once the key issues had been identified and summarised, they were redistributed to participants in Round 2, who were then asked to rate each of the priorities (see *Delphi Process*). The ranking of overall priorities did not happen until the end of the Delphi process.

The aim of the Delphi process is to gain consensus. However, many Delphi studies employ arbitrary levels at the data analysis stage (ranging from 51% to 80% agreement), with no scientific rationale for selection (Keeney et al., 2011). For the purpose of this study, a 75% level of agreement was adopted, which is consistent with that recommended by Keeney et al. (2006).

Following Round 2 and 3, statistical aggregation allowed for quantitative analysis and interpretation of group responses (Rowe & Wright, 1999). Results were tabulated to determine the percentage of consensus reached, which was considered appropriate considering the small sample size. Following the third round, responses were again analysed using descriptive statistics to determine the number of statements that reached consensus (equal to or greater than 75% agreement). This then resulted in: a list of at least the top ten items relating to the current services and supports available to people with ABI and their family caregivers that address issues of behavioural problems (Part A); a list of the top ten priorities regarding how family caregivers can be further supported in managing behavioural problems following ABI in community settings (Part A); and consensus regarding the content of the FDBM program and design format of the pre-test post-test feasibility study (Part B).

4.6 Delphi Results

4.6.1 Participants

Eleven out of 18 key stakeholders returned signed consent and completed all three rounds of the Delphi process. Participant demographic details are available in Table 4.2. Of the 11 participants, 73% (n=8) were clinicians (two social workers, a psychologist, a registered nurse/psychologist, a rehabilitation physician, a clinician and researcher, and a speech pathologist), and 27% (n=3) were family caregivers. Seventy-three percent (n=8) of participants were female, and 73% (n=8) worked in the health service industry. Participants had an average of 19 years' experience in the management of BOC presented by individuals with ABI in community settings.

Table 4.2 *Participant demographics*

Role	Department/ Health Service/ Private Practice (if applicable)	Gender	Yrs experience in managing BOC following ABI
Speech Pathologist	SA Health Health Service	F	22
Family Caregiver/ Rostering Officer	SA Health Health Service	F	14
Social Worker	Sa Health Health Service	M	12
Disability Coordinator	Federal Funded Non-Gov Agency	M	14
RN/Psychologist	SA Health Health Service	F	20
Clinician & Researcher	SA Health Health Service	F	10
Psychologist	SA Health Health & Private Sector	M	25
Rehabilitation Physician	SA Health Health Service	F	15
Family Caregiver (Adult child)	-	F	16
Family Caregiver (Spouse)	-	F	33
Family Caregiver (Parent)	-	F	30

4.6.2 Behaviour management strategies used by family caregivers

In Round 1, a total of 95 responses were obtained regarding what behaviour management strategies family caregivers used in community setting. After removal of exact duplicates by the researcher, a team decision-making process was used to group together similar responses, resulting in 20 separate categories (See Table 4.3). The team comprised of the researcher (a Developmental Educator), and her supervisors (a Brain Injury Rehabilitation Consultant, a Professor of Physiotherapy and a Professor of Psychiatry).

In Round 2, consensus was reached that family caregivers *often* ‘identify and manage triggers’ in the management of BOC (e.g. if the person is tired [trigger] ask if they need a rest, noticing mood changes and responding appropriately). A further ten strategies were close to reaching consensus (between 55%-73% agreement), which were then redistributed in the Round 3 questionnaire. In Round 3 consensus was reached that the following six strategies are also used *often* by family caregivers: ‘distraction’ (e.g. change topic/ shift person’s attention/ make a joke); ‘agree with person’s demands to avoid challenging behaviour’; ‘reason with the person’; ‘avoid triggers’; ‘medication’; and, ‘setting realistic goals’. Consensus was also reached that the following strategies are used *rarely* by family caregivers: ‘being dominant/ directing the person with ABI’, and ‘locking doors/ securing physical environment’. See Table 4.3 below.

Table 4.3 *Behaviour management strategies reaching consensus*

Round 1 Themes	Round 2		Round 3	
	NO	YES	NO	YES
STRATEGIES USED OFTEN	NO	YES	NO	YES
Distraction (e.g. change topic/shift person's attention/ make a joke)				✓
Attempt to ignore behaviour				
Negative consequences following behaviour				
Reward positive behaviour (e.g. use tokens, food rewards, verbal praise)				
Agree with person's demands to avoid challenging behaviour				✓
Reason with the person				✓
Avoid triggers				✓
Identify and manage triggers		✓		✓
Access support services for education/ information/ support to develop behaviour plans				
Call on others to help and give emotional support				
Call on police or ambulance to assist in managing behaviours				
Medication				✓
Timeout				
Use of respite				
Creating meaningful routines				
Setting realistic goals				✓
Physical activity				
Being dominant/ directing person with ABI			✓	
Do not leave them alone				
Locking doors/ secure physical environment			✓	

4.6.3 Services available

In Round 1, a total of 67 responses were obtained regarding services that were available in SA to support family caregivers with the management of BOC following ABI. This number was reduced to 19 items after removal of exact duplicates (see Table 4.4).

In Round 3, consensus was reached (minimum of 75% agreement) that there were only two services in SA that were specific to supporting family caregivers with managing BOC in community settings following ABI: Families4Familmies Inc., and private specialists (e.g. [neuro]psychologists & [neuro]psychiatrists).

A number of participants were unaware that some of these services existed. Only 45% (n=5) of participants were aware that Disability SA and Carers Respite Service offered support regarding behaviour management following ABI; 36% (n=4) were aware that Noarlunga Mental Health Service, Diverge and Men's Health offered relevant services, 18% (n=2) felt Parnangga (Christies Beach) offered relevant support and only 9% (n=1) felt this support was available through Uniting Communities Metro Project.

Table 4.4 *Services/supports offering support to family caregivers specific to behaviour management following ABI*

Round 1 Themes	Participants aware of this service*	Round 3 Consensus	
		NO	YES
OFFER SPECIFIC SUPPORT*		NO	YES
Brain Injury Rehab Community & Home (BIRCH)	73% (n=8)		
Brain Injury Rehab Unit (BIRU)	82% (n=9)		
Brain Injury SA	73% (n=8)	✓	
Springboard	55% (n=6)	✓	
Disability SA (The Positive Behaviour Support Team)	45% (n=5)		
Families4Families	91% (n=10)		✓
Private Specialists (e.g. [neuro]psychologists, [neuro]psychiatrists, OTs)	100% (n=11)		✓
Community Re-entry Program (CRP)	64% (n=7)		
Metro Options (Uniting Care Wesley)	40% (n=4)		
Uniting Communities Metro Project	9% (n=1)	✓	
Carers SA	55% (n=6)		
Carers Respite Service	45% (n=5)		
General Practitioners	82% (n=9)		
Noarlunga Mental Health Services	36% (n=4)	✓	
Lifeline	64% (n=7)	✓	
Drug and Alcohol Services (DASSA)	64% (n=7)	✓	
Secondary consulting with Diverge (Victoria)	36% (n=4)	✓	
Mens Health	36% (n=4)	✓	
Parnangga (Christies Beach)	18% (n=2)	✓	

*in relation to supporting family caregivers with behaviour management following ABI

4.6.4 Key FDBM intervention components

In Round 1, a total of 89 responses were obtained regarding what intervention components participants thought should be included in a behaviour management program aimed at supporting family caregivers of individuals with ABI. This was reduced to 11 themes after removal of exact duplicates and grouping together similar responses, utilising a team decision-making process (see Table 4.5).

Table 4.5 *Intervention components reaching consensus*

Round 1 Themes	Round 2		Round 3	
	Consensus		Consensus	
SHOULD INTERVENTION COMPONENTS BE INCLUDED	NO	YES	NO	YES
Education regarding ABI		✓		
Information about the link between ABI and mental illness				✓
Person-centered/ individualised approach		✓		
Behaviour management strategies				✓
Assessment/ observation of challenging behaviours		✓		
Ongoing counseling/ support for families				✓
Respite (regular respite (and emergency respite) provided in specialised unit with well-trained staff)				✓
Strengths focus		✓		
Accessing emergency support (guidelines as to how/who/when and where to access support)				✓
Support from (neuro)psychologist and/ or (neuro)psychiatrist				✓
Information on current systems				✓

In Round 2 it was agreed that the following intervention components should be included in a behaviour management program: ‘education regarding ABI’ (including common cognitive and behavioural sequelae), ‘person-centred/individualised approach’ (e.g. discussing issues with the family and individuals with ABI – what is their perspective? What is meaningful to them?), ‘assessment/observation of challenging behaviours’ (how and why – e.g. the importance of observing behaviours in natural settings, identifying triggers and reinforcers, and keeping track of what works and what does not), ‘strengths focus’ (identifying strengths and challenges of the individual, and where possible building on strengths).

The following items also reached consensus following Round 3: ‘information about the link between ABI and mental illness’ (e.g. depression and anxiety); ‘behaviour management strategies’ (e.g. positive communication skills; antecedent behavioural approaches and Positive Behaviour Support [PBS] approaches, with a focus on positive reinforcement); ‘ongoing counselling/support for families’ (e.g. peer support and support groups for family members, phone support when needed); ‘respite’ (regular and emergency respite provided in specialised units with well-trained staff); ‘accessing emergency support’ (clear guidelines on how/who/when to access support, ability to contact ABI trained professionals 24/6 in crisis); ‘support from (neuro)psychologist and/ or (neuro)psychiatrist’ (early regular and responsive support); and, ‘information on current systems’ (e.g. how to obtain support when needed, how to work through government and non-government support systems, list of helpful resources in the community).

4.6.5 Key FDBM education components

In Round 1, a total of 88 responses were obtained regarding the topics participants felt should be included in an education component of a behaviour management program aimed at supporting family caregivers of individuals with ABI. This was reduced to 12 themes after removal of exact duplicates and grouping together similar responses (See Table 4.6). In Round 2 consensus was reached regarding a majority of items identified, including: ‘possible cognitive and behavioural changes following ABI’ (including common changes and possible reasons for behaviour, including physical, social, emotional and psychological); ‘role changes after ABI’ (e.g. changes in family dynamics and how that impacts on the

person with ABI and caregivers); ‘case studies/examples’ (of strategies that people have found helpful in managing common BOC following ABI); ‘behavioural, cognitive and communication sequelae that can be prone to misattribution errors’ (e.g. reduced initiation = “they’re just being lazy”); ‘identifying triggers’ (potential physical, environmental and social); ‘behaviour management strategies’ (e.g. positive communication skills, developing meaningful routines, information regarding antecedent and Positive Behaviour Support [PBS] approaches, and positive reinforcement); ‘person-centred approach’; ‘self-care strategies’ (importance of family caregivers’ looking after themselves, and strategies to keep safe and sane); ‘information on support agencies’ (what support and services are available and knowing when/how to access these; and, ‘what to do in a crisis’ (developing an emergency behaviour plan – knowing where to go and who to contact). The remaining two themes, including ‘what is an ABI’ and ‘grieving’ also reached agreement in Round 3.

Table 4.6 *Education components reaching consensus*

Round 1 Themes	Round 2		Round 3	
	Consensus		Consensus	
	NO	YES	NO	YES
SHOULD INTERVENTION COMPONENTS BE INCLUDED				
What is an ABI (basic biology of ABI)				✓
Possible cognitive and behavioural changes following ABI		✓		
Role changes after ABI		✓		
Grieving				✓
Case studies/ examples		✓		
Behavioural, cognitive and communication sequelae that can be prone to misattribution errors (e.g. reduced initiation = “they’re just being lazy”)		✓		
Identifying triggers		✓		
Behaviour management strategies		✓		
Person-centred approach		✓		
Self-care strategies		✓		
Information on support agencies		✓		
What to do in a crisis (developing an emergency behaviour plan – knowing where to go and who to contact)		✓		

4.6.6 The FDBM program

4.6.6.1 Program Components

The Delphi participants agreed that the current topics included within the intervention phase were important, but felt these additional topics were also necessary: role changes and grieving for families following ABI, and information on what supports and services were available regarding behaviour management (specific to the geographic location of participants), including *when* and *how* to access these services.

A majority of participants (82%, n=9) indicated that the education phase should be conducted using face-to-face sessions rather than the proposed self-study modules. In Round 3, agreement was reached on the following format: face-to-face sessions every week plus follow-up phone calls, supporting family caregivers to work through the self-study activities. The issues identified with this format included the increased time commitment, and less flexibility in completing the workbook.

4.6.6.2 Individualised behaviour management plan

Eighty-two percent of participants (n=9) felt that meeting with family caregivers for 1.5 hours weekly over eight weeks was an appropriate length of time for this intervention. However, it was suggested that due to individual situations, some families may need longer, and that the program should be reviewed at more intervals to stretch out the time for monitoring and adjustment. There was also concern that, on top of a four-week theoretical model, individualised intervention added up to a heavy time commitment for families. In Round 3, consensus was reached that the intervention should instead be held for 1.5 hours *fortnightly* for six visits. This lessened the time commitment required by families, and it was thought that a less intensive, longer lasting program might be better received. In Round 3, agreement was also reached that the intervention should be reviewed at week 10, 14 and 18. It was also agreed that there should be a two-hour follow up at three months post intervention, allowing time for family caregivers to practice newly learnt skills.

4.7 Discussion

4.7.1 Introduction

The aim of this study was to gain consensus from key stakeholders (including rehabilitation professionals and family caregivers) on (1) current family practices and available support to families regarding behaviour management following ABI in SA community settings, and (2) best practice in supporting family caregiver to manage BOC following ABI in community settings. It also sought to gain feedback regarding the content and format of the FDBM program. The findings of Part A of the Delphi will now be discussed within each of the relevant research questions. The findings relevant to the development of the FDBM program will be presented in the following chapter, which presents the program.

Firstly, it is important to note that the current study allowed participants to draw from their own definition of BOC, and their personal perspectives (experience and expertise), which reflects the broad and subjective nature of this issue. It is for this reason that participants consisted of both family caregivers and professionals, which would include the likelihood of variations in service-user and service-provider perspectives regarding brain injury rehabilitation and the system of service delivery (McDermott & McDonnell, 2014).

4.7.2 Strategies used by family caregivers

The results of this study suggest that a number of strategies were being utilised by family caregivers, including: ‘distraction’; ‘agreeing with the person’s demands’; ‘avoiding triggers’; ‘identifying and managing triggers’; ‘setting realistic

goals'; and 'medication'. This variability in the behaviour management strategies used is in line with studies conducted by Tam and colleagues (Tam, McKay, Sloan, & Ponsford, 2015) and Braine (2011). These approaches consist of recommended antecedent strategies (i.e. interventions that manipulate events prior to the occurrence of BOC that decrease the likelihood of it occurring in the future, while also promoting desired behaviours) following brain injury, including distraction, identifying and managing triggers (Jacobs, 2010; Jacobs, 1995), and setting realistic goals (Feeney & Ylvisaker, 1995).

However, there are other common and basic antecedent strategies recommended by behaviour specialists that have not been identified as being used by family caregivers in this study. For example, the importance of creating a positive environment (consisting of choice, control and meaningful experiences) is emphasised in the literature (Ponsford et al., 2013; Ylvisaker et al., 2003) and, although this was identified as a strategy used by family caregivers in Round 1 of this study, consensus was not reached regarding its use.

These strategies play an important role in behaviour management following brain injury, as neuropsychological research has found that trauma resulting in damage to the ventral or dorsal frontal lobe impedes the ability of an individual to learn from the consequences of their behaviour (Damasio, 1994; Rolls, 2000; Schlund, 2002). Therefore, individuals who experience cognitive difficulties (e.g. memory impairments or difficulty with information processing), may not be responsive to contingency strategies (i.e. strategies manipulating the response to behaviour that reduce the likelihood of BOC and encourage desired behaviours) such as positive reinforcement (when a reward is presented immediately following the

desired behaviour) and extinction (when a particular behaviour is not reinforced) procedures (Feeney & Ylvisaker, 1995; Willis & LaVigna, 2003). This suggests the need to further educate family caregivers regarding the importance of antecedent strategies, which focus on making background setting events as positive as possible for the individual (Ylvisaker et al., 2005). As eluded to above, such procedures may include assuring an individual has adequate amount of choice and control, is engaged in personally meaningful activities, receives positive communication from communication partners, and is taught positive communication alternatives (Ylvisaker & Feeney, 1998; Ylvisaker et al., 2005).

Antecedent strategies appear to be gaining increasing momentum, with a number of intervention experiments demonstrating their effectiveness (Arco & Bishop, 2009; Feeney & Ylvisaker, 2006; Feeney & Ylvisaker, 2003; Feeney & Ylvisaker, 2008). Furthermore, in recent research conducted by Tam and colleagues (2015), family caregivers reported that giving the individual with brain injury more control over their lives and restructuring their living environment were effective strategies. However, not all individuals with brain injury experience cognitive changes, and many are therefore also able to learn from contingency strategies (Feeney & Ylvisaker, 1995). The effectiveness of contingency strategies has also been highlighted in the ABI literature (Stewart & Alderman, 2010; Wood & Alderman, 2011), which suggests the important roles that both antecedent and contingency strategies play in behaviour management. Indeed, it has been suggested that these approaches should not be implemented in isolation, and that a comprehensive behavioural intervention should actively integrate antecedent and consequence strategies (Borgmeier & Rodriguez, 2015).

Common contingency procedures such as positive reinforcement and extinction were also identified in Round 1 (*'Reward positive behaviour [e.g. use tokens, food rewards, verbal praise]'* & *'attempt to ignore the behaviour'*); however, consensus was not reached regarding the use of these among family caregivers. These are two of the most common methods for increasing/maintaining a desired behaviour and decreasing the occurrence of BOC following brain injury (Jacobs, 1995), yet it seems these are not common strategies being utilised in community settings. This suggests that family caregivers do not have the confidence to implement these more comprehensive procedures, which is understandable given the complex nature of behaviour management, and the limited support families receive in addressing this issue (Kitter & Sharman, 2015; McDermott & McDonnell, 2014; Murray et al., 2006). It is therefore unreasonable that family caregivers, who have not been trained to assess, formulate, devise and implement behavioural strategies, are expected to tackle this issue alone.

The lack of confidence of family caregivers in implementing behaviour management procedures is also suggested by the findings, given that consensus was reached that family caregivers often *'agree with the person's demands'* and use *'medication'* to manage BOC. Although medication is commonly used to manage aggression following brain injury, there is no firm evidence base for this (Fleminger, Greenwood, & Oliver, 2008). According to Alderman (2003), the temptation to use sedative medications, and the sensitivity of people with ABI to the debilitating side effects of these medications, is concerning. In some cases, medication may have a negative impact on functioning (e.g. language, attention/concentration, speed of information processing), and finding a proper balance between severe sedation and too-limited action can be impossible (Saout et al., 2011). Indeed, the use of sedatives

can be considered as a form of “chemical restraint” (Currier & Allen, 2000), and is subsequently associated with necessary precautionary monitoring through the Office of the Senior Practitioner (Disability SA, 2016). It has been suggested that the difference between “chemical restraint” and a treatment approach depends on whether the medication is given as part of a care plan or is merely used to control an individual’s behaviour (Allen et al., 2003; Currier & Allen, 2000). The concern is that limited availability of education and alternative behavioural supports means that family caregivers may fall back on strategies such as *medication* (or chemical restraint) and *giving in to the person’s demands*. Lacking the confidence and social support (including quick-responding backup that is available in hospitals and specialised rehabilitation facilities), and the fear of confronting aggressive and often unpredictable behaviours may leave no other viable alternatives. This is clearly illustrated in the case study presented by Willis and LaVigna (2003), in which a mother finds herself the primary caregiver of her 17-year-old son with brain injury and significant BOC. The mother was unable to implement the strategies used in the hospital, including timeout and restraint procedures, and would therefore try to avoid altercations with her son that might precipitate angry episodes, and allow him to do what he wanted, in an attempt to avoid the likelihood of physical aggression.

According to the Delphi participants, it is not common for family caregivers to call on others to help and give emotional support regarding the management of BOC. This is concerning, with literature suggesting that social support helps family caregivers cope with BOC (Ergh, Hanks, Rapport, & Coleman, 2003; Tam et al., 2015). However, these findings are in line with studies conducted by Ergh and colleagues (Ergh, Rapport, Coleman, & Hanks, 2002), which link caregivers with low social support to caring for individuals with the most severe cognitive,

neurobehavioural, and functional impairments. This may be partly due to the demanding nature of the caregiving role, isolating families from opportunities to develop these supportive relationships (Ergh et al., 2003). The results of the current study therefore emphasise the need for services to provide family caregivers with opportunities to network with other families with shared experiences.

4.7.3 South Australian services and supports

There is growing literature regarding the impact of brain injury on family caregivers, with emphasis placed on the burden of managing BOC. However, despite this, there is limited support and services available to family caregivers which address this issue.

The findings of this study have highlighted the significance of this gap in service provision. Consensus was reached that there were only two service types in SA that were specific to supporting family caregivers with behaviour management following ABI in community settings: Families4Families Inc., and private specialists (e.g. [neuro]psychologists & [neuro]psychiatrists).

Families4Families Inc. and private specialists offer invaluable support to family caregivers regarding behaviour management, however, there are limitations to this support. Although Families4Families Inc. runs group education sessions regarding behaviour management following ABI, this network does not provide specialised individual behaviour consultation for family caregivers. This support *is* offered by private specialists, however, many individuals with ABI are unable to access the specialist clinical neuropsychological services they need under the current

Medicare system (Littlefield et al., 2012). This significant cost for families, who are often already financially strained (Kitter & Sharman, 2015; McDermott & McDonnell, 2014), along with the delays in accessing these services in SA (Department of Health, 2012) present barriers to families who need regular ongoing support. Considering these were the only community-based services identified to support family caregivers with the management of BOC, this clearly highlights the need for more specialised services.

It is surprising that the government-funded bodies for supporting individuals with brain injury, including SABIRS (BIRCH & BIRU) and Disability SA, did not reach consensus as services providing specific support to family caregivers regarding behaviour management following ABI in community settings. These findings are especially interesting given that, at the time of this study, 64% of participants (n=7) worked for SA Health. Furthermore, 73% (n=8) of participants indicated that they were aware of the services offered by BIRCH (specific to supporting family caregivers with behaviour management), which indicates that participants, rather than being unaware of the service, felt it did not offer the specialised support required. For example, these findings may reflect the time-limited (a maximum 6 months) services provided by BIRCH. This is insufficient for many, as BOC often have long-term implications for individuals (Kelly et al., 2008), with literature highlighting the need for life-long access to services and supports (Masel & DeWitt, 2010; Tam et al., 2015). Furthermore, eligibility criteria for BIRCH services allows the exclusion of individuals who exhibit behaviour not deemed 'manageable' (Department of Health, 2012). It was also noted by participants that the Clinical Psychology service offered through SABIRS is *difficult to access*. Similarly, there are limits to behavioural support provided by Disability SA, with their Positive

Behaviour Support Team (PBST) only providing services to adults residing in Disability Services' accommodation services (Disability Services, 2013). This perhaps explains why only 45% (n=5) of participants were aware that Disability SA offers support to family caregivers regarding behaviour management.

These findings suggest that specialised behaviour management is predominantly provided by non-government organisations. This limited government support may reflect the 'invisible' nature of this disability, with individuals often faced with the challenge of simply persuading agencies that the problem exists (Forsyth, 2002). As stated by Masel and DeWitt (2010), if brain injury was recognised as a chronic condition, being reimbursed and managed on a par with other chronic diseases, individuals might receive the support they so richly deserve.

In Round 1 of this study, participants identified a broad range of services (see Table 3), however consensus was reached that a majority of these were not relevant to supporting family caregivers with behaviour management. These results suggest a disjointed model of care, with no clear steps of service provision. It is likely that such a system leaves family caregivers feeling overwhelmed, and increases the likelihood of 'service-hopping', with families accessing multiple services in an attempt to find the required support. These findings are in line with research conducted by Simpson and colleagues, which examined the unmet needs of service utilisation among adults with severe brain injury living in the community, comparing those who did and did not display BOC (Simpson, Sabaz, Daher, Gordon, & Strettles, 2014). The participants of this study were all active clients of the New South Wales (NSW) Brain Injury Rehabilitation Program (BIRP) community rehabilitation team. The research showed that individuals with BOC accessed significantly more types of

BIRP and non-BIRP services, with BOC being an independent predictor of higher levels of service utilisation. Furthermore, participants with BOC reported greater levels of unmet needs. Individuals with BOC accessed more services from social work, clinical psychology and mental health services. Interestingly, in participants with BOC but no co-morbidity, an equal number had accessed or had unmet needs for mental health services, which suggests that such services are still being used in some cases to help manage BOC for individuals with no mental health problems (Simpson et al., 2014).

Considering this notion of ‘service-hopping’, surely this is an issue needing attention, not only for the wellbeing of the families involved, but also economically? As reported by Simpson et al. (2014), given the increasing pressure on resources globally, the issue of BOC is an important focus for health services research, as identifying patterns in service use are critical to inform policy, planning and funding processes. The economic benefits of community-based behaviour management have been documented (Feeney, Ylvisaker, Rosen & Greene, 2001; Willis & LaVigna, 2003); furthermore, it has been suggested that community access to specialised neurobehavioural services could save the government millions of dollars per year as a result of the reduced use of calming and anti-psychotic medications (Littlefield et al., 2012).

This disjointed system also allows organisations to ‘handball’ the responsibility of individuals with BOC, with organisations often stating severe behavioural disorders as exclusion criteria (Munce et al., 2014). In such a system individuals with ABI and family caregivers may get caught in limbo, in a web of referrals and a constant state of transition. As stated by McDermott and McDonnell

(2014), it is during this period between accessing services that family caregivers feel ‘cut loose’ (p. 84).

Family caregivers have reported the need for more coordinated services, with a streamlined interconnected support system (Kitter & Sharman, 2015). This need for a ‘centralised hub’ has also been identified by the Department of Health (2012), creating partnerships between government and non-government organisations and across government sectors with transparent pathways to accessing specialised services when required.

It has been clearly demonstrated throughout the literature that families experience significant burden and stress as a result of behavioural changes following ABI. The prevalence of BOC among ABI populations studied has also been significantly high. Therefore, considering approximately 31,000 individuals are living with an ABI in South Australia (AIHW, 2007), one can only presume that BOC following ABI present a significant issue for many individuals and families living in our communities. Furthermore, considering the notion of “service-hopping” and the significant cost of pharmacological treatment discussed above, one can only imagine the significant cost associated with this issue. This again emphasizes the need for developing cost effective and community based neurobehavioural services within South Australia.

Future services and supports

Although there is a lack of research from a SA perspective, the need to develop more specific services with regards to behaviour management in community

settings has been recognised. In 2012, the State-wide Rehabilitation Clinical Network developed a model of care intended to be used to support service change over the following seven years (Department of Health, 2012). This model proposes state-wide specialist ABI rehabilitation services, including the establishment of a behaviour consultancy service, which provides “support, liaison, advice and training to other services and agencies and also to support individuals living in the community with ABI, their families and care providers” (p.3). Furthermore, as described in Chapter Two, individuals between 18 and 64 years in SA will be able to access the NDIS from July 2017 (dependent on where they live). It will be interesting to ‘watch this space’ to see what changes in the service provision may occur, whether these changes will be inclusive of supporting family caregivers with the management of BOC, and how (if) issues of recognising and diagnosing mild ABI (Forsyth, 2002) and related behavioural sequelae will be addressed.

4.7.4 Best practices

This study revealed a high level of agreement between participants, with consensus reached on all items presented in Round 1 regarding the intervention components that should be included in a behaviour management program aimed at supporting family caregivers. This suggests a widely accepted understanding of gaps in current services and family caregiver needs regarding the management of BOC. This consensus is also reflected in literature, with similar support needs being highlighted.

During the Delphi process, consensus was reached that family caregivers should be provided with information regarding ABI and common cognitive and

behavioural changes. This need for further education has been highlighted in the literature, with family caregivers reporting dissatisfaction with the amount of information they have received specific to ABI (Biester et al., 2016; Braine, 2011; Turner et al., 2011). In research conducted by Hawley and colleagues (Hawley et al., 2003), it was found that approximately one third of families claimed that no information was provided to them by the hospital after brain injury, with over 70% of families (regardless of injury severity) reporting unmet information needs. Furthermore, families have indicated the importance of having honest and accurate information relating to the diagnosis and prognosis of brain injury (Gan et al., 2010; Hawley et al., 2003; McDermott & McDonnell, 2014; Murray et al., 2006).

The Delphi participants also agreed that family caregivers should be provided with information regarding role changes following ABI. This has been identified as one of the most devastating effects of brain injury (McDermott & McDonnell, 2014), with family caregivers often taking on multiple roles to account for the change in shared responsibilities (e.g. financier, mother, father, housewife, and primary caregiver) (Braine, 2011).

In addition to adjusting to these role changes, family caregivers are left to manage changed behaviours (Braine, 2011; Turner et al., 2007) with limited support (Murray et al., 2006). The need for providing information specific to behaviour management strategies was agreed upon during the Delphi process, giving family caregivers the tools needed to implement and monitor behaviour management interventions. Although BOC are considered the most detrimental as individuals attempt to re-integrate back into the community (Kelly et al., 2008), family caregivers have reported to have little knowledge or resources on how to deal with

changed behaviours (Gan et al., 2010; Kitter & Sharman, 2015; Murray et al., 2006; O'Callaghan, McAllister, & Wilson, 2012), and are at risk of 'losing hope' in these situations (Nalder, Fleming, Cornwell, & Foster, 2012).

The Delphi results, in consensus with the literature, highlight the need for access to respite during the person's transition to home (Gan et al., 2010; Turner et al., 2011), and the need for life-long access to services and supports (Gan et al., 2010; Tam et al., 2015). Consensus was also reached that family caregivers should be provided with information on current systems, and what to do in a crisis. However, this is an issue of concern considering research clearly highlights the lack of specific services available to family caregivers regarding behaviour management within current systems (Kitter & Sharman, 2015; Simpson et al., 2014). Furthermore, consensus was reached that family caregivers should have access to support from neuropsychologists/neuropsychiatrists. This is also an issue within SA, as many individuals with ABI are unable to access the specialist neuropsychological services they need under the current Medicare system (Littlefield et al., 2012), or other suites of specialist supports, including clinical or behavioural psychology. This significant cost for families, along with delays in accessing these services in SA (Department of Health, 2012), presents barriers to families who need this regular ongoing support.

Participants also reached consensus that family caregivers should be provided with education regarding self-care strategies. This need has also been identified in the literature (Kitter & Sharman, 2015), with research highlighting the interconnectedness between caregiver's emotional wellbeing and efficacy (Kreutzer, Marwitz, Godwin, & Arango-Lasprilla, 2010). Providing families with self-care

strategies, such as stress-management techniques (e.g. coping strategies and maximizing local support) can therefore be equally as important as training them to manage problems in the person with ABI (Sander, Maestas, Clark, & Havins, 2013). However, research has shown that caregivers frequently focus on the needs of the individual with brain injury (Gan et al., 2010; Murray et al., 2006).

The results from this study provide further clarity about the supports that should be provided to family caregivers specific to behaviour management following ABI. However, the high level of consensus between key stakeholders and the literature is concerning, suggesting that this gap in services is not only a widespread issue, but has been widely acknowledged. The question is then, how can we use this data as a positive momentum to facilitate the required change in service provision?

Considering there appears to be (1) consensus regarding the need for more specialised programs to support family caregivers in the community regarding behaviour management (Fisher et al., 2017a), and (2) evidence supporting family involvement in the management of BOC (Fisher, Lennon, Bellon, & Lawn, 2015), the underlying issue is that there is no validated behaviour management approach for individuals with an emphasis on family involvement.

The development of the FDBM program therefore makes important contributions to current research by presenting an informed family-directed approach for managing BOC in community settings. The FDBM program is outlined in the following chapter.

4.7.5 Limitations

A number of potential limitations associated with use of the Delphi method must be acknowledged. These include selection bias, small number of iterations (only three rounds), and the small sample. However, there are no set guidelines determining the number of participants to ensure validity of results, with 10-18 panel members recommended in the literature (Okoli & Pawlowski, 2004). A purposive sample was also necessary since the purpose of a Delphi study is to seek expert opinion, not represent the general public (Fink & Kosecoff, 1985). However, a significant limitation regarding the sample was the small proportion of family caregivers (27%). Although the service providers were able to comment on what strategies family caregivers are using, these results are rather suggestive of what techniques are in use, not a definitive account of what strategies are actually being used. However, the larger proportion of service providers (73%) played an important role in providing further insight into what services are available and clinical expertise in identifying best practices in supporting family caregivers with behaviour management (i.e. knowledge of ABI biology and evidence-based behaviour support practices).

From the 18 key stakeholders invited to participated, only 11 returned consent and completed the three rounds of the Delphi process. This may reflect the greater commitment required from the iterative design, rather than a single survey design.

The key representatives from state-wide organisations were contacted due to their expertise, with the snowball sampling technique helping to identify family caregivers. It is possible that family caregivers who have strong opinions or negative

experiences with the service system were more likely to participate. However, as a majority of participants consisted of professionals, this representation of both perspectives assisted in the triangulation of this data.

It is possible that with further iteration, that more items would have reached consensus, resulting in a more accurate account of the current system SA system of care regarding community-based behaviour management following ABI. In this study, items not close to reaching consensus (>50% agreement) were omitted from Round 3. However, as reported by Powell (2003), the findings of a Delphi study represent expert opinion, rather than indisputable fact. Furthermore, participants were asked to identify a minimum of five and a maximum of 10 items, and although this was recommended by the literature (Keeney et al., 2011), this condition could have altered the study results and provided methodological bias.

Although this research highlighted a number of strategies used by family caregivers to manage BOC, the Delphi method also did not incorporate qualitative feedback from participants, allowing an in-depth examination of the issue (Iqbal & Pison-Young, 2009). This may have revealed more insight into the strategies used, and revealed if/what prior information or training influenced the use of these strategies. This may have also revealed what specific BOC were being managed with the strategies identified.

4.8 Conclusion

This Delphi study provided a current perspective of the strategies families used to manage BOC in relatives with ABI, and the services that were available to

support families with this issue in SA community settings. This study also provided feedback on the content and delivery protocol of the FDBM program based on the systematic review.

The results of this study suggest significant concerns in the management of BOC following ABI in community settings in SA. It appears that families are not using many commonly recommended behaviour management strategies following ABI. Furthermore, the results suggest an extensive gap in community-based services that are specific to supporting family caregivers with the management of BOC in relatives following ABI.

According to these findings, family caregivers were often using medication and 'agreeing with the person's demands' even though these strategies might not be the best options. However, considering the burdensome nature of the caregiver role, the lack of education regarding behaviour management strategies, and lack of specialised community-based services, it is no surprise that such methods were being used. Family caregivers are not trained to assess, formulate, devise, and implement behavioural strategies, and therefore cannot be expected to tackle this issue with little or no specialised support or education.

Consensus was reached that only two types of services in SA provided specific support to family caregivers regarding behaviour management: Families4Families Inc. and private specialists. These services did offer invaluable support, however Families4Families Inc. did not offer specialised individual behaviour management, and the significant cost and delays in accessing services provided by private specialists presented barriers to family caregivers who need regular ongoing support.

The findings of this study therefore suggest the need to further educate and support family caregivers in acquiring the skills needed to implement effective behavioural interventions for their family member with ABI, and to empower them to feel confident in this process. It is clearly evident that the current disjointed system of care is not sufficiently meeting the needs of families living with ABI in the community, and appears to be a system that places more economic burden on the government. This suggests the need for more specialised behaviour management services specific to ABI that are accessible according to individuals' long-term needs, and embedded in a more streamlined and centralised system that assists family caregivers to navigate these services.

This study has revealed a high level of consensus regarding best practices in supporting family caregivers with the management of BOC following ABI, with key stakeholders reaching agreement on all items presented within the Delphi process.

The findings of this study further highlight the need for family caregivers to be provided with education regarding ABI, including basic biology, common behavioural and cognitive changes, and grieving and role changes associated with ABI. Consensus was also reached that family caregivers should be provided with specific behaviour management strategies, self-care strategies, and information on support agencies and crisis management, and that information should be presented using a strengths-focus and person-centred approach. These major themes are highlighted in the literature as unmet needs for family caregivers, suggesting the need to further support family caregivers regarding behaviour management to be a widespread and widely acknowledged issue.

Although there is consensus that family caregivers require more specialised support to manage BOC within the community, and evidence supports the involvement of family caregivers, there is no validated behaviour management approach for individuals with ABI with an emphasis on family involvement.

The development of the FDBM program aims to fill this gap in current research, by informing a family-directed approach for the management of BOC. The Delphi process has made significant contributions to this program by further refining and validating the content and methods of delivery.

CHAPTER FIVE

THE DEVELOPMENT OF THE

FAMILY-DIRECTED BEHAVIOUR MANAGEMENT

(FDBM) PROGRAM

Related publication:

Fisher, A., Bellon, M., Lawn, S., & Lennon, S. (2017). The development of a family-directed approach to supporting behaviour changes in individuals with ABI in community settings: A Delphi study. *International Journal of Therapy and Rehabilitation, Under Review.*

5.1 Introduction

This chapter introduces the Family-Directed Behaviour Management (FDBM) program. First, a definition of family-directed intervention is provided, followed by a description of the theoretical framework underpinning this program. The development of the content and delivery protocol of the FDBM is then presented, including the contributions of the systematic review (Fisher et al., 2015) and Delphi process (Fisher, Bellon, Lawn, & Lennon, 2017b) in informing this process.

5.2 Family-directed versus clinician-led interventions

Distinguishing between family-directed versus clinician-led interventions is important. In this study, family-directed interventions refer to professionals working in partnership with family caregivers, with an emphasis on education and supporting family caregivers in developing and implementing intervention strategies. Using this approach, family caregivers take a lead role in the process, making educated decisions about which behaviour management techniques are most appropriate to their situation, and record and monitor the progress of the program. This notion of ‘family-led’ intervention is consistent with values around empowerment and self-determination, giving families the opportunity to play a role in shaping their environment, and to feel valued and respected in this process (Petr & Walter, 2005). Furthermore, the concept of empowerment assumes the client (family caregiver) is

ultimately driving the change process (Radohl, 2011), which is reflected in this family-directed approach.

In contrast, a clinician-led intervention refers to clinicians directing family caregivers throughout the process. The key difference between family-directed versus clinician-led intervention is that the former focuses on the knowledge and increasing capability of family caregivers to ‘drive’ the management process.

5.3 Theoretical lens

There is increasing recognition that the development of behavioural interventions should draw on theories of behaviour and behaviour change (Michie, Johnston, Francis, Hardeman, & Eccles, 2008). It has been suggested that an appropriate strategy for developing and evaluating complex interventions should begin with a “theory” phase and then be followed by a “modelling” and experimental phase (Medical Research Council, 2000; Michie et al., 2008). It is during the “theory” phase that evidence is collected, which then informs the theoretical basis of intervention. This is then followed by the “modelling” phase, which involves identifying what to target (behavioural determinants) and what strategies to use (to change these determinants) (Michie et al., 2008). It is likely that interventions will be more effective if they focus on the causal determinants of behaviour and behaviour change (i.e. theoretical mechanisms of change) (Michie et al., 2008). Furthermore, such interventions allow theories to be tested and further developed according to different contexts, populations and behaviours (Davidoff, Dixon-Woods, Levion, & Michie, 2015; Michie et al., 2008).

The FDBM program is predominately based on a positive behaviour support (PBS) framework. This theoretical and procedural lens is recommended by Feeney and Ylvisaker (2011) in supporting individuals with ABI who exhibit BOC. This theoretical lens was considered appropriate because, not only does the literature support its use with individuals following ABI (Feeney & Ylvisaker, 2008; Feeney et al., 2001; Arco & Bishop, 2009), but PBS also encapsulates a strengths-focussed and person-centred approach (Carr et al., 2002) to behaviour intervention.

The FDBM program is also premised on family-centred care (FCC), which espouses the idea that families should work collaboratively with professionals to maximise rehabilitation outcomes, and that family members' expertise should be acknowledged and utilised in the decision making process (Hostler, 1999). There are no specific guidelines for guiding family involvement within behavioural interventions for individuals with ABI (see Fisher et al., 2015).

The development of the FDBM program has been informed by a systematic review regarding family involvement in behavioural interventions for individuals with ABI (Fisher et al., 2015), and research regarding unmet family information needs and best practices in supporting family caregivers in behaviour management following ABI (Biester et al., 2016; Braine, 2011; Foster et al., 2012; Gan et al., 2010; Kuipers et al., 2014; Turner et al., 2011).

5.3.1 A Positive Behaviour Support (PBS) framework

The core aim of the FDBM program is to enhance the capability of family caregivers in managing BOC in relatives with ABI in community settings, within an

individualised, context-sensitive and evidence-based approach. Therefore, the focus was on educating family caregivers in understanding behaviour changes for individuals with ABI and in implementing evidence-based behaviour support strategies.

PBS, as introduced in Chapter Two, is an applied science that utilises educational methods to expand an individual's behaviour repertoire, and systems change methods to enhance the individual's quality of life and minimise BOC (Carr et al., 2002). PBS emerged in the 1980s as an approach that could be used in community and school settings to address significant BOC without resorting to painful or stigmatising procedures (Dunlap et al., 2010). The behavioural principles underlying PBS are based on learning theory, including classical (or *respondent*) conditioning and operant (or *instrumental*) conditioning, which conceptualises behaviour as operating on the environment and maintained by its consequences (Alderman & Wood, 2013; Cattalani et al., 2010). PBS is based on ABA principles and also prescribes to principles of normalisation and person-centred values.

This person-centred approach is based on the notion that “creating a life of quality and purpose, embedded in and made possible by a supportive environment, should be the focus of our efforts as professionals” (Carr, 2007, p. 3). Indeed, community-based services are consistent with the principles of normalisation, which infer that individuals with disabilities should live in the same settings as others and have the same opportunities/lifestyle as others (Nirje, 1985; Wolfensberger, 1983). With the principles of normalisation based on attaining socially valued roles and life conditions, Wolfensberger (2011) has proposed adopting the term “social role valorisation” as a replacement for “the principle of normalisation”, with the belief

that this term more accurately describes what the theory of normalisation has been all about: enhancing the social roles of individuals who are at risk of social devaluation (Wolfensberger, 2011). In the context of a PBS framework, the principles of social role valorisation in enhancing the individual's "competencies" (Wolfensberger, 2011, p. 437) are emphasised. This increases the likelihood that he or she will be accorded respect from others (Wolfensberger, 1983).

The guiding assumption of PBS is that if an individual's needs are effectively met (i.e. when they are competently engaged in meaningful activities over which they have adequate control), then quality of life is correspondingly enhanced, resulting in the reduction or elimination of BOC (Feeney & Ylvisaker, 2010; Carr et al., 2002). As reported by Lucyshyn et al. (1997), PBS is not about changing the individual with BOC, but about building effective environments that make the BOC "irrelevant, inefficient, and ineffective" (p. 31).

ABA has provided PBS with a conceptual framework relevant to behaviour change, and a number of assessment and intervention strategies (Carr et al., 2002). ABA is characterised by the following seven themes (Baer et al., 1968; Ylvisaker et al., 2003; Feeney & Ylvisaker 2010):

1. *Applied* interventions address real-world concerns important to individuals and stakeholders.
2. *Behavioural* interventions focus on measurable behaviours, their interrelationships with the individual's social/environmental contexts, and specific outcomes of intervention.

3. *Analytic* functional assessment includes observation of the target behaviour and systematic manipulation of relevant variables in those situations to identify the function(s) of the behaviour.
4. *Technological* interventions are specified so procedures are replicable.
5. *Conceptual* procedures are thoroughly specified and classified within appropriate conceptual systems to ensure that the theoretical orientation of the intervention is clear.
6. *Effective* interventions provide something of practical value to the individual and key stakeholders in relevant situations. It is for this reason that single-subject experimental procedures are routinely used in evaluating ABA interventions.
7. *Generalised* interventions are designed to have enduring effect on important everyday activities in relevant real-world environments, which are monitored for maintenance, stimulus generalisation (transfer of acquired skills/behaviour to other relevant settings), and response generalisation (transfer of trained behaviours to other associated behaviours).

PBS uses a framework of Antecedent-Behaviour-Consequence (ABC) analysis, highlighting both triggering antecedents (i.e., events/conditions preceding a behaviour that influence its likelihood of occurrence) and maintaining consequences (i.e. events/conditions following a behaviour that influence its likelihood of occurrence) (Skinner, 1938). However, as discussed previously, due to the often impeded ability to learn from the consequences of behaviour following brain injury (Damasio 1994; Rolls, 2002; Schlund, 2002), PBS strategies for this population emphasise antecedent-based strategies (Ylvisaker & Feeney, 1998). These

approaches are also grounded in traditional ABA principles, including stimulus control, setting events, and establishing operations (Ylvisaker et al., 2003).

The FDBM program uses and adapts these processes, with particular emphasis placed on strategies that provide value to the individual with ABI through identifying the function of BOC, which is then used to guide the intervention process. Family caregivers are educated in these underlying assumptions and are supported in collecting and analysing ABC data. The FDBM program also emphasises a proactive approach, focussing on the management of setting events and triggering antecedents in promoting positive behaviours within the individual's natural environment. The specific PBS processes and strategies applied will be further drawn upon throughout this thesis.

5.4 Development of the FDBM program

The systematic review presented in Chapter Three supported a multicomponent design, including an education phase followed by individualised sessions. This review also informed the key topics included in the program, with other education programs commonly including: information on common neurobehavioural sequelae of brain injury; factors contributing to the occurrence of BOC; general principles of behaviour management (including antecedent and consequence analysis); identifying and managing triggers; and, crisis management. Further ideas were supported by the project team (the researcher and supervisors), relevant literature (Jacobs, 1995; Ponsford et al., 2013; Ylvisaker & Feeney, 1998), ABI resources developed by the Brain Injury Association of Queensland (Dark, n.d;

Queensland, n.d) (now *Synapse*), and the online training resource ‘working with people with traumatic brain injury’: staff self-study Module 5 (Martin, 2011). The content was then further refined and verified through the Delphi process (Part B: Chapter Four) according to feedback and recommendations from family caregivers and rehabilitation professionals. Two additional family caregivers and one rehabilitation professional were then invited to review the workbook and make further suggestions regarding its development. This is a novel component of the FDBM program, with content coproduced by key stakeholders to further validate the content.

The key components of this program are in line with the PBS framework, and emphasise the strength-focused, person-centred and proactive approaches identified in the literature and Delphi process. As discussed above, the PBS framework emphasises the use of antecedent-based strategies for individuals with ABI, given that common cognitive impairments may impede the ability to learn from the consequences of behaviour. The FDBM program therefore focuses on educating family caregivers to support behavioural changes in relatives with ABI, rather than emphasising a reactive approach to BOC when they occur. Indeed, the aim is to provide family caregivers with the skills to pre-empt BOC where possible.

Consensus reached during the Delphi process highlighted that the program should include information on role changes and grieving for families following an ABI, as well as information on when and how to access services regarding behaviour support (specific to the geographic location of participants). Key stakeholders also indicated that the education sessions should be conducted using face-to-face sessions

rather than self-study modules, with follow-up phone calls to support family members to work through self-study activities.

Incorporating this feedback, the FDBM program consisted of a four-week education phase and six fortnightly individualised sessions. The weekly content and delivery format of the FDBM program is illustrated in Table 5.1.

Table 5.1 Overview of the revised FDBM program incorporating Delphi results

Week	Content	Format	Phone contact
Week 1	Session 1: Why do behaviours change after brain injury? <i>(including section on family caregivers' adjustment- role changes & grieving)</i> Basic management strategies	Face-to-face group session (2 hours)	
Week 2	Session 2: Understanding Anger Session 3: Observing & defining behaviour	Face-to-face group session (2 hours)	Support with activities, questions
Week 3	Session 4: Is behaviour being triggered or reinforced? Session 5: Introducing behaviour management strategies	Face-to-face group session (2 hours)	Support with activities, questions
Week 4	Session 6: Identifying behaviour management strategies that might work for you Session 7: What to do in a crisis/ <i>knowing where to go and who to contact</i>	Face-to-face group session (2 hours)	
Week 5-15	Developing individualised behaviour management plan	6 fortnightly individual sessions (1.5 hours each)	

Note: sections shaded indicate those added/revised as a result of the Delphi study

5.4.1 Education phase

During this phase, family caregivers meet with the facilitator for four weekly two-hour group education sessions. During these sessions they are guided through the FDBM Education Workbook (see Appendix 7). This was developed by the researcher in response to the literature highlighting the need for information to be presented in both written and verbal form (Oddy & Herbert, 2008) and provided in ‘lay-person’ language (Gan et al., 2010). The workbook consists of seven modules relating to the module topics presented in Table 5.1. After developing the content, the researcher worked in collaboration with David Heinrich from Flinders Medical Illustrations, who drew narrative illustrations according to content and specific directions from the researcher.

The FDBM Education Workbook includes meaningful examples that family caregivers can relate to, and is broken up with activities, encouraging families to apply newly acquired knowledge to their individual situations. For example, participants are asked to define BOC in observable terms, and later try and identify possible triggers or events that may be reinforcing these behaviours. The facilitator also makes weekly follow-up contact with participants to offer further support and guide them through the self-directed activities (such as collecting ABC data and implementing strategies identified) if needed. As recommended by the Delphi study, the education workbook also includes information on what supports and services are available in SA, and when and how to access these services. In the final week, the facilitator models techniques and discusses these in terms of the participants’ individual situations.

Although the education phase does require a significant time commitment from participants (i.e. face-to-face sessions every week for two hours), results from the Delphi study suggested that families may be more receptive to a face-to-face format rather than self-study modules. The group format also gives families the opportunity to network, share experiences, and support each other in managing BOC. This format also ensures consistency in the content covered for each participant.

5.4.2 Individualised behaviour management plan

Following the education phase, family caregivers continue to meet individually with the facilitator for approximately 1.5 hours fortnightly for 11 weeks. This format was recommended by participants in the Delphi study; it was suggested that due to individual situations, some families might need longer than the originally proposed eight weekly sessions. Furthermore, it was suggested that a less intensive and longer lasting program might be better received.

During the individual sessions, the facilitator and family caregiver work in a collaborative manner to develop and implement an individualised behaviour management plan which focuses on the target behaviours identified. These interactive sessions aim to elicit problem solving regarding the BOC, and provide family caregivers with further information regarding the role of antecedents and consequences in maintaining and reducing BOC (Jacobs, 1995). As the focus of this intervention is on training family caregivers in the management of behaviours, they are given the responsibility to implement and monitor intervention strategies, with the opportunity to discuss their progress during the sessions with the facilitator.

5.5 Conclusion

There is currently no validated behaviour management approach for individuals with ABI with an emphasis on family involvement. The FDBM program presents a step towards addressing this gap in current research by developing a family-directed approach for the management of BOC. The FDBM program is premised on a PBS framework and principles of FCC, and has been informed by the systematic review examining family involvement in behavioural interventions for relatives with ABI, in addition to literature examining family support needs. The Delphi process has then further refined and validated the content and methods of delivery of the FDBM.

The FDBM is an intensive face to face program that is conducted over a 15-week period, consisting of two hours per week contact for the first four weeks, followed by 1.5 hours contact per week for the remaining 11 weeks. In the following chapter, the pilot study is presented, which investigated the feasibility and acceptability of the FDBM program in community settings.

CHAPTER SIX

STUDY THREE: THE FDBM PILOT STUDY

6.1 Introduction

This chapter outlines the aims of the pilot study, followed by a description of the methods utilised, and the results. Participants are presented in case study format, including a description of their involvement in the program and assessment results. This format was considered appropriate given the final sample size. In the initial design of the study, a larger sample was anticipated, and a pre-post design was selected. However, as only two participants completed the program, modifications were made to supplement and build on the pre-post study, which deviates from a traditional A-B-A design. The case study format provides more comprehensive data on each family's experiences and involvement in the program. This is then followed by feedback regarding participant involvement and suggestions for the further development of the FDBM program. The results of this study are then discussed according to research objectives.

6.2 Aims

The aim of the pilot was to determine if the FDBM program was a feasible and acceptable intervention in supporting family caregivers to manage BOC following ABI in community settings.

The following research questions were addressed:

Feasibility

- Did the FDBM program have impact on:

- frequency and severity of targeted BOC?
- family caregiver's level of confidence in managing BOC?
- family caregiver's levels of burden?
- Were the outcome measures used appropriate for capturing any changes using a pre-post design?

Acceptability

- Did family caregivers find the FDBM program satisfactory in supporting them to manage BOC in relatives with ABI?
- Did family caregivers find the information and strategies provided to be appropriate and helpful in supporting them to manage BOC in relatives with ABI?
- How did family caregivers think the FDBM program could be improved to better support them in managing BOC in relatives with ABI?

6.3 Methods

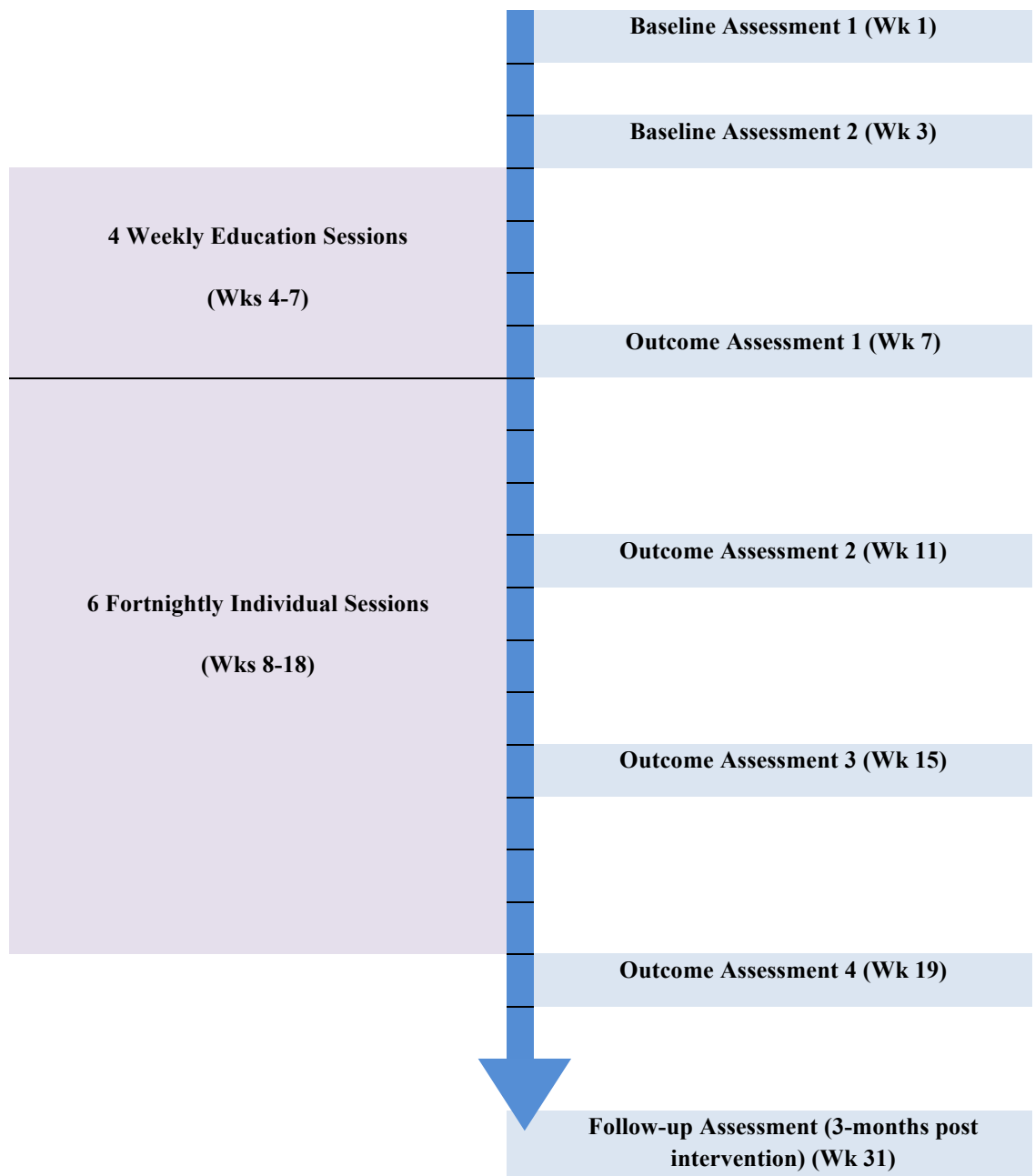
6.3.1 Design

A pre-test post-test design was chosen for the purpose of this study. However, in order to examine outcomes following the education phase (i.e. before completing the individualised sessions), and to allow sufficient time for monitoring and adjustment (as recommended in the Delphi study), additional assessment points were included following education sessions (Figure 6.1). Venter and colleagues (Venter, Maxwell, & Bolig, 2002) refer to this as an 'intensive design', which adds a longitudinal component to the traditional pre-test post-test design. Furthermore, in

utilising this intensive design, a minimum of five assessment points has been shown to strengthen analysis compared to the traditional pre-test post-test design (Maxwell, 1998).

The pre-test post-test design adopted consisted of two baseline assessments (at week one and week three), which obtained the level of support needs and psychosocial functioning of relatives with ABI, in addition to scores relating to outcome measures prior to the commencement of intervention (with two assessment points enhancing reliability). Five outcome assessments were then conducted at week seven, 11, 15 and 19, with a follow-up assessment at three-months post intervention (week 31). The FDBM program and assessment timeline is presented in Figure 6.1. The baseline and outcome measures utilised are presented within section 6.3.4.

Figure 6.1 *The FDBM intervention and assessment timeline*



Ethics approval for this study was obtained from the Royal Adelaide Hospital Human Research Ethics Committee (Protocol No: R20151116), and the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University (Project Number: OH-00110). See Appendix 8 for approval letters.

6.3.2 Participant recruitment

Participant criteria for selection in this study required that they were:

- at least 18 years-old at the time of this study
- the primary caregiver of a relative with ABI who met the following criteria:
 - aged between 18-65 years at the time of this study
 - had a medically diagnosed ABI
 - sustained a brain injury when 15 years of age or above
 - was living in the community (not inpatient)
 - had a recognised challenging behaviour
 - was at least six months post discharge from inpatient rehabilitation services, because recovery is most rapid within 3-6 months following brain injury (Ponsford, Sloan & Snow, 2013)
- currently involved in the management of BOC by their relative with ABI, with weekly face-to-face contact

The researcher identified a key contact (clinician or therapist) working within each of the following services/programs who was willing to assist with identifying potential participants: South Australian Brain Injury Services (SABIRS); Disability Services SA; Families4Families Inc.; and, the Community Re-entry Program (CRP).

These key contacts were asked to disseminate information on this study to family members who satisfied each of the inclusion criteria, and distributed information packages to those who were interested in participating. This package included a letter of introduction (see Appendix 9) and an information sheet (Appendix 10) outlining the details of the study and involvement (including research

aims, inclusion criteria, participant involvement, confidentiality and the anticipated benefits of this research). There was also a consent form for participation (see Appendix 11), contact permission form (see Appendix 12), a screening questionnaire (see Appendix 13) to determine the presence of BOC and a reply-paid addressed envelope included. Family caregivers who wanted to be involved were asked to sign and return these forms to give the researcher permission to contact them.

The screening questionnaire was adopted from Sabaz and colleagues (2014), who developed a cut-off criteria for determining ‘challenging behaviours’ based on the Over Behaviour Scale (OBS: Kelly et al., 2006). The screening questionnaire consisted of the nine behavioural domains in the OBS, with cut-off criteria developed according to the severity level, frequency and perceived impact for each. Behaviours were deemed ‘challenging’ (i.e. a behaviour of concern) if participants indicated ‘yes’ to any of the items presented. This took participants approximately five minutes to complete.

Participants who registered their interest, and who met inclusion criteria, were admitted to the study and asked to attend an initial assessment to gather demographic data and record baseline measures. A second baseline assessment was then conducted after two weeks to improve the reliability of baseline data. The assessment process took no longer than 45 minutes and was carried out at a mutually agreed location.

Sample size

This pilot study did not require a sample size calculation as it was not powered to detect significant treatment effects. The aim of this study was rather to conduct a preliminary examination of the feasibility and acceptability of the FDBM program and to gather feedback for its further development.

6.3.3 Intervention

The FDBM intervention was presented in Chapter Five, and the workbook is presented in Appendix 7. The FDBM pilot study was designed to be carried out over a 31-week period (including all baseline and outcome assessments). The intervention itself was an intensive face to face program that was conducted over a 15-week period, consisting of two hours per week contact for the first four weeks, followed by 1.5 hours contact for the remaining 11 weeks.

To ensure consistency with the information provided, the education sessions were guided by PowerPoint presentations, and the individualised sessions were guided by structured questions that prompted the participant to reflect on what strategies worked well and what areas of their plan needed modifying (see Appendix 14). These methods provided structured checklists which improved the fidelity of the intervention (Hott, Limberg, Ohrt, & Schmit, 2015) by ensuring the key components of the intervention were consistently delivered to participants.

6.3.4 Outcomes

Quantitative data

The primary and secondary baseline and outcome measures completed by family caregivers are presented in Table 6.1. The primary outcome measures are those that relate directly to the BOC targeted and the family caregivers' confidence in managing these, whereas the the secondary measures provide important data regarding support levels, social participation and caregiver appraisal.

Table 6.1 *Assessment points and data collection measures utilised*

Assessment point	Data collection measures
BA1 – BA2	Demographic information (week 1 only) SPRS-2 CANS OBS* CAS Confidence questionnaire*
OA1- OA5	OBS* CAS Confidence questionnaire*

Note: Additional frequency measures were utilised at alternative time points. Details are provided for each participant within the results section*

*NOTE: BA = Baseline Assessment; OA = Outcome Assessments; *Primary outcomes*

During the first baseline assessment, demographic information was gathered concerning both the family caregiver and relative with ABI using a purpose-developed questionnaire (see Appendix 15).

Baseline characteristics were then gathered during both baseline assessments using the following measures:

- Care and Needs Scale (CANS): an eight-category instrument developed in order to capture the range of support needs required for everyday functional activities and functional living following TBI (Tate, 2004) (see Appendix 16). The CANS consists of two sections: the Needs Checklist, which documents the *type* of support required, and Support Levels, which documents the *extent* of support required. The Need Checklist, which consists of 24 items, is further categorized into four groups according to intensity of need. These categories, A to D, cover very high level needs, such as tracheostomy management and harmful behaviours, through to low level of need, including informational and emotional supports. The second section consists of 8 Support Levels that are also arranged hierarchically from 0 (does not need contact) to 7 (cannot be left alone) (Tate, 2010). The participant indicated what supports were needed within each category, and then an overall support level (0-7) for their family member with ABI.
- Sydney Psychosocial Reintegration Scale (SPRS-2) (Relative-rated form): a 12-item inventory designed to measure psychosocial functioning in people with TBI (see Appendix 17). It consists of three domains: Occupational activity, Interpersonal relationship, and Independent living skills, with the focus being on the change in psychosocial functioning from the premorbid level (Tate,

Hodgkinson, Veerabangsa, & Maggiotto, 1999). Responses are made on a 5-point scale in terms of the amount of change since the brain injury, with 0 being equivalent to extreme change, and 4 being no change, including “better than before” (with a maximum total of 16 for each domain) (Tate, et al., 2010). Given that these scores provided a comparison with the premorbid level, these results were converted to percentages (with the maximum 100% indicating the premorbid level).

The following primary and secondary outcome measures were used at all assessment time points (collecting data for two-week intervals) to gather information regarding the behaviour profile of relatives with ABI, levels of caregiver appraisal, and caregiver confidence in managing BOC in relatives with ABI pre and post intervention:

- The Overt Behaviour Scale (OBS): a 34-item inventory comprising nine categories designed to measure common BOC observed following ABI (Kelly et al., 2006). The instrument measures levels of aggression, inappropriate sexual behaviour, perseveration, wandering, inappropriate social behaviour and lack of initiation (see Appendix 18). Within each of these categories, the rater is first asked if the behaviour is recognised as problematic; they then complete the more specific items relating to severity and frequency levels within that category (ratings from 1 to 6). Although the OBS was designed to record behavioural data using a time-sampling approach (over the past three months) (Kelly et al., 2006), the time span

being sampled has been reduced in accordance with the baseline and outcome measurement intervals (two weeks) (i.e. 1=absent across two weeks; 2=once in last two weeks; 3=once in last week; 4=once daily; 5=multiple times daily).

- The Caregiver Appraisal Scale (CAS): a 35-item questionnaire used to measure levels of burden experienced by caregivers of individuals with TBI (Struchen, Atchison, Roebuch, Caroseli, & Sander, 2002). It is conceptualised into four dimensions: perceived burden of caregiving; caregiving satisfaction and relationship with individuals with TBI; caregiver ideology; and caregiving mastery (see Appendix 19). Family caregivers are asked to indicate to what extent they agreed with each of the 35 statements using a 5-point scale (1=strongly disagree; 2=disagree; 3=no strong feelings either way; 4=agree; 5=strongly agree). Given that the maximum scores vary for each domain (Perceived Burden= /75; Relationship Satisfaction= /55; Caregiver Ideology= /25; Caregiver Mastery= /20) these were converted to percentage scores to be presented in graphs.
- A purpose-developed confidence questionnaire: a three-item questionnaire designed to gather information regarding confidence in managing BOC, identifying why their relative with ABI exhibits ABI, and identifying appropriate management strategies (see Appendix 20). In each of these areas, families are asked to indicate how confident they feel using a five-point scale (-2=not at all confident; -1=not very confident; 0=neutral; 1=somewhat confident; 2=very confident).

In order to gain feedback regarding the acceptability of the intervention, short feedback questionnaires were conducted at the following three time points: following the four-week education phase, following the 11-week individualised sessions, and at three-months follow-up (see Appendix 21). These consisted of Likert-type items designed to gather feedback regarding the acceptability of the FDBM program.

Qualitative data

In order to gain additional feedback regarding the acceptability of the intervention, semi-structured interviews were also conducted by the researcher following completion of the acceptability questionnaires at the three time points indicated above. These interview questions were designed to gain specific feedback relating to (1) whether participants found the program satisfactory in supporting them to manage BOC, (2) whether information and strategies provided were helpful, and (3) how they felt the program could be improved. Questions raised during the semi-structured interviews are presented in Appendix 22. The feedback questionnaires and interviews were completed at the intervention location, which was determined around the convenience of participants.

6.3.5 Analysis

Quantitative

All outcome measures were examined using visual analysis. Longitudinal data (collected over seven assessment points) was analysed using the Percentage of data points Exceeding the Median of baseline phase (PEM) approach (Ma, 2006).

The PEM approach, which calculates the overlap according to the baseline median, is capable of computing the PEM scores that reflect the effect size in the presence of ceiling or floor data points (Ma, 2006). Given the limited number of baseline assessments in the current study, and the fluctuating data within these assessments, the PEM approach was therefore considered appropriate. A PEM of 90% and higher is suggestive of effective treatment, 70% - 90% suggests moderate effect, 50%-70% suggests mild effect, and below 50% suggests ineffective treatment.

Qualitative

The interviews were audio-recorded and transcribed by the researcher, and were analysed using thematic analysis (Patton, 2015). This was carried out manually given the small sample size. This involved coding qualitative data, with similar themes grouped together and given appropriate headings denoting the ‘themes’ reflected in the statement (Kuckartz, 2014).

The first stage of analysis consisted of line-by-line coding (Charmaz, 2014), during which small segments of data were labelled. For example, the segments ‘I am more aware... I’m reaching for a tool – I’m not just thinking *oh dear where is this going..*’ and ‘I recognised faster..so now.. I have different things that I try that actually work’ were compared to all coded data and grouped within the theme ‘Increased confidence in managing BOC’. The researcher and a supervisor independently examined each of the interview transcripts to identify frequently mentioned and meaningful themes raised by family caregivers. They then met to discuss, compare, and reach consensus on initial coding decisions, which added rigor to the qualitative analysis (Strauss & Corbin, 1990). After reaching consensus on

emerging themes, these codes were sorted and synthesised into broader conceptual categories (Charmaz, 2014) identified relevant to research objectives, including (1) satisfaction and usefulness of the FDBM program, (2) content and delivery of the education sessions, and (3) feedback for further development. For example, the theme ‘increased confidence in managing BOC’ was placed within the broader category of ‘satisfaction and usefulness of the FDBM program’.

This was not a linear process, with the researcher examining categories multiple times, expanding and re-grouping the codes into categories, in addition to reflective discussions between the researcher and supervisors to ensure the analysis was representative of the data. The researcher also kept a journal throughout the FDBM pilot process, which included the researcher’s thoughts, observations, reflection and informal interactions with participants. This was referred to during the coding process, which was used to enhance data exploration and aid clarification of categories (Charmaz, 2014).

6.4 Results

6.4.1 Participants

Of the 15 packages distributed by the key contact clinicians, three family caregivers returned signed consent for participation. One participant withdrew before the second education session due to a family crisis (suicide attempt by relative with ABI). The remaining two participants completed the full FDBM program and all data collection. Participant demographic details are presented in Table 6.2. Both participants were female, including one mother and one daughter of two men with

ABI. Pseudonyms have been used and some details have been omitted to protect identities.

The results of the pilot study are presented in case study format. This is then followed by the participants' overall feedback regarding participation and the content and delivery of the sessions, which was then used to further refine the FDBM program.

Table 6.2 *Participant demographics*

Family caregiver	Participant 1- 'Kate'	Participant 2- 'Lauren'
Sex	F	F
Age	57	38
Relationship	Mother	Daughter
Length of caregiving role	20yrs	16yrs
Contact with relative with ABI	Approx 4 nights/ 3 days weekly	Approx 4 visits (i.e. 1-2 hrs) weekly
Living status	Separately	Separately
Employment	Casual	Full-time
Family member with ABI	'Angus'	'Bob'
Sex	M	M
Age	38	64
Age at time of injury	17	49
Injury circumstances	MVA	Pedestrian hit by a car
Medication	Propranoalol, Lamotrigine, Olanzapine	Augmentin Duo Forte, Pantoprazole, Clonazepam, Loperamide, Metoclopramide, Quetiapine, Oxazepam, Escitalopram
Health issues	Broken hip	Kidney infection, limited lung capacity, renal staghorn, issues swallowing

Living status	Own house	Supported housing with 8 others
Marital status	Single	Single
Employment	Unemployed	Unemployed
Interventions/ support received	ABI community group workshops – 2 days per week ABI family support group workshops – 1 session per month	ABI community-based rehabilitation program
Criminal history	-	-

6.4.2 Participant 1 – “Kate”

Kate was 57-years-old at commencement of this study. She lived on her own, but spent most weeknights with her son, Angus, in his own home. Kate had been caring for Angus since his brain injury 20 years earlier.

Angus was 17-years-old at the time of his severe head injury. He had just finished school and had enrolled in the army. Angus currently uses a wheelchair, has a tremor, and presents with inappropriate social behaviours and perseveration.

Kate worked casually, however describes the majority of her time being consumed with supporting Angus. She was married at the time of his injury, but had since separated.

At the time of this study, Kate was happy with their professional support team, which consisted of their GP and clinical psychologist. However, she was having difficulties with managing Angus’ verbal perseveration (specifically repetitive phrases relating to his ex-girlfriend – i.e. “I will marry...”) and what she described as “psychotic” displays of behaviour (i.e. delusional ideas about Hitler living in the neighbouring house).

6.4.2.1 Baseline assessment

Angus' support needs (CANS)

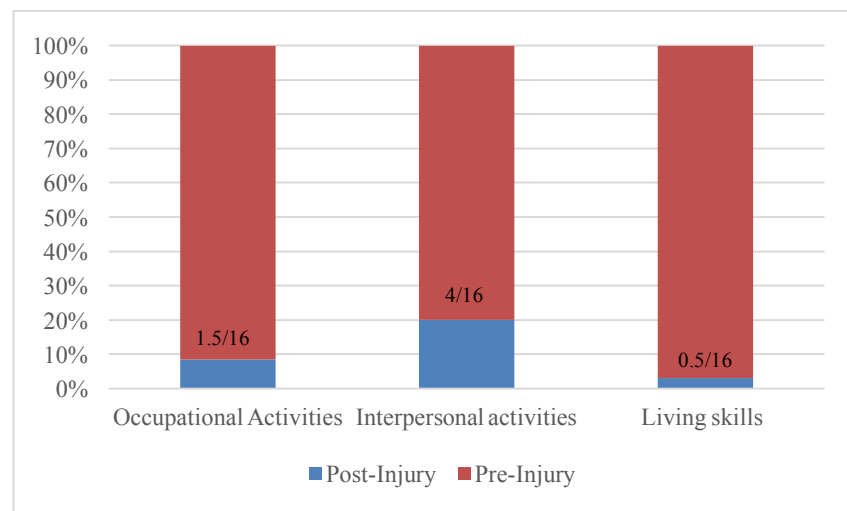
The CANS results for Angus are provided in Appendix 23. Angus required Level 7 support (i.e. cannot be left alone: needs nursing care, assistance and/or surveillance 24 hours per day), and requires assistance, supervision direction and/or guiding with a range of behavioural/cognitive disabilities, basic activities of daily living (ADLs) and social participation. Angus was able to communicate his needs verbally; however, he needed physical assistance with daily activities/tasks. He used a wheelchair and, due to a broken hip (sustained shortly after the brain injury), had difficulties with weight-bearing. Angus also required support managing his finances, interpersonal relationships and emotional support. His care consisted of 25 hours/week of paid support in addition to support from his mother, Kate.

Angus' living situation (SPRS-2)

Nine years following his injury, Angus received financial compensation for his accident. These funds were used to build a house to meet his physical needs. Kate felt this has had a significant positive impact on his behaviour, giving him a sense of control and independence. However, according to Kate, receiving compensation also had its downfalls, with Angus no longer eligible for services, or even a concession card for transport. At the time of this study he was very social and enjoyed getting 'out and about', visiting cafes and attending social events. Angus has been unemployed since the injury, but attended weekly social workshops through brain injury peer support groups.

Figure 6.2 shows the mean baseline levels of Angus’ psychosocial recovery according to the SPRS-2. Angus experienced significant change from his premorbid lifestyle. Kate reported major changes (i.e., average total scores, 0-2; i.e., extreme to a lot) regarding Angus’ occupational activities and living skills. However, significant changes were seen across all life domains. The raw baseline data for each subtheme within these categories is presented in Appendix 24. Each of the three domains were broken into relevant categories (i.e. Occupational activities = work, work skills, leisure, and organising activities). These were then rated according to the amount of change since the injury (i.e. 0 = extreme change; 4 = no change or improvement), with a maximum score possible for each 16 for each domain (representing no change since the injury).

Figure 6.2 Angus – Psychosocial Recovery (SPRS-2)



Behaviours of concern (BOC)

According to Kate, Angus’ physical rehabilitation was progressing well. However, his “psychotic” episodes spiked, and his behaviour became ‘out of

control'. Sometimes he was withdrawn, and at other times would become aggressive, lunging towards others, and yelling.

These “psychotic” episodes increased to the point that Angus not only refused his medications, but any form of liquid, as he thought he was being poisoned. The situation reached crisis point. Kate was unable to make contact with Angus’ neuropsychiatrist, and was refused help through the emergency helpline and their GP because he needed to be signed off by the neuropsychiatrist. Kate was forced to make difficult decisions, and Angus was eventually sedated and admitted to hospital.

A behaviour support plan was developed for Angus, however this appeared to focus on how to respond to behaviours, rather than also including information on why behaviours were occurring, and identifying preventative strategies.

When faced with Angus’ verbal perseveration, incidents of delusion or aggressive behaviours, Kate reported often not knowing what to do; she tried to verbally reassure or distract Angus, and often removed herself from the situation, waiting for the incident to pass if possible. There were times that she also sought help from Angus’ neuropsychiatrist, which often resulted in increased doses of psychotropic medications.

Angus’ behaviour profile (OBS)

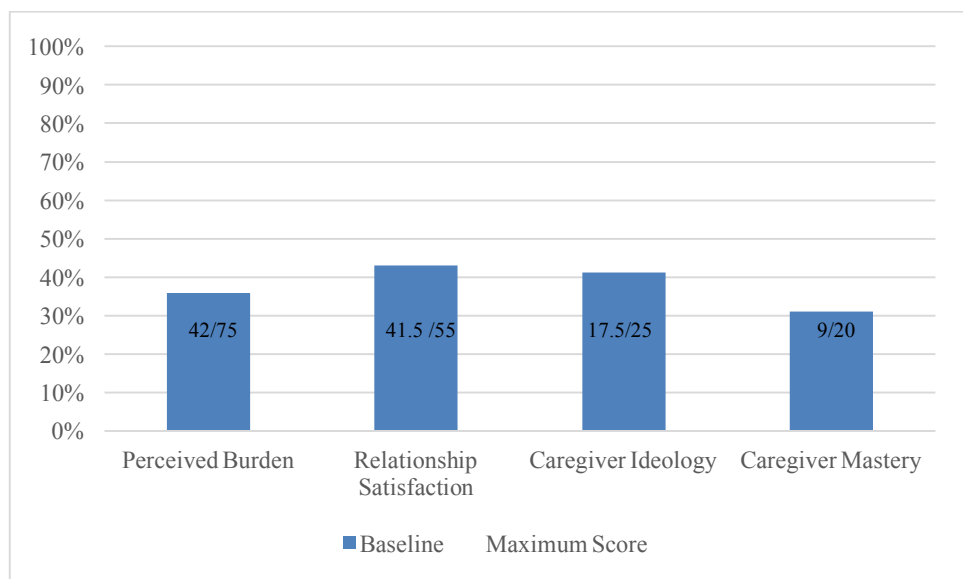
According to the OBS scores at baseline (see Appendix 25), Angus was engaging in a variety of BOC. Perseveration and lack of initiation were occurring once a day or more (mean score = 4), socially inappropriate behaviours were occurring at least once a week (mean score = 3), and verbal aggression was occurring

once a month or more (mean score = 1.5). Physical aggressions against objects and people, and sexually inappropriate behaviours were occurring less than once a month (mean score = 0.5). Moderate to extreme ratings of subjective impact indicated substantial distress and disruption experienced by Kate, with aggression, perseveration, inappropriate social behaviours, and lack of initiation causing the most impact (mean score 2.5 – 3.5).

Caregiver appraisal (CAS)

All raw data for Kate’s CAS scores are presented in Appendix 26. Kate reported high levels of perceived burden (42/75) and low perceptions of caregiver mastery (9/20). In contrast, Kate was satisfied with areas of caregiving related to relationship satisfaction (41.5/55), and caregiver ideology (17.5/25). Kate’s mean baseline CAS scores are presented in Figure 6.3.

Figure 6.3 Mean caregiver appraisal scores (CAS) - Kate



Confidence in managing BOC

Kate reported being “somewhat confident” on a five-point Likert-type scale in identifying why challenging behaviours occurred and in responding to these behaviours on the purpose-developed questionnaire.

6.4.2.2 FDBM Intervention

Kate completed the full FDBM program (education phase plus individualised sessions) over a 24-week period instead of a 15-week period. Education sessions were conducted over five weeks (rather than the intended four weeks), due to sickness. The six individual sessions were conducted over a period of 18 weeks instead of 11 weeks due to sickness and Kate’s employment commitments.

Education phase

During the four-week education phase, Kate was actively engaged, asking questions and reflecting on her own situation, and completed all activities. She also reported reviewing the relevant sections of the education workbook prior to coming to the sessions.

Kate identified the behaviour she wanted to target in this program (perseveration) and defined this using observable terms (see Table 6.6). This activity took some prompting from the researcher, encouraging Kate to step back and think about the behaviour objectively.

Prior to her involvement in this program, Kate placed emphasis on ensuring Angus had a meaningful routine, and that his home environment was appropriate according to his physical abilities. However, she reported being reminded of the importance of these antecedent strategies during the education phase and, as a result, placed further emphasis on his involvement in daily activities and increasing his choice and independence. She also discussed the importance of this with Angus' support workers, passing on information from the education workbook.

Kate reported going to see a neuropsychologist during the education phase who was also monitoring behaviours, and attending a two-hour information session on understanding and managing BOC following brain injury through a peer support network. She reported no significant life changes during this time.

Individualised sessions

During the first individualised session, Kate reviewed the Antecedent-Behaviour-Consequence (ABC) data she recorded during the education phase. The behaviours, possible triggers and contributing responses (responses thought to maintain/increase occurrence of behaviour) identified through this process are presented in Table 6.3.

Once Kate had identified possible triggers and responses contributing to the occurrence of BOC, she was prompted to think about the possible function (purpose) of the behaviour. The researcher reminded Kate of the direct link between the neurological damage and the behaviour, with damage to the frontal lobe often

resulting in perseveration, but also that environmental factors can also contribute to the frequency of this behaviour.

Table 6.3 *Target behaviour, possible triggers and maintaining consequences - Angus*

Target Behaviour	Possible Triggers	Possible responses maintaining the behaviour
Perseveration		
1) Repeated fixations on females (ex-girlfriend in particular). For example, will repeatedly state <i>"I'm going to marry ..."</i>	<ul style="list-style-type: none"> - Exposure to romantic gestures between others (e.g. advertisements/T.V/music/partners being romantic in public) - Seeing individual who looks like ex- girlfriend - Being over stimulated (busy environments/too much coffee) - Being under stimulated (not kept busy) 	- Responding to and discussing topic fixated on
2) fixation on delusional ideas regarding Hitler. For example, will repeatedly state <i>"Hitler lives in the house next door"</i>	<ul style="list-style-type: none"> - Authoritarian approach from caregivers (e.g. being told what to do rather than asked) - Exposed to army related experiences/ advertisements - Being over/under stimulated 	- Responding to and discussing topic fixated on

Kate reported thinking that Angus' perseveration was a coping mechanism; but, after discussing her ABC data, she instead suggested that this behaviour may be a warning sign that he was becoming agitated or a sign that he was over or under stimulated (e.g. busy/noisy environments when he is tired, or when he is not engaged

in an activity/task). During this process Kate also reported previously giving the behaviour much attention; however, she considered that this may have been in fact reinforcing the behaviour and not addressing the underlying causes. The BOC was therefore seen to serve both an ‘escape’ function (e.g. to avoid undesirable environments or activities) and an ‘access’ function (e.g. to gain attention/involvement) (Storey & Post, 2015).

During the individual sessions Kate expressed that Angus would like more female attention, but she felt he was not capable of ‘holding down’ a girlfriend. He had previously seen a sex worker, but had himself decided to stop these visits. As a result, Kate placed more emphasis on making sure he had sufficient opportunities to socialise with women during his weekly routine; she felt it was not necessarily the sexual intimacy that he craved, but the social and flirty ‘banter’ with girls when he was out and about. The strategies she reported using during the education phase and throughout the individualised sessions are presented in Table 6.4.

Table 6.4 *Behaviour management strategies utilised - Kate*

Management strategies utilised		
	Proactive	Responsive
Education Phase	<ul style="list-style-type: none"> • Further involve Angus in daily activities (e.g. watering garden, hanging washing) • Further involve Angus in decision making around daily activities • Clear communication (e.g. using short and simple sentences, keep calm and in control) • Allow more time for completing activities 	-

Individual session 1	<ul style="list-style-type: none"> • Avoid loud/busy environments when Angus is tired, • Try to ensure Angus gets a good night sleep (calm evening routine and not to bed too late) • Further involve him in house activities (e.g. watering garden, hanging washing) where possible 	<ul style="list-style-type: none"> • Briefly acknowledge what Angus says when he begins to perseverate, and then divert his attention by discussing desired topic or give him a task/something else to focus on • If he continues, leave for a short period- i.e. 3 minutes (e.g. say need to get something from car)
Individual session 2	<ul style="list-style-type: none"> • Prompt Angus to identify a place/activity help him feel calm, and prompt him to utilize this when he displays warning signs • Manage triggers, ensure involvement & choice regarding activities, use of effective communication - see strategies above 	<ul style="list-style-type: none"> • Continue diversion strategies for perseverative behaviours • Praise effort when utilises identified strategies to reduce elevation
Individual session 3	<ul style="list-style-type: none"> • Manage triggers – see above • Ensure involvement & choice regarding activities – see above • Use of effective communication - see above • Remind Angus that he can use his ‘comfy chair’ if he needs to 	<ul style="list-style-type: none"> • Continue diversion strategies for perseverative behaviours • Prompt Angus to use his comfy chair when he displays warning signs – use his ‘secret’ word
Individual sessions 4-6	<ul style="list-style-type: none"> • Manage triggers – see above • Ensure involvement & choice regarding activities – see above • Use of effective communication - see above • Remind Angus that he can use his comfy chair if he needs to 	<ul style="list-style-type: none"> • Continue diversion strategies for perseverative behaviours • Prompt Angus to use his Jester chair when he displays warning signs • Praise effort when spends time in comfy chair (with or without prompting) to reduce elevation

During the first individualised session, Kate reported that perseverative behaviours were occurring at much less intensity than they had been previously.

However, at this time she reported a couple of instances of aggression which she found very concerning.

Kate identified that prior to becoming agitated, Angus presented with increased levels of perseveration, and his shoulders became tense and he spoke with increased pace and volume. During the second individual session Kate made a plan to discuss this with Angus when he was in a calm head space, and to prompt him to identify places/activities that helped him to feel calm. The researcher modelled how Kate might do this, using language such as *“I’ve noticed that sometimes you become agitated... this is really normal – sometimes I get agitated too. It’s hard to know when you are becoming agitated, but I have noticed that your shoulders become tense... is there anything that you think might help you feel calm in these situations?”* Kate had some ideas of strategies that she felt helped Angus to relax, but gave him the opportunity to identify these for himself before suggesting these. She then asked him if he wanted to identify a ‘secret word’, and when he would present with warning signs that he was becoming agitated, she would say the secret word and prompt him to his identified ‘calm place’, which was ‘the comfy chair’. The importance of using verbal praise to positively reinforce this behaviour was also emphasised, with Kate having the opportunity to practice her response with the researcher. During the second week she also ensured that she was still utilising antecedent strategies to prevent incidents where possible.

During the third individual session, Kate said there had been no incidents of anger, and only ‘a couple’ of minor incidents of perseveration, for which her diversion strategies were effective. She reported not using the comfy chair during this week. The researcher discussed the importance of positively reinforcing Angus’

use of the comfy chair, with this being modelled and practiced during this session. Antecedent strategies were also reviewed.

During the fourth session, Kate reported that Angus had become agitated twice during this fortnight; however, the first time he went to his comfy chair following her prompt, and the second time he initiated this on his own. Kate's behaviour support plan appeared to be having a positive impact, and Kate appeared to be engaged in the process.

However, during this time, Kate had been informed that Angus' main support worker would be leaving, with very little warning, resulting in feelings of apprehension. She was not sure how Angus would cope with this big change. Furthermore, he had a good relationship with his worker and Kate felt he would also be losing a friend. During this session, the researcher and Kate discussed how this transition could be best managed to reduce its impact on Angus. As a result of his minimal warning, Kate asked the support worker to come back for a few visits whilst Angus adjusted to his new staff.

According to Kate, Angus coped with this transition much better than she expected. They also found a temporary worker who developed quick rapport with Angus, with Angus also being actively involved in interviewing new staff. This was certainly a trying time for Kate, who was faced with difficulties of maintaining her work hours but also covering shifts with Angus. She also employed a new worker who missed many shifts without notice and proved to be very unreliable. Kate felt the different workers made it difficult to be consistent with responsive strategies she had in place, but she had set up a good routine with daily activities. She also had

thorough communication and crossovers with staff, whom she encouraged to read the FDBM education workbook to gain further insight into his situation.

Due to the inconsistencies with staff and her work commitments, Kate was unable to make the fifth individual session; as a result, this catch up was conducted via two phone conversations during the fortnight. Kate felt her strategies were still effective, but expressed difficulties with some staff and again emphasised issues regarding the consistency of response strategies. The researcher prompted Kate to consider Angus' changing needs, and talked through how she would monitor and adjust strategies. Kate was encouraged to complete and review a behaviour support template during their fifth and final session.

During the final (sixth) session, Kate reported that Angus had been using his comfy chair, but had not been using his secret word. She also found that recording the frequency of BOC prompted staff to be more observant of behaviours and gave her the opportunity to discuss behaviours and strategies with staff. The final plan produced is included in Appendix 27.

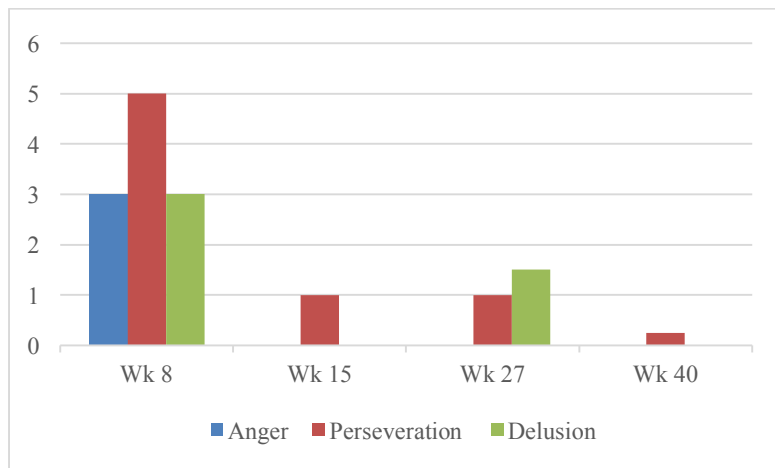
At three-month follow-up, Kate reported no significant changes/life events since completion of the program. She reported attending one appointment with Angus' neuropsychiatrist, and one two-hour workshop regarding behaviour changes following ABI through a peer support network. She reported receiving no other support regarding the management of Angus BOC during this time.

6.4.2.3 Outcomes

Frequency of Angus' BOC

In order for Kate to monitor the frequency of the target behaviours over the course of the program, she (and support staff) completed frequency tallies over four consecutive days at the following intervals: week 8 (directly following the third education session); week 15 (following the third fortnightly individualised session); week 27 (before the final individualised session); and at three-month follow-up (week 40). The frequency reports at each time point are presented in Appendix 28, with the mean frequency of behaviours presented in Figure 6.4. The frequency of BOC reduced during the intervention, and at weeks 15, 27 and follow-up (week 40). No occurrences of aggressive behaviours were reported at these intervals, and no reports of delusional behaviours occurred at week 15 or follow-up.

Figure 6.4 Target behaviour frequency - Angus

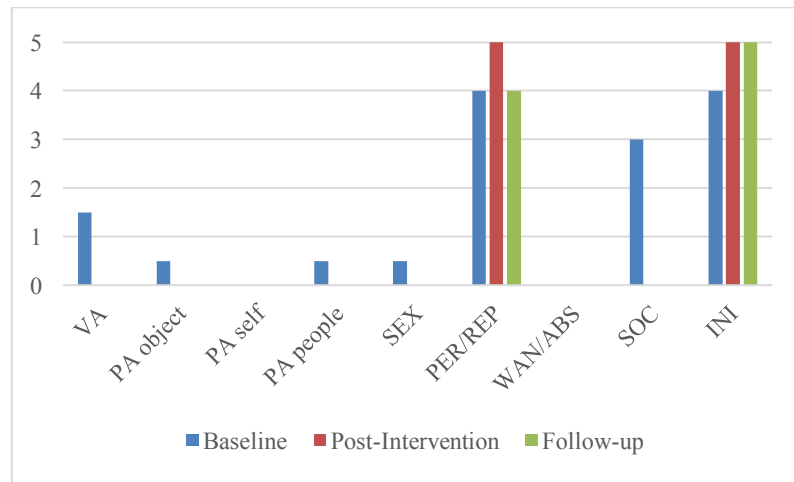


Angus' behavioural profile (OBS)

The frequency of Angus' BOC at baseline, at completion of the program and at follow-up is displayed in Figure 6.5 according to the OBS. At baseline Kate

reported several incidents of BOC; with many of these behaviours not reported at follow-up.

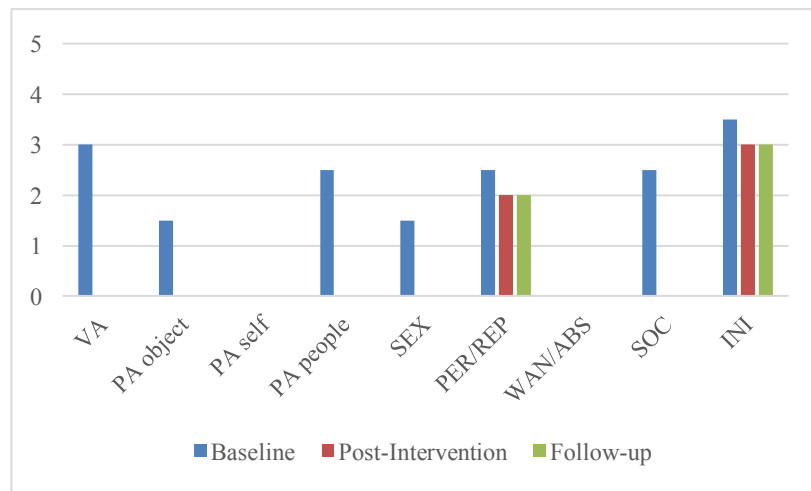
Figure 6.5 Angus' mean frequency behaviour profile (OBS) at baseline, post intervention and follow-up



Note: OBS = Overt Behaviour Scale; VA = verbal aggression; PA = physical aggression; SEX = inappropriate sexual behaviour; SOC = inappropriate social behaviour; WAN = wandering/ absconding; PER/REP = perseverative/ repetitive behaviours; INI = lack of initiation

The mean impact of behaviours at baseline and at completion of the program is presented in Figure 6.6. Higher scores reflect greater impact (1=none, 5=extreme). There appeared to be some reduction in the impact of perseverative behaviours and reduced initiation post intervention and at follow-up. The reported impact of perseverative behaviours decreased from moderate to minor.

Figure 6.6 Mean impact of behaviours (OBS) at baseline, post intervention and at follow-up



The frequency and impact of behavioural domains relevant to target behaviours (i.e. perseveration) at each of the seven assessment points and PEM scores are included in Appendix 25. Given Kate’s concern regarding aggressive behaviours, these have also been presented.

There was significant fluctuation in the behaviours during the baseline recordings (BA1, BA2), with no occurrences of verbal or physical aggression (against objects or people) reported following the second individualised session (OA2), which was maintained at follow-up. There were no reported improvements in the frequency of perseveration and lack of initiation, however the reported impact of perseverative behaviours decreased from moderate to minor.

The PEM approach was used to examine longitudinal data; this calculates the overlap according to the baseline mean. For verbal aggression there was a PEM reduction of 80% according to the mean baseline (2.5) for both frequency and impact, suggesting moderate effect of the intervention. There was also a PEM reduction score of 80% relating to frequency and impact of physical aggression against objects (Figure 6.7) and physical aggression against people (Figure 6.8).

Figure 6.7 Frequency and impact of physical aggression against objects - Angus

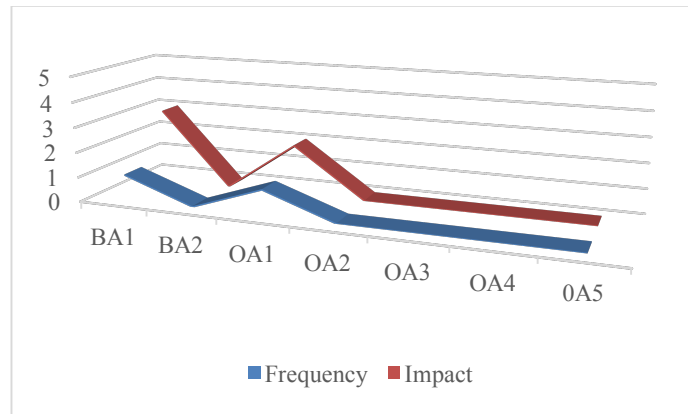
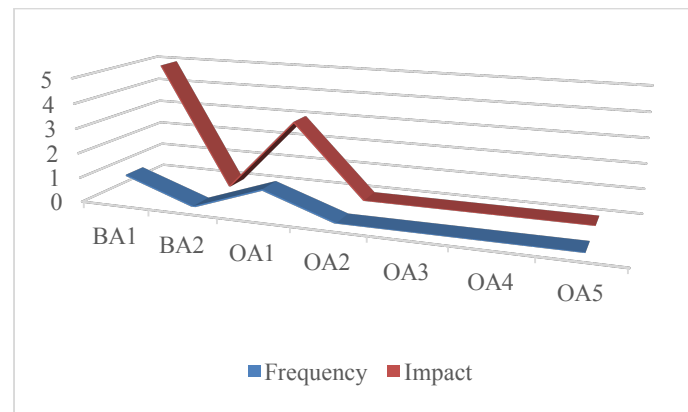


Figure 6.8 Frequency and impact of physical aggression against people - Angus

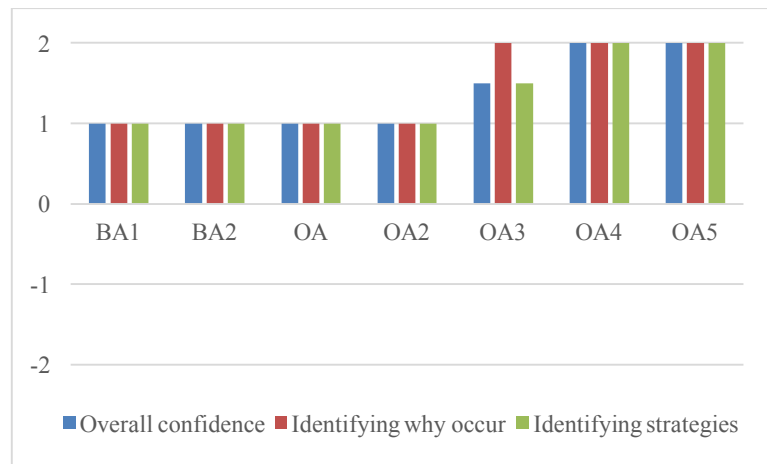


Kate's confidence in managing BOC

Kate's perceived confidence in managing BOC is presented in Figure 6.1.4. Higher scores reflect increased confidence (2 = very confident, -2 = not at all confident). At baseline (BA1 & BA2) Kate reported being "somewhat confident" in each of these domains, with no change reported following the education phase (OA1) or second individualised session (OA2). However, following the fourth individualised and sixth individualised sessions Kate reported being "very confident" in each of these domains.

There was a PEM improvement of 60% in Kate’s levels of confidence in managing BOC, which suggests mild effect according to this domain.

Figure 6.9 *Kates perceived levels of confidence in managing challenging behaviours*

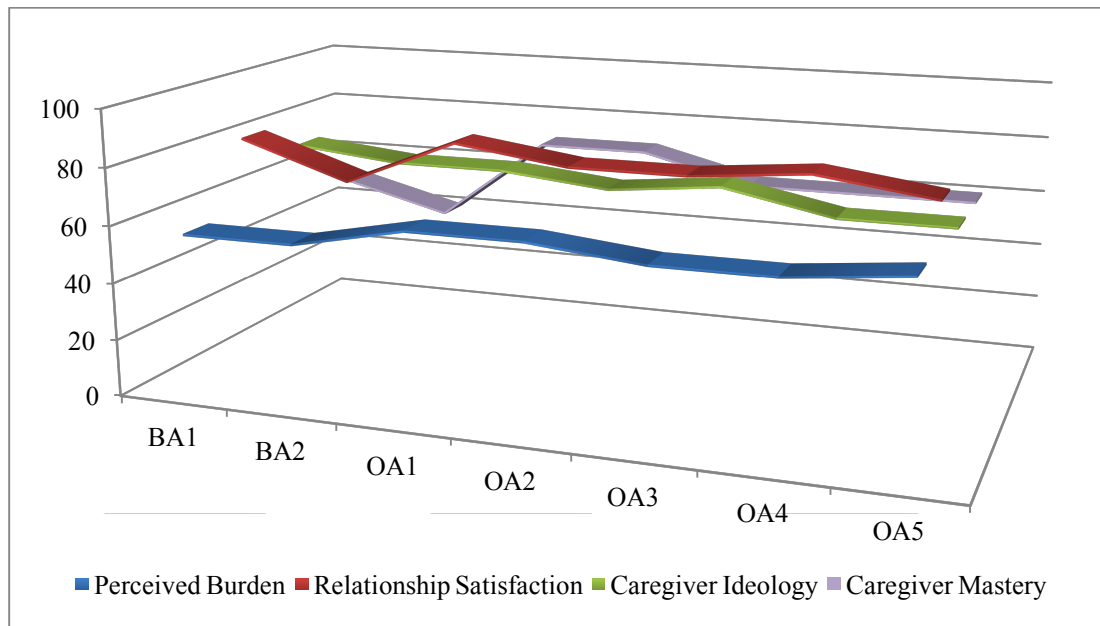


Caregiver Appraisal (CAS)

Kate’s CAS data and PEM scores relating to perceived burden, relationship satisfaction, caregiver ideology and caregiver mastery at each assessment point is presented in Appendix 26, with percentage scores for each domain presented in Figure 6.1.1.

There was a PEM improvement of 100% regarding Kate’s perceived levels of caregiver burden, relationship satisfaction and caregiver mastery, although no change in caregiver ideology (see Figure 6.1.5). This suggests the intervention to be highly effective in each of these domains according to the CAS.

Figure 6.1.1 *Perceived caregiver appraisal (CAS) - Kate*



6.4.2.4 Summary

Kate completed the full FDBM program, including four education sessions plus six individualised sessions. During this time she defined BOC she wanted to target, including verbal perseveration and delusions. The results revealed a decrease in Angus' BOC, with aggressive behaviours eliminated at the second assessment phase. According to the OBS there was little improvement in frequency of perseverative behaviours; however, Kate's frequency measures showed a significant improvement. There were also improvements seen in her levels of confidence in managing and a trend of improvement regarding levels of caregiver burden (according to the CAS).

6.4.3 Participant 2 – “Lauren”

Lauren was 38-years-old and worked full-time in addition to supporting her father, Bob. Lauren had been helping with her father’s care for 16 years, but had been the sole family caregiver for 10 years.

Bob was 49-year-old self-employed painter and decorator at the time of his severe brain injury. He was under the influence of alcohol when he walked onto the road and was hit by a car. At the time of this study he used a wheelchair, had limited verbal communication, lack of motivation, and displayed high levels of agitation. He also had ongoing health issues, including reduced lung capacity, issues with swallowing, urinary tract infections, and kidney stones. There were also concerns that he may be developing dementia.

Bob was living in supported accommodation with three others, and ten different staff supporting him in shifts throughout the week. Lauren was the legal guardian of Bob and was very involved in managing his care and advocating for his support needs. She reported little time for herself, and was medicated with anti-depressants.

Lauren felt support staff had limited training regarding behavioural support and that there was little consistency with Bob’s care. Lauren was specifically concerned about Bob’s repetitive behaviours, and high levels of agitation, and felt there should be better strategies in place to manage these behaviours.

6.4.3.1 Baseline assessment

Bob's support needs (CANS)

Bob's support needs were evaluated using the CANS (see Appendix 29) Bob required Level 7 support (i.e. cannot not be left alone: needs nursing care, assistance and/or surveillance 24 hours per day), and required assistance, supervision direction and/or guiding with a range of behavioural/cognitive disabilities, basic activities of daily living (ADLs) and social participation (Group A – D). Bob had limited verbal communication. He required full manual support with bed transfers and physical support with all daily activities/tasks. He also required support in managing his finances, and with interpersonal relationships, and initiating leisure/recreation activities. His care consisted primarily of paid support workers (24-hours/7 days) and support from Lauren.

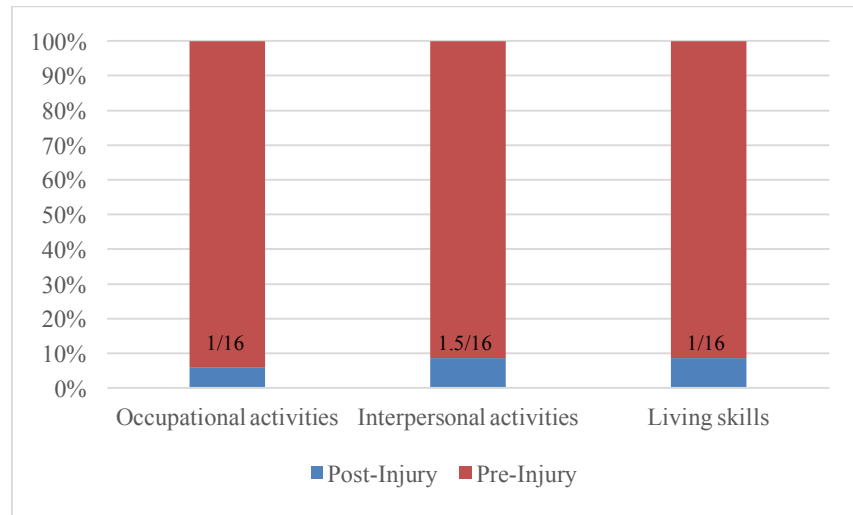
Bob's living situation (SPRS-2)

Prior to his injury, Bob was living independently, was self-employed and was very social. He had been unemployed since his injury and received 24-hour support. He had been involved with a peer support network previously; however, Lauren reported attending this was not currently possible due to his high support needs; support staff were having difficulties encouraging (and physically supporting) him to leave his bed.

Figure 6.1.2 shows the mean baseline levels of Bob's psychosocial recovery according to the SPRS-2. Lauren reported major changes (i.e. average total scores, 0-2; i.e., extreme to a lot) regarding Bob's occupational activities, interpersonal

activities, and living skills compared to his premorbid lifestyle. The raw baseline data for each subtheme within these categories is presented in Appendix 30.

Figure 6.1.2 Psychosocial Recovery (SPRS-2) - Bob



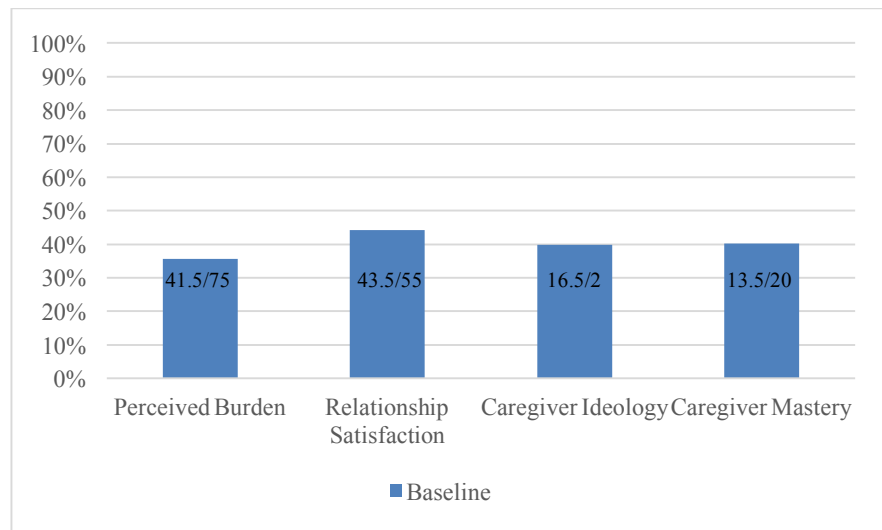
Bob's behavioural profile (OBS)

According to the baseline OBS scores (see Appendix 31), Bob was engaging in a variety of BOC, with perseveration occurring several times a day (mean score = 5), and verbal aggression and lack of initiation occurring once a week or more (mean score = 3). Physical aggression against objects and people, and socially inappropriate behaviours were occurring once a month or more (mean scores = 2-2.5), socially inappropriate behaviours, and lack of initiation occurring at least once daily (mean score = 4). Moderate to extreme ratings of subjective impact indicate the substantial distress and disruption being experienced by Lauren in each of these domains (mean scores = 3-3.5). Bob demonstrated incidents of screaming and agitation requiring PRN.

Caregiver Appraisal (CAS)

All raw data for Lauren’s CAS scores at baseline are presented in Appendix 32. Lauren reported high levels of perceived burden (mean 41.5/75). Lauren reported being satisfied with areas of caregiving related to relationship satisfaction (mean 43.5/55), caregiver ideology (mean 16.5/25) and caregiver mastery (mean 13.5/ 20). Lauren’s mean baseline CAS scores are presented in Figure 6.1.3.

Figure 6.1.3 Mean caregiver appraisal scores (CAS) - Lauren



Lauren’s confidence in managing BOC

Lauren reported being “very confident” on a five-point Likert-type scale in identifying why BOC occurred, and being “somewhat confident” in managing the behaviour and identifying the most appropriate strategies.

6.4.3.2 FDBM Intervention

Lauren completed the full FDBM program (education sessions plus individualised sessions) over a 29-week period. The education sessions were conducted over ten weeks (rather than the intended four weeks), with Lauren rescheduling all four sessions due to Bob's medical emergencies, BOC, and sickness. The six individual sessions were conducted over a period of 20 weeks (rather than the intended 11 weeks) due to Lauren being unwell and Bob's medical emergencies.

Education phase

During the four-week education phase, Lauren was actively engaged, asking questions and reflecting on her own situation, and completed all activities.

Lauren identified the behaviours she wanted to target in this program (perseveration, agitation and verbal aggression) and defined these using observable terms (see Table 6.1.6).

Lauren expressed the need to further develop Bob's weekly routine, ensuring that he was participating in meaningful activities. She was concerned that his days were predominately spent attending medical appointments and watching television, which was suggested when completing his weekly routine during one of the set activities.

Lauren collected ABC data; however, she found this challenging because she often relied on reports from support staff. She did however make further observations during her visits to Bob.

Individualised sessions

During the first individual session, Lauren reviewed her ABC data. However, in discussing this data, she was often subjective, rather than reporting on objective observations. For example, she often presumed his dislike of specific staff or presumed the function of behaviour before analysing observation data. The researcher prompted Lauren to ‘step back’ and review data in a more objective manner. The behaviours, possible triggers and contributing consequences (responses thought to maintain or increase the likelihood of behaviour occurring) identified are presented in Table 6.5.

Lauren was prompted by the researcher to think about the possible function (purpose) of the BOC, It was hypothesised that Bob’s BOC served both an escape function (e.g. from specific staff and activities) and an access function (e.g. to gain social or medical attention) (Umbreit, Ferro, Liaupsin, & Lane, 2007).

Lauren understood that Bob’s perseverative behaviour was linked to the direct implications of the neurological damage, but felt this was further exacerbated by staff responses, because staff often appeared not to understand what he seemed to be communicating. She also felt his agitation and insults were largely impacted by limited choice and control in his daily routine, and were further maintained by staff interactions and their responses to this behaviour. Behaviours appeared to be triggered by particular staff approaches to manual lifting and shower routine.

Table 6.5 *Target behaviour, possible triggers and maintaining consequences – Bob*

Target Behaviours	Possible Triggers	Possible responses maintaining the behaviour
1) Perseveration – Agitated/ repetitive behaviours (e.g. “7:30”, “I’ve had enough”, “hello, hello”)	<ul style="list-style-type: none"> - Showering/ toileting routine - Pain/ medical issues - Movement (e.g. bed to lifter) - Overstimulation (e.g. loud and busy environments) - Calling him by nickname 	- Discussing/questioning topic of perseveration
2) Verbal insults towards staff (e.g. “Poofter”, “Bitch”, “Pain in the bum”)	<ul style="list-style-type: none"> - Showering/ toileting routine - Pain/ medical issues - Movement (e.g. bed to lifter) - Particular staff 	- Staff laughing at insults/ making jokes in response
3) Continuous screaming	<ul style="list-style-type: none"> - Showering/ toileting routine - Pain/ medical issues - Movement (e.g. bed to lifter) - Particular staff 	<ul style="list-style-type: none"> - Staff providing attention when he is screaming - Staff calling Lauren to come in to settle situation

The strategies she reported using, and suggesting staff to use during the education phase and throughout the individualised sessions are presented in Table 6.6.

Table 6.6 Behaviour management strategies utilised - Lauren

Management strategies utilised		
	Preventative	Responsive
Education Phase	<ul style="list-style-type: none"> • Prompting staff to include more meaningful activities in Bob's daily routine • Reduce noise/ distraction in house and simplify communication methods (i.e. simple sentences and allowing time for Bob to process information) 	N/A
Individual session 1	<ul style="list-style-type: none"> • Developing visual routine, incorporating meaningful activities 	<ul style="list-style-type: none"> • (wrote up strategies but not yet being implemented)
Individual session 2	<ul style="list-style-type: none"> • Provide written information with clear recommendations to: <ul style="list-style-type: none"> ○ not use Bob's nickname ○ not to repeatedly ask Bob if he wants a shower after already stating 'no' ○ provide him with positive attention when he appears to be in a positive head space, rather than waiting until he is 'calling out' 	<ul style="list-style-type: none"> • Provided written information prompting staff to: <ul style="list-style-type: none"> ○ Ignore insults, do not laugh at them or take them personally – instead to ask Bob if something he needs, observe if anything is upsetting him and/or direct him to activity
Individual session 3	<ul style="list-style-type: none"> • Same as above 	<ul style="list-style-type: none"> • Same as above
Individual sessions 4-6	<ul style="list-style-type: none"> • Provide Bob with positive interaction (e.g. playing games, food preparation, going for walk) when he appears to be in a calm and positive headspace (i.e. not only providing attention when he is shouting/ screaming) 	<ul style="list-style-type: none"> • When Bob is shouting/ screaming (or saying "hello, hello"), staff were requested to respond with "everything is ok. Would you like me to sit with you?" If he answers no, suggested to state that you will be in the

next room if he needs
anything/ use distraction
techniques where appropriate

Due to Bob residing in supported accommodation with high staff turnover, Lauren had limited control over the implementation of strategies. She decided to develop a small poster for staff, which introduced Bob, and a few hints that might support staff in promoting positive behaviours.

Due to delays in collecting frequency data, Lauren did not put up her poster until after the second individualised session. In the meantime, she discussed his routine with staff and the importance of them spending time engaging Bob in meaningful activities.

During the third session, Lauren reported apparent improvements in Bob's behaviour and felt that simply by staff not using his nickname, this seemed to be having positive effect on him (i.e. resulting in more positive interactions). During the following week she also collected feedback from staff, seeking information on what suggested strategies were perceived to have a positive impact on Bob's behaviours and if these strategies helped staff with their confidence in supporting Bob (see Appendix 33 for feedback template). The response indicated all of the strategies were being utilised; however, the sections relating to the effectiveness of these strategies were not completed. The staff felt that the information she provided was helpful, and that it was having a positive effect on Bob's behaviour; however, they felt medical issues were still a significant trigger for target BOC.

Lauren often spoke about her ‘strained’ relationship with the support staff and the managers of the support accommodation agency. When Lauren spoke to them about updating his behaviour support plan, she felt they were not committed to the process, and felt they often ‘dismissed’ her ideas and recommendations.

The researcher prompted Lauren to consider their caregiving role; the challenges, and the things that they were also doing well. They also discussed the importance of developing a respectful and positive relationship in successful collaboration regarding Bob’s care plan. The researcher suggested Lauren might try to balance suggestions made to staff with genuine praise, also acknowledging what they are doing well. It was thought that this might impact their willingness to implement behavioural strategies identified.

Before the fourth session, Bob had surgery to have a kidney stone removed. Although it did take him a couple of weeks to recover from the surgery, Lauren reported that his mood improved dramatically. Furthermore, this had a positive effect on manual transfers (i.e. from bed to chair), which meant staff were able to engage him in more outdoor activities (i.e. walks and shopping).

During the fourth individualised session, Lauren reported that things were going well, and that a nurse was placed in the house, which meant she was not called as much for minor medical issues. However, she still expressed concern with specific staff, who did not appear to have a rapport with Bob, and whose interaction style appeared to be a trigger for BOC.

Lauren also expressed some concern that even the limited suggestions she provided to staff were perhaps too much, and decided to prioritise strategies, and give staff one ‘focus’ for the week. This included a response strategy for when Bob

was shouting/screaming (or saying ‘hello, hello’), which included a scripted response of ‘everything is ok, would you like me to sit with you?’ If he answered no, the workers were also advised to let him know that they were in the next room if he needed anything. Importantly, staff were also directed to give Bob positive interactions and engage him in meaningful activities (such as playing Uno and help with food preparation) when he appeared to be in a positive headspace (rather than only paying him attention when he became distressed).

At the following session, Lauren reported that the staff were taking Bob out regularly, but she was now concerned that this might be happening *too often*. The emphasis was then on educating staff around identifying triggers and ‘warning signals’ preceding Bob’s BOC, and strategies to help them effectively communicate with Bob.

At this time, although Lauren could identify possible strategies, including alternative communication techniques, she felt staff were not committed to making necessary environmental changes or open to discussing changes in his support plan. This prompted Lauren to begin the process of updating his support plan with external support, and to begin looking at alternative accommodation options that may be better suited to Bob’s support needs. These processes added additional strain on Lauren’s relationship with managing staff.

During the fifth session, and the final session, Lauren completed and reviewed a behaviour support template. The final plan produced is included in Appendix 34.

At three-month follow-up, Lauren reported that Bob would soon be transitioning to a new accommodation facility. She otherwise reported no significant

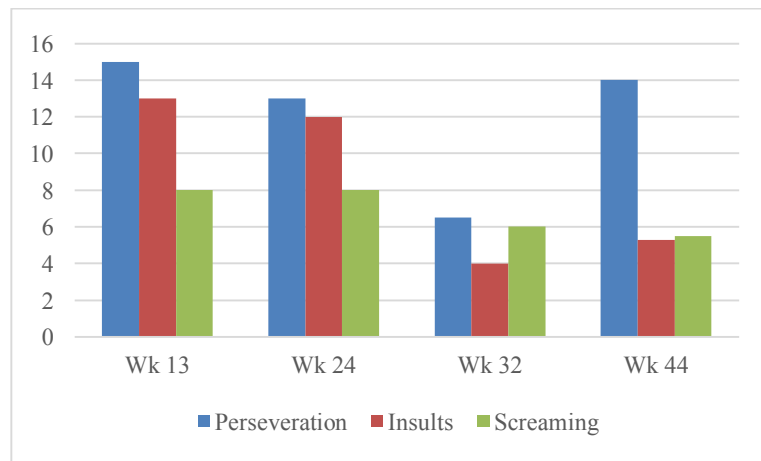
changes/life events since completion of the program. She also reported receiving no other support regarding the management of Bob's BOC.

6.4.3.3 Outcomes

Frequency of Bob's BOC

In order for Lauren to monitor the frequency of the target behaviour over the course of the program, frequency tallies were completed over four consecutive days at the following intervals: directly following the education phase (week 13); following the third fortnightly individualised session (week 24); before the final individualised session (week 32); and, three-month follow up (week 44). Lauren completed the observations directly following the education sessions, and asked support staff to complete the observations at the following two data collection points. However, she needed to prompt staff over a two-week period to complete the observations. There were some inconsistencies with the interpretation of the behaviour being observed. The frequency reports at each time point are presented in Appendix 35, with the mean frequency data displayed in Figure 6.1.4. There was reduction reported in each of the target behaviours, with the most significant reduction seen in staff insults, with this reducing from 15 times daily in week 13 to four times daily by week 32. The frequency of perseveration also reduced from 15 times daily to six times daily. There were no significant changes in the frequency of screaming, reducing from eight times daily to six times daily at week 32.

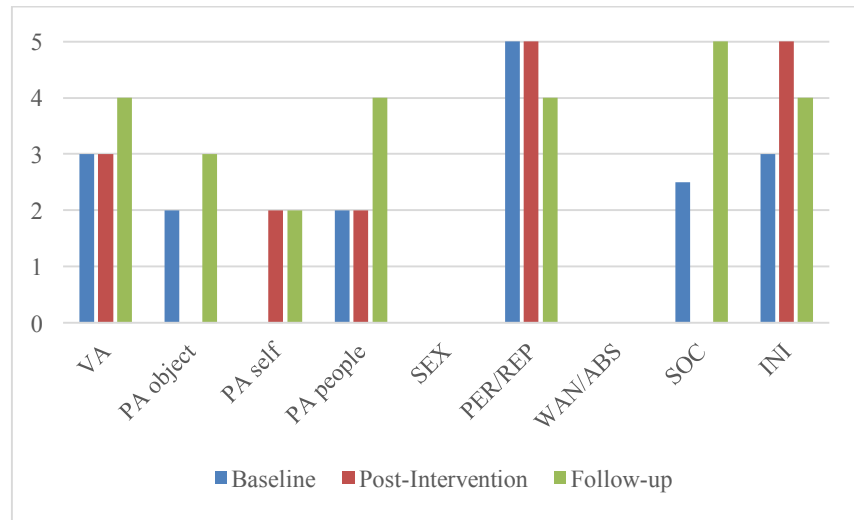
Figure 6.1.4 *Target behaviour frequency – Bob*



Bob's behavioural profile (OBS)

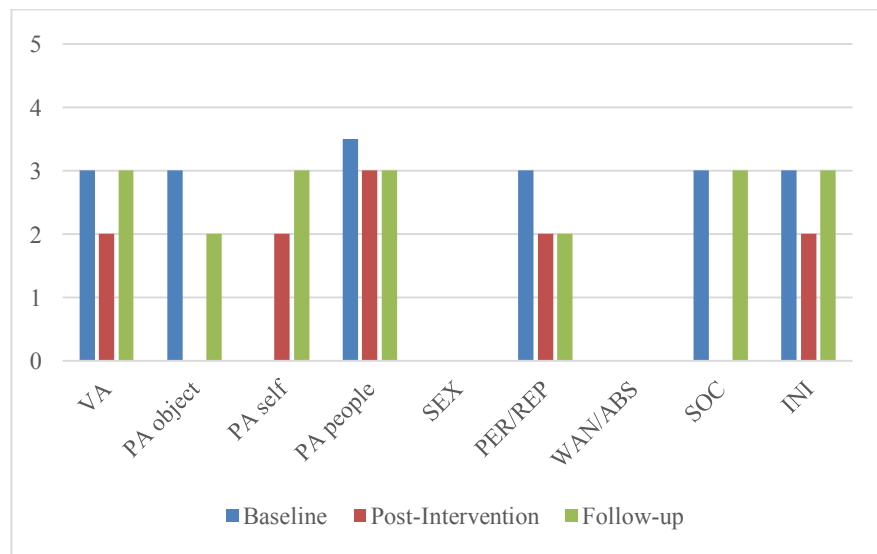
The frequency of Bob's BOC at baseline, at completion of the program and at follow-up according to the OBS is presented in Figure 6.1.5. The frequency of verbal aggression showed no improvement post intervention, and actually increased; physical aggression, which was occurring once per month or more at baseline, was eliminated post-intervention, but was occurring once per week or more at follow-up; physical aggression against self was not occurring as baseline, but was reported as occurring once per month or more post intervention and at follow-up; physical aggression against people showed no improvement post intervention, and increased from once per month or more to once per day at follow-up; repetitive behaviours showed no improvement at follow-up, but reduced from multiple times a day to once per day at follow up; socially inappropriate behaviours were reported as occurring once per month to weekly at baseline, were eliminated at post-intervention, but were occurring multiple times each day at follow-up; and, lack of initiation was occurring once per day at baseline, increased to multiple times a day at post intervention, and reduced to once per day at follow-up.

Figure 6.1.5 Bob's mean frequency –OBS at baseline, post-intervention and follow-up



The mean impact of BOC at baseline and at the completions of the program (according to the OBS) is presented in Figure 6.2.2. Higher scores reflect greater impact (1=non, 5=extreme); the impact of behaviour refers to the family caregivers' experience of stress, worry, concern, or fear as a result of the behaviour, but also the practical difficulties (e.g. needing additional staff or having to acquire additional supports such psychiatrists or police).

Figure 6.1.6 The mean impact of Bob's behaviour of concern at baseline and completion of the FDBM program

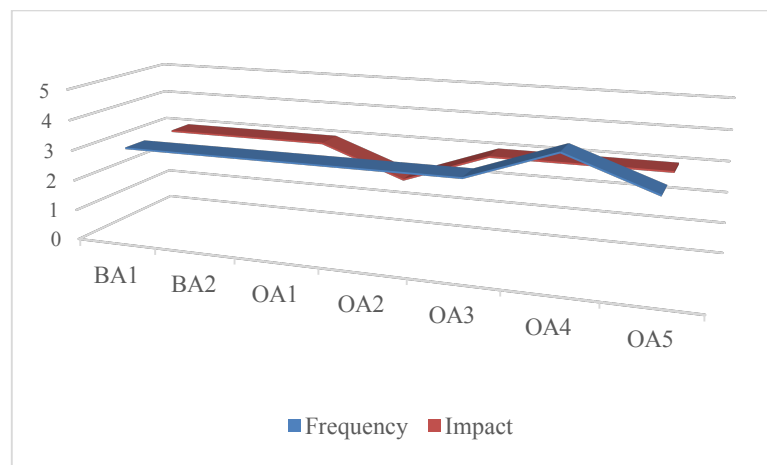


The impact of verbal aggression reduced from moderate (3) to minor (2) at post intervention, and increased to moderate impact at follow-up. There was also a reduction in the impact of perseverative behaviours from moderate at baseline to minor at post-intervention and follow-up. The impact of lack of initiation reduced from moderate to minor at post-intervention, but increased to moderate at follow-up.

The frequency and impact of behavioural domains relevant to target behaviours (i.e. verbal aggression [Figure 6.1.7 and perseveration [Figure 6.1.8]) at each of the seven assessment points are presented below according to the OBS. The raw data and PEM scores are included in Appendix 31.

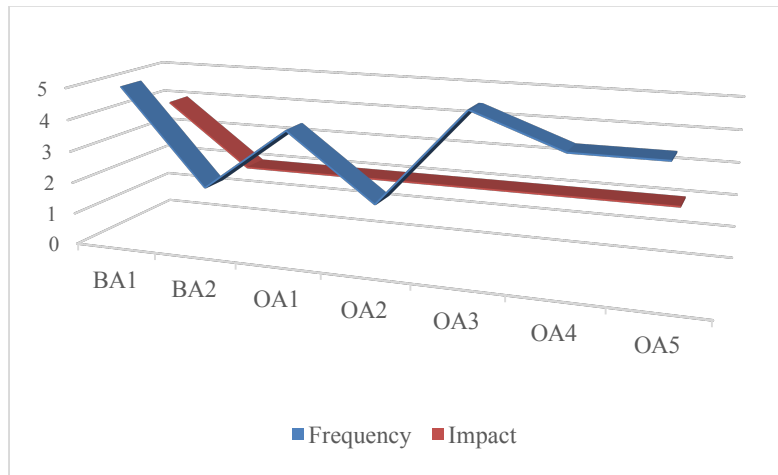
There were no reported improvements in the frequency or impact of perseveration and lack of initiation; however, the reported impact of perseverative behaviours decreased from moderate to minor.

Figure 6.1.7 Frequency and impact of verbal aggression according to OBS - Bob



For verbal aggression there was a PEM reduction of 0% regarding frequency and 20% regarding impact according to the mean baseline (3), suggesting ineffective intervention. This was confirmed with visual inspection.

Figure 6.1.8 Frequency and impact of perseveration according to OBS - Bob



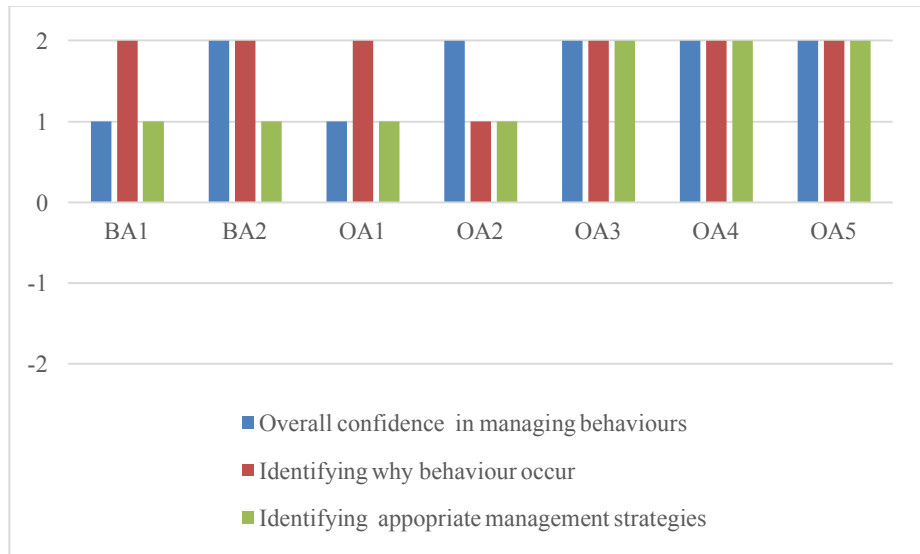
For perseveration there was a PEM reduction score of 20% relating to frequency, suggesting ineffective treatment. There was a PEM reduction score of 100% regarding the impact of perseverative behaviours, which suggested effective intervention; however, according to visual inspection, no reduction in impact was reported following the second baseline assessment.

Lauren's confidence in managing BOC

Lauren's perceived confidence in managing BOC are presented in Figure 6.2.5. Higher scores reflect increased confidence (2 = very confident, -2 = not at all confident). Lauren's confidence levels varied from 'somewhat confident' to 'very confident', changing to very confident in all domains from OA3 onwards.

There was a PEM improvement of 80% in Lauren's levels of confidence in managing BOC, suggesting moderate effect. There was a PEM improvement of 60% related to identifying appropriate management strategies, which suggested mild effect according to this domain.

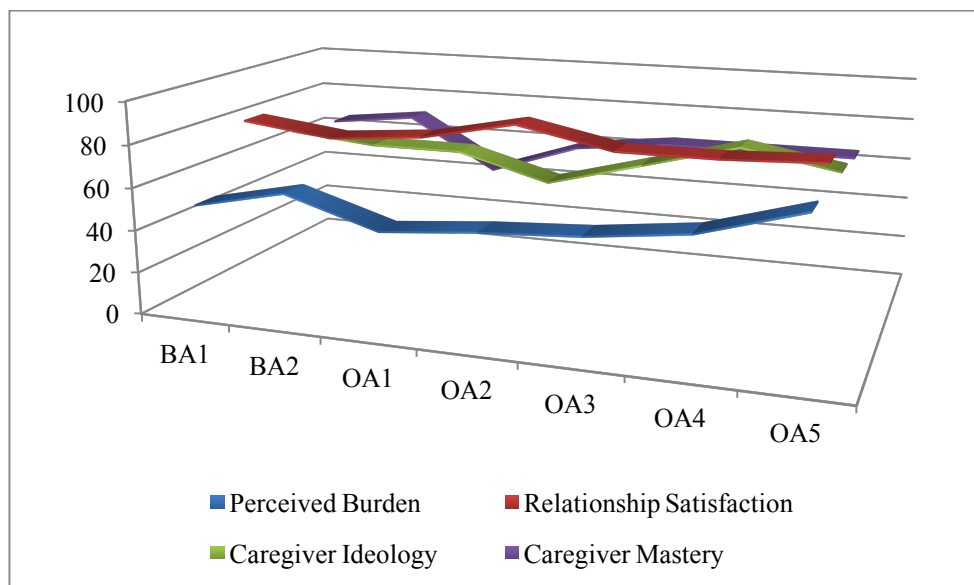
Figure 6.1.9 Lauren's perceived levels of confidence in managing BOC



Caregiver appraisal (CAS)

Lauren's CAS data and PEM scores are presented in Appendix 32 with percentage scores for each domain presented in Figure 6.2.1.

Figure 6.2.1 CAS Scores – Lauren



PEM improvements seemed effective for relationship satisfaction (100%), and ineffective for caregiver burden (40%), caregiver ideology (40%) and caregiver mastery (0%). Visual inspection suggested that the magnitude of improvement was limited.

6.4.3.4 Summary

Lauren completed the full program, including the four education sessions plus six individualised sessions. She identified the following BOC to target for intervention: verbal perseveration, screaming, and insults. The results revealed a decrease in problem behaviours at completion of the program according to the frequency recordings, but no changes according to the OBS. Kate also recorded increased confidence in managing BOC, and there was a minor trend in improvement regarding levels of caregiver burden (CAS). Lauren identified pain to be a significant contributing factor in the occurrence of Bob's BOC, and Bob received surgery during the intervention to address medical matters.

6.5 Participant Feedback

Both Kate and Lauren reported high levels of satisfaction regarding their involvement in the FDBM program, reporting the education components and individualised sessions to be 'extremely helpful' overall (on a five-point Likert-type scale), contributing to a greater understanding of why BOC occur and their ability to identify useful management strategies (with both responding 'yes definitely' to these

items). The raw data from questionnaires post-education sessions, post-individualised sessions and at follow-up are presented in Appendix 36.

Qualitative data gathered from semi-structured interviews were analysed thematically within the following categories: satisfaction and usefulness of the program; content and delivery of the program; and, feedback regarding the development of the program. The findings within each of these categories is summarised below according to questionnaire and interview responses, with exemplar quotes for each theme presented in Table 6.9.

Table 6.9. *Exemplar quotes from thematic extraction – semi-structured interviews*

Satisfaction and usefulness of the FDBM program
Increased confidence in managing BOC
<p>Kate: <i>...I am more aware.. I can take the intensity out of [the behaviours]. I'm now thinking.. 'wow, I can pat myself on the back – we stopped that from going south'... you know, if we change it around.. that I have more tools that I'm actively using. You know, I'm reaching for a tool – I'm not just thinking 'oh dear where is this going' and not taking action – I'm on to it.</i></p> <p>Kate: <i>...and you know, it's making me feel more proactive, you know, I feel like I'm in more control.. because I'm being proactive and learning</i></p> <p>Lauren: <i>I am now able to more quickly identify what he wants.. whereas before.. like when says 'am I going home?', I'd say 'you are at home' and he'd become so agitated.. now as soon as I notice it I am able to clarify with him so he remains calmer"</i></p> <p>Lauren: <i>I recognise faster when he starts to trigger.. whereas before I didn't have that information behind me. So now when I am with him, if he starts to get agitated I have different things that I try that actually work..</i></p>
Generalising skills learnt:
<p>Kate: <i>.... And I take all that with me now... whether it's listening to teacher in a reception class or whether I'm in a group with ABI... and watching the dynamics and the movement... and one participant might ring me up to have outlet... and I can see yes, this is happening and this is happening... so I'm finding that I'm a bit more ...</i></p> <p>Kate: <i>... out at a social activity or something... I'll actually sort of see something playing out – this isn't relating to (family member) but someone in the group – and I see something playing out and now I probably look at it with... you know, from what I've learnt, I look at it and think 'oh, that's this going on... and this going on...' so I see a bigger picture now.</i></p>

Lauren: ... it helps me in the sense that, if I come across other people [with brain injury], I'm actually implementing these strategies as well... [before] I wouldn't really want to engage because I wouldn't want to do the triggers – because sometimes you do not communicate for fear... that something bad is going to come out of it...

Content and delivery of education sessions

Information clearly presented

Kate: I loved the examples... you know, having the examples really reinforces it. It just gives it... you know, I can learn from that and apply it to our situation

Lauren: it was very comprehensive and you have been quite on the point with the information that you have gone through

Appropriate delivery format

Lauren: ... I think it is good to start as a group to give information before going on to the plan... because it is those people that can connect and be a support network for each other...

Helpfulness of the FDBM education workbook

Lauren: the book was helpful in the sense that during the week, after you left, I could go back and think about things as they come into my head... There is lots of useful information in there

Kate: ... and you know this has actually got a name – this is what's going on here in my life with [Angus]... and there is a piece of paper in that book that actually explains what is going on and breaks it down... yea, and that's great

Benefits of being educated by someone knowledgeable in field

Kate: Probably the one biggest overwhelming thing that I like about the sessions is that I'm talking to someone who actually gets this stuff... besides being 'tutored' or 'learning' I'm also talking to someone who can identify and understands

Benefits of the individualised & flexible delivery format

Kate: ... the fact that it is one-to-one, opposed to doing something in a group. And it's totally relevant to our situation – the day to day stuff. It's individual. It's about [Angus], it's about me and what's going on in his... environment

Lauren: ... when a person comes in to do a behaviour assessment they may only see the person for two hours and briefly talk to the family... over a few month you have effectively broken down the behaviours, done more specific testing... like in that three month you are supporting us with that.. and this support isn't being provided in the community... because I had a psychiatrist write dads behaviour plan out and he met dad for one hour

Lauren: ... I think what is a selling point for me is that it is so flexible, because while yes while you lock in plans to come to the appointments and that, life happens

Feedback for development of FDBM program

Desire for more ongoing support

Kate: Oh I'm going to miss it – having someone to bounce off... and you know, you get it. And I can't often have the debriefs – I don't actually have anybody I can do that with because... you know, they are not going to understand... and there are so many people I wouldn't have those conversations with because I feel like I am off-loading...

Lauren: ...I think now my plan is I'll need to catch up with you every now and then over coffee (laughs) and then I could just go 'this is what is happening in my life... these are the ideas that I have...'

Further simplified content

Lauren: You wouldn't want to go with too much more information on that [cognitive strategies presented in Module 1], given my background is that I at least know, to some degree, brain injury... disability, but I'm wondering if for some other people it may be too much to grasp...

6.5.1 Satisfaction & usefulness of the FDBM program

Thematic analysis identified the following regarding the satisfaction and usefulness of the FDBM program: (1) increased confidence in managing BOC; and, (2) the generalisation of skills learnt. Both Kate and Lauren reported increased ability to identify factors contributing to the BOC and in identifying and managing triggers. They also reflected on times when they utilised or saw the relevance of information presented with other individuals with ABI.

Within the exit questionnaire at three-month follow-up, Kate again reported the FDBM program to be 'extremely helpful', and emphasised the benefit of having the toolbox of strategies to draw from. She reported still using the strategies identified during the program, and had referred to the education workbook 'more than five times' since completing the program. Lauren reported the program to be "very helpful" at follow-up, and reported referring to the workbook '1-2 times' since completion.

At follow-up both Kate and Lauren reported still using behavioural strategies. Kate also reported a decrease in Angus' medication due to his positive behaviour. She felt, as a result, he had increased clarity and was more engaged with his surroundings.

6.5.2 Content and delivery of the FDBM program

Both Kate and Lauren felt that information was presented in a clear manner and that the FDBM Workbook was easy to read with meaningful examples (responding 'yes definitely' to these items on the feedback questionnaire). Thematic analysis also identified the following themes: (1) information was clearly presented, (2) the delivery format (i.e. education phase following by individualised sessions) was appropriate, (3) the FDBM education workbook was helpful, and (4) the benefits of being educated by someone knowledgeable in this field, and (5) the benefit of the individualised and flexible delivery format.

According to the feedback questionnaires, Kate and Lauren reported the FDBM Education Workbook as easy to use. They also both found the individual sessions with the researcher and the follow-up phone calls helpful, and felt that the program went for an appropriate length of time.

6.5.3 Feedback for the development of the FDBM program

Neither of the participants had any specific suggestions for improving the program. However, thematic analysis identified the following themes: (1) the desire

for ongoing support; and, (2) to further simplify content in some sections. Both Kate and Lauren expressed the desire for more ongoing support.

Lauren suggested that the amount of information included within the first education session might be overwhelming for families without any background knowledge regarding brain injury. Kate felt the workbook was easy to read, but said that she did learn a lot of new terms; however, she expressed comfort “knowing there is a nice big word to describe something that is going on”.

Kate was grateful for her involvement in the program, and expressed her desire for more individuals in her situation to be able to access the same support.

Kate:... “I cannot see any changes needed.. I just, in my mind, I keep thinking ‘if only it could be out there for everybody who needs it... I see situations in our circle all the time where.. – how amazing would it be if these people had more skills...?’”

Lauren felt that the program was a big time commitment; however, she acknowledged the significant extra time the program took due to the rescheduling of sessions around other commitments and medical emergencies. She felt this flexibility was very important.

6.6 Facilitator’s reflection

Throughout the education phase, individualised sessions and assessment collection points, the researcher kept a journal of observations regarding the delivery of the FDBM program. These reflective notes suggested the need to simplify the content in some sections, and the need for ongoing support. The researcher also reflected on the process of completing activities, and what changes might further

assist participant involvement (e.g. the use video examples in allowing families to practice defining behaviours and reporting on antecedent and consequent events). She also reflected on the process and importance of building rapport with participants, and the experience of training families to implement strategies, rather than personally conducting the functional behaviour assessment and implementing and monitoring strategies herself. Extracts from the researcher's journal are included in Appendix 37.

6.7 Discussion

This pilot study has examined the feasibility and acceptability of the FDBM program in supporting family caregivers to manage BOC in relatives with ABI in community settings using a pretest posttest design. Results suggest that the FDBM program might be a feasible and acceptable intervention approach, with improvements seen in the frequency and severity of BOC, family caregiver participants' level of confidence in managing BOC, and participants reporting high levels of satisfaction regarding the content and delivery of the program.

6.7.1 Feasibility

6.7.1.1 Participants

Three participants returned consent, and two participants completed the full FDBM program. This small response rate certainly raises questions regarding the length and intensity of the FDBM program (including multiple data collection

points), and possibly the method of recruitment. However, research does suggest difficulties in recruiting large sample groups in behavioural research, with a total of only 112 participants across the 10 studies included in the systematic review (Fisher et al., 2015). 201

The participant who did not complete the program withdrew prior to the second individualised session due to her son with ABI attempting suicide. This is a reminder of the significant challenges faced by some families, and the consequent implications this has on the delivery of family supports. Although the importance of involving family in brain injury rehabilitation is recognised (Umbreit et al., 2007), the significant disruption brain injury has on the family system (Davis, Gemeinhardt, Gan, Anstey, & Gargaro, 2003) must be considered. The demands placed on family members can be burdensome and, despite the families' best intentions, this may limit their motivation, ability, or capacity to be actively involved in rehabilitation programs (Foster et al., 2012). This is also in consensus with research that reports fatigue, stress and lack of time to be barriers to accessing services, with families overburdened with responsibilities (Braine, 2011; Lefebvre et al., 2005; Turner et al., 2007). It should also be noted that families with relatives with more severe disabilities regarding function and participation which places more demand on their care role (Wang & Barnard, 2008) may need more intensive individualised support. Furthermore, given family carers might also include those who support individuals with high risk behaviours (i.e. suicide, self-injurious behaviours) and those needing 24-hour support, finding the time to attend such a program may present significant barriers. This again emphasises the need for innovative delivery methods.

The two participants who completed the full FDBM program provided varying degrees of support to their relatives with ABI, with Kate providing sole

support three-four days weekly, and Lauren providing ongoing support and frequent visits, in addition to the 24/hr paid support Bob received in supported accommodation. Their level of involvement understandably impacted the participants' ability to implement behavioural strategies. However, even though Lauren was not directly responsible for the personal care of her father, she did consider herself the 'primary' caregiver and certainly did appear to play a primary role in overseeing his support needs.

In considering both participants' involvement and outcomes, the findings suggest the FDBM program might be a more feasible intervention approach when family members have a more direct role in the day-to-day caregiving role of their relative with ABI. Indeed, Lauren reported difficulties in implementing and monitoring strategies and behaviours due to the limited contact hours she had with her father. However, Lauren did report increased confidence and high satisfaction regarding her involvement, suggesting that the program may be an acceptable approach in supporting family members in understanding and managing BOC in relatives with ABI regardless of the amount of direct support they provide.

These findings suggest the inclusion criteria to be appropriate, but that such differences should be considered in the delivery of the program and in analysing outcomes. For example, when individuals with ABI are supported by both family caregivers and paid support staff, emphasis is placed on the need for positive working relationships between family and support staff to ensure consistency with intervention approaches utilised. This is in consensus with research conducted by Tveradov and colleagues (2016) in which one of the top unmet needs reported by families was being able to give their opinions to those involved in their relative's care.

In delivering the FDBM program to families in such situations, it may be beneficial to have the family and key support staff present during the sessions. This would likely give staff greater insight into the families' expertise and experience, and provide them both with the education and opportunity to discuss and develop a more comprehensive behaviour support plan. However, it is acknowledged that this would create additional barriers in organising the delivery of training around the commitments of both family caregivers and support staff. Indeed, simply working around the availability of family caregivers alone presented some challenges in the current study.

Lauren also reported significant strain between herself and support staff. According to Oddy and Herbert (2008), this is not uncommon, with this strain being partly attributed to the family's sense of powerlessness, which may result from their inability to influence the speed of recovery of their relative. In addition, with the often upsetting behaviour presented by the individual with ABI, this may lead to frustration and anger (Oddy & Herbert, 2008). Oddy and Herbert (2008) also suggested that staff members should be educated around why family members react as they do, encouraging them to see the critical behaviour of family members as sign of the family's distress and their means of coping with this.

6.7.1.1.1 Recommendations for recruiting participants for future feasibility studies

In recruiting participant for larger scale feasibility studies it may be helpful to conduct focus groups with relevant organisations, emphasising the importance of the research and providing detailed information regarding participant involvement. This

may result in key contacts from organisations disseminating information regarding the study to more family members.

The research should also ensure that the participant introductory letter places initial emphasis on the potential benefits and importance of the study; prompting families to consider that the perceived benefits of the program outweigh the energy and commitment required. This concept is familiar to behaviour management, with people being less likely to engage in the desired behaviour (i.e. participation) if the benefits are not perceived to outweigh the energy they have to commit to the process (Jacobs, 1995). The participant introductory letter for the pilot study began by highlighting a multi-component program requiring availability over an eight-month period, which may have also contributed to the small sample in the current study.

6.7.1.2 Intervention

The FDBM program focused on training family caregivers in implementing and monitoring behavioural strategies using a multi-phase intervention design. This format, which included an education component followed by individualised sessions, is consistent with multi-phase interventions included in the systematic review (Chapter Three: Fisher et al., 2015). However, in line with the family-centred approach utilised, the FDBM program further emphasises the importance of acknowledging families' experience and expertise in the process. Although the systematic review revealed promising findings regarding the involvement of families, the studies reviewed did not specify the specific role family played within the intervention process. The FDBM program rather places the family caregiver at the centre of this process, with the content of the program also co-produced by key

stakeholders (including family caregivers) through the Delphi process (Chapter Four). The education workbook was also specifically developed according to the support needs of family caregivers, and provided them with an additional resource to review beyond completion of the program.

The focus of the FDBM program was to enhance the capability of family members in managing BOC, rather than providing the support directly to individuals with ABI; when the researcher met with participants, her primary focus was on asking questions relating specifically to their wellbeing and their competence in implementing strategies. These sessions also importantly placed emphasis on the things the participants were doing well, positively reinforcing their efforts and then further developing these skills. Indeed, research has shown families to praise their relatives with ABI in his or her efforts to adjust, but have failed to recognise how well they themselves have adapted (Smith & Godfrey, 1995). Therefore, in this study, every opportunity was taken to reinforce the fact that the family had done a good job of supporting their relative with brain injury, with such comments serving to give family members a sense of hope (Smith & Godfrey, 1995).

The length of involvement (intended for 31 weeks including baseline and follow-up assessment points) extended to 44 weeks for Lauren, and 40 weeks for Kate. The current study emphasised the importance of flexibility in delivering such supports to families, who may be fatigued and time poor (Degeneffe, 2001; Kreutzer, Gervasio, & Camplair, 1994; Oddy & Herbert, 2003; Ponsford, Olver, Ponsford, & Nelms, 2003; Turner et al., 2007). The importance of flexibility in service provision in this area is widely acknowledged (Kratz et al., 2017; Tverdov, McClure, Brownsberger, & Armstrong, 2016). This flexibility may also help professionals foster rapport with families through acknowledging their significant responsibilities

and commitments, with families deriving a great deal of comfort from the feeling and experience of being understood. This is further emphasised by Gagnon et al. (2016), with their study suggesting that the acknowledgement of the families' adjustment following brain injury can impact on their continued engagement in their supportive role.

The need for flexibility, however, may present some barriers in service options. Although the flexibility of such programs are deemed vital for families, this degree of flexibility would likely be unfeasible within a structured service model. This perhaps could be addressed by providing multiple (i.e. two or three) education sessions each week of the education phase, giving the families alternative options for attendance. The feasibility of such a delivery format should be further explored in larger feasibility studies.

6.7.1.2.1 Outcomes

Frequency and severity of BOC

Although participants reported reduced frequency and intensity of BOC, this was not reflected in the OBS, which was one of the key outcome measures. This inconsistency in data may reflect the increased confidence reported by Kate, with behaviours that were a concern prior to intervention perhaps not presenting such an issue post intervention, with this then impacting data collection. However, it should also be noted that the OBS relies on retrospective knowledge to gain a summary of an individual's behaviour profile (Tverdov et al., 2016), and is not designed as a frequency measure. Furthermore, frequency categories used in the OBS (i.e. 1 = *absent across two weeks*; 5 = *multiple times each day*), provides no indication of

changes in frequency of behaviour that occur 10-15 times daily, as was the case in the current study.

A further method for improving accuracy of reporting may be to measure the duration of the behaviour (i.e. how many minutes the behaviour lasts), as a way of measuring the episodic severity of the behaviour (Feeney, 2010b; Gardner et al., 2003; Oddy & Herbert, 2008; Ponsford et al., 2013; Smith & Godfrey, 1995). This would have further validated (or not) subjective reports of the reduced ‘intensity’ of behaviours. However, with families given the full responsibility of implementing and monitoring behaviours, caution should be taken in over-burdening families in their involvement.

The behaviours that showed the least decline in frequency according to the OBS for both participants (perseveration and reduced initiation) were behaviours that were seen to relate most specifically to neurological damage.

These findings emphasise the importance of collecting both quantitative and qualitative data. The questionnaires and semi-structured interviews helped to triangulate the gathered through quantitative measures, and provided important feedback to inform the further development of the FDBM program. These qualitative methods are therefore seen as important to incorporate in larger scale feasibility studies.

Confidence

Both participants reported being “somewhat confident” in managing behaviours during baseline and “very confident” overall at completion of the program. This increased confidence was also reflected in qualitative feedback, with

participants reporting their increased ability to analyse why behaviours occurring and respond to behaviour appropriately.

The findings of this study also suggest the possible generalisation of skills beyond the participants' specific situation, with both Kate and Lauren reporting that they applied their newfound knowledge to BOC exhibited by other individuals with ABI.

Caregiver appraisal (CAS)

Involvement in the FDBM program did not appear to have a significant impact on levels of burden experienced by participants; however, interestingly there was a minor trend in improvement for both Kate and Lauren. It would be interesting to explore this further in a larger feasibility study with a longer follow-up period given that previous research reports behavioural interventions to have no significant impact on levels of caregiver burden (Carnevale, Anselmi, Busichio, & Millis, 2002; Sinnakaruppan et al., 2005). As suggested by Sinnakaruppan and colleagues (2005), one possible explanation for this could be that family members are aware that their relative will never be the same person that they were before the injury. Carnevale and colleagues (Kelly et al., 2006) further referred to this as the fixed aspects of caregiver burden after ABI that may be less responsive to change after intervention and more variable in day-to-day aspects of burden that are more amenable. Furthermore, this may reflect the families' realistic concern regarding their relative's future (Sinnakaruppan et al., 2005).

The unestablished link between the impact of behavioural interventions and caregiver burden (Carnevale et al., 2002) was what informed the decision to measure perceived caregiver confidence in the current study. This has not been recorded in

previous studies involving family in behavioural interventions following ABI (see Chapter Three: Fisher et al., 2015); however, this information provides much needed insight into the perceived capability of family caregivers in managing BOC in relatives with ABI. It would also be interesting to explore any correlation between levels of confidence and burden in future studies.

6.7.1.2.2 Limitations and research design recommendations for future feasibility studies

The outcome measures utilised in the pilot study were considered appropriate in capturing changes pre and post intervention; however, it would have been useful to conduct frequency tallies as all time points (including baseline and outcome assessments) as they were a good indicator that the FDBM program appeared to decreasing the frequency of BOC. In following studies participants should therefore be prompted to identify target behaviours at baseline to provide opportunity to complete baseline frequency recording. When defining this behaviour in observable terms during education phase, emphasis will then need to be placed on ensuring consistency with BOC recorded during baseline.

In the current study, qualitative data revealed a decline in severity of BOC for both participants; however, as suggested, this may have been reflection of reports of increased confidence in managing BOC, possibly impacting their perceptions (and recording) of the behaviour. Further data would therefore be useful to triangulate this data, such as a quantitative measures of episodic severity (i.e. recording the duration of behaviour).

Qualitative data in the pilot study suggested some evidence of the generalisability of skills learnt beyond their specific situation. It would be good to explore this further, with the inclusion of self-efficacy and problem solving measure pre and post intervention. This is important in further exploring the impact of FDBM program in enhancing families' ability to monitor and adapt strategies when needed.

Consideration should also be given to the research design adopted in future studies. Given the small number of family caregivers who returned consent and completed the FDBM program, a robust single-subject design may be more appropriate to further strengthen the findings. Single-subject methods are also commonly used in behavioural research (Tate et al., 2014), with increasing attention given to comprehensive guidelines for robust design, helping to strengthen the evidence base for such interventions (Tate et al., 2017). Utilising such a design would facilitate adequate methodology and reporting to allow for replication, and identification of potential moderators in meta-analysis, and evaluation of the scientific quality of the research (Tate et al., 2017).

6.7.2 Acceptability

According to the feedback questionnaires and interviews, both Kate and Lauren reported high satisfaction with the content and delivery of the program. However, both participants had some difficulty with reporting the behaviour in observable terms. This process could be facilitated with the use of video clips, with this approach being used effectively as a training tool for families of individuals with brain injury (Wade et al., 2008).

Both participants provided positive feedback regarding the multi-component delivery of the FDBM program (education phase following by individualised sessions). Kate liked how the education phase provided a toolbox of strategies that could be drawn from later, and Lauren reported the multi-component structure to be the thing she liked most about the program overall. This structure was adapted from Carnevale's NSBM program (Carnevale et al., 2002), with multi-stage behavioural interventions also supported by the systematic review (Fisher et al., 2015). The participants also both reported benefits in having the FDBM education workbook to guide education sessions, and reported revisiting the workbook within their own time during and following completion of the program. This also concurs with the literature which suggests the need for information to be provided in both written and verbal form (Oddy & Herbert, 2003). The accessibility of the workbook will be further explored in the following chapter.

Kate reported the thing she liked most about the program was learning more about the 'clinical stuff'. In the delivery of this information relating to basic ABI biology, the researcher used visual illustrations, however, in reflection she felt she could have used more visual prompts to further engage families in this information. For example, perhaps a basic brain model would further help conceptualise the content discussed, particularly for more visual learners. The use of innovative teaching strategies is emphasised by Smith and Godfrey (1995), suggesting that visual illustrations (i.e. their use of a tennis ball in a jar to demonstrate to concept of coup and contra coup damage) greatly enhances the participants' understanding of the information presented.

6.7.2.1 Feedback for further development of the FDBM program

Neither of the participants provided specific suggestions for the further development of the FDBM program; however, they both expressed the desire for longer-term support. This concurs with research conducted by Foster et al. (2012), in which families reported appreciating informal catch-ups with trainers, giving them the opportunity to ask questions and discuss their concerns. Indeed, when it comes to behaviour management, it is not a one solution problem; the individuals' needs and abilities change over time, and so do their behaviours. Strategies may also stop working (i.e. due to saturation of reinforcers) and need to be modified in accordance to the changing interests and support needs.

The need for ongoing support for families specific to behaviour management is recognised in the literature (Gagnon et al., 2016; Kreutzer et al., 1994). However, within the current financial climate where resources are limiting the time spent with families, the issue is how this support may be carried out. Ongoing one-on-one individualised support may not be feasible; however, peer group support may provide some answers. Families have reported great benefits from peer support groups (LaVigna & Willis, 2012), giving them the opportunity to draw support from other families in similar situations (Foster et al., 2012; Sinnakaruppan et al., 2005). Perhaps then, following the individualised sessions, family caregivers who have completed the program could be invited to attend follow-up group sessions. Given that families will have all received the same education, they may be valuable supports for each other in prompting revision of the workbook, the monitoring of strategies, and possible new strategies. This should be further explored in a larger feasibility study of the FDBM program.

Although both participants reported that information was well-presented and easily understood, Lauren suggested that the education phase may be too content-heavy for families without any background knowledge regarding brain injury. This also emphasises the importance of having information provided in both verbal and written form (Oddy & Herbert, 2003), giving families the chance to revisit information if needed in their own time.

6.7.2.2 Recommendations for further development of the FDBM intervention for future feasibility studies

Participant feedback and facilitator reflections have led to a number of suggestions for the further development of the FDBM program. For example, the first session should focus on the key strategies included in the workbook, rather than include each of the separate strategies for each of the cognitive difficulties presented. More specific strategies relevant to the individual's situation should then be drawn upon during the individual sessions. The fourth session should also include less specific detail regarding the implementation of behavioural procedures, but rather provide an overview; again, if these specific procedures are relevant, they can be revisited and modelled during the individualised sessions.

The participants of the pilot study also reported high satisfaction regarding the individualised sessions. However, given the length of this phase of the intervention (conducted over an 11-week period) and the reported need for more ongoing support options, the research suggests that these formal sessions could rather be conducted for two hours fortnightly over eight weeks, followed by scheduled peer support sessions. In the current pilot study, the six sessions conducted did not allow

sufficient space to cater for monitoring and adjustments, and sessions were often longer than the allocated 1.5 hours. Four sessions are therefore considered sufficient, given ongoing support options are available. It is suggested that following completion of the program, all participants should be invited to meet for a final review session, and invited to schedule regular meetings to offer peer support regarding behavioural issues. In an ideal scenario, if such a program were to be provided as a service option, the facilitator should be available to attend peer support sessions at scheduled time points to provide revision and keep families up-to-date with evidence-based practices.

Over the course of this PhD program, the researcher has also reflected on the terminology used in the title of the FDBM program. With the emphasis on *supporting* behaviour change in individuals with ABI (i.e. the proactive approach underlying the PBS framework), rather than ‘managing’ BOC (with emphasis on a responsive approach), the researcher has proposed the title to be changed to the Family-Directed Approach to Brain Injury: PBS program (*FAB-PBS*). This title has therefore been used in related journal publications.

6.7.4 Limitations

Some limitations should be acknowledged. There were time limitations present. This 3.5 year PhD program consisted of the development of the FDBM through a multi-stage design, with the final 12 months dedicated to this Pilot Study. Therefore, this study did not allow for a preferred six or nine-month follow-up. This should be incorporated in a larger scale feasibility study.

A significant limitation of the current study was the small sample size. Recruitment proved problematic over the 12-month time frame allocated for the pilot study. Furthermore, family members may have limited 'reserve' due to the demands of the caregiving role, which may have impacted on their desire to participate in this time-intensive program. Further pilot testing is therefore required to inform the development of a larger feasibility study, with examination of factors influencing participation being an important part of this process.

There are also a number of additional confounding variables impacting conclusions drawn. These included Lauren's fluctuating mental health issues, Bob's ongoing medical issues and surgery during this time, and Lauren's focus on transitioning Bob to a new accommodation setting at follow-up. Kate also attended an additional information session regarding the management of BOC through a peer support network, providing further opportunity for education and skill-development.

Furthermore, as discussed, there was no frequency tally completed at baseline, with the OBS being the only indication of any changes in frequency pre and post intervention. However, as the OBS rather provides a retrospective summary of behaviour, this was not sufficient in recording accurate changes in the frequency of target BOC. The frequency tallies appeared to be a good indicator that the FDBM program was having an impact on target BOC; however, as these behaviours were only identified during the education phase, a baseline recording was not conducted. This should be addressed in future studies, with recommendations presented in the following chapter.

In addition to delivering the FDBM intervention to participants, the researcher also collected assessment data and conducted interviews with participants,

which may impact the reliability of data. Although the researcher repeatedly emphasised the focus on the development of the program, and encouraged critical feedback, it is possible participants would have felt more able to express concerns if an additional researcher had gathered this data. However, the researcher felt she had built good rapport with participants and, because she had facilitated and observed participant involvement, this insight may have helped in guiding more relevant questions to seek important feedback.

It should also be acknowledged that although the family caregivers completed the FDBM program, there was not coordination to ensure all other people in contact with Angus and Bob were trained in this approach. This inconsistency with regards to implementation of the behavioural strategies should be considered when interpreting results, and should be given greater consideration in future studies examining the feasibility of the FDBM program.

6.8 Conclusion

Despite the limitations, the findings of this pilot study indicate that Kate and Lauren perceived definite benefits from their involvement in the FDBM program. Both participants reported high satisfaction with the program and increased confidence in identifying strategies and responding to BOC in relatives with ABI. These preliminary results do suggest that the FDBM program may be an acceptable and feasible program in increasing the capability of family caregivers in managing BOC in relatives with ABI, thereby warranting further investigation to inform a larger feasibility study.

This preliminary data suggests no meaningful changes in BOC as measured by the OBS, and levels of caregiver burden post intervention; however, the data did reveal a trend in improvement for both participants, with further investigation needed to establish any correlation between participation and reduced levels of caregiver burden.

Recommendations for the further development of the FDBM program highlight important considerations in recruiting participants, refining content, delivering the intervention, and setting up long-term support alternatives. Although outcome measures utilised within the pre-test post-test design were appropriate in providing preliminary insight into the feasibility and acceptability of the program, further considerations are recommended in the design of a larger feasibility study.

Participant feedback and facilitator reflections suggest the need for simplifying the FDBM Program. To gain further feedback regarding the accessibility and helpfulness of the FDBM education workbook, an additional survey study was conducted with an additional cohort of family caregivers. This is presented in the following chapter. The final recommendations for the further development of the FDBM program will then be presented in Chapter Eight.

CHAPTER SEVEN

STUDY FOUR: SURVEY STUDY

7.1 Introduction

This chapter presents the aims, methods and results of a survey study gathering feedback regarding the acceptability and perceived helpfulness of the FDBM Education Workbook as a standalone educational resource. The development of the workbook was informed by the systematic review examining family involvement in ABI behaviour management (Fisher et al., 2015) and through a Delphi study seeking feedback from family caregivers of relatives with ABI and rehabilitation professionals (Fisher et al., 2017b, *Under Review*). Feedback regarding the acceptability of the workbook was then obtained from participants during the FDBM pilot study; however, due to the small sample (n=2), this additional survey study was developed to gather further feedback from families with varying levels of education. This focus was considered important given the apparent high education levels of participants in the pilot study, and the emphasis the literature places on information provided to family caregivers in accessible language.

7.2 Aims

The aim of this study was to determine if the FDBM Education Workbook was written in a way that family members can understand, and if they found the book helpful in understanding behaviour changes and identifying management strategies. In particular, this study contributed to the following research questions examining the acceptability of the FDBM program by gaining additional feedback on the accessibility of the workbook for family caregivers:

- Did family caregivers find the FDBM program satisfactory in supporting them to manage BOC in relatives with ABI?
- Did family caregivers find the information and strategies provided to be appropriate and helpful in supporting them to manage BOC in relatives with ABI?
- How did family caregivers think the FDBM program could be improved to better support them in managing BOC in relatives with ABI?

7.3 Ethical considerations

A modification request was submitted to seek approval for this component of the FDBM feasibility study. This was submitted with the rationale of gaining more feedback from families with varying backgrounds and education levels regarding the accessibility of the educational resource. This ethics modification request was approved by the Royal Adelaide Hospital Human Research Ethics Committee (Protocol No: R20151116). See Appendix 38 for approval letter.

7.4 Participant recruitment

Participant criteria for selection in this study required that they:

- were at least 18 years of age
- have a family member with brain injury who exhibits behaviours of concern
- resided in lower SES postcode regions (according to the Index of Relative Socio-economic Advantage and Disadvantage, ABS, 2008).

The researcher identified key contacts (clinicians or therapists) working within the following services/ programs who were willing to assist with identifying potential participants:

- South Australian Brain Injury Services (SABIRS)
- Disability Services SA
- Families4Families Incorporated

Contacts from these organisations made initial contact with potential family caregivers meeting the eligibility criteria, and distributed the survey package to those who were interested. The survey package included a letter of introduction outlining the detail of the study (see Appendix 39.), the FDBM workbook feedback form (see Appendix 40) and the FDBM Education Workbook (see Appendix 41). A reply-paid addressed envelope was also included for families to return the survey.

The book was distributed to the first 25 family caregivers that expressed interest. Furthermore, given the time restrictions for data collection in addition to the cost of printing, contacts were encouraged to distribute the workbooks only to those who expressed a commitment to review the FDBM Workbook and complete the survey within the required time frame to ensure a high response rate.

7.5 Survey design

Participants were asked to read the 82-page education workbook over a two-week period and complete the one-page feedback form. This survey was designed to determine the extent to which: the workbook used accessible language and

information was clearly explained; topics were presented in enough detail; the narrative illustrations were helpful; and, the workbook improved understanding of BOC following brain injury and identifying strategies that might be useful. Participants were also invited to make any further comments about what they liked most, what they felt could be improved, and any additional feedback they wanted to include.

A copy of the workbook feedback form is available in Appendix 46. Participants were asked to rate each item using a four-point Likert-type scale (1= Strongly Disagree; 2=Disagree; 3=Agree; 4= Strongly Agree). The participants were also asked to provide demographic information, including postcode, gender, age and what level of study they have completed since school, and their main language/s spoken. This was important to gain information relevant to gauging the participants' education level. Data analysis of the survey study involved both qualitative and quantitative data through the use of both closed and open-ended questions, allowing both the assessment of the strength of responses to a declarative statement and flexible responses (Carter & Lubinsky, 2016).

7.6 Data analysis

Likert-type items fall into the ordinal measurement scale as the interval between numeric values cannot be measured. The scale therefore permits the measurement of a degree of difference but not the specific amount of difference. As recommended for ordinal scales, the mode for central tendency was used to analyse

the survey responses (Boone & Boone, 2012). The mode is the score that occurs most frequently in a distribution (Carter & Lubinsky, 2016).

Qualitative data were analysed thematically, in which responses that were similar were grouped together (Grbich, 1999). In line with the thematic analysis utilised in the pilot study, this was conducted by (1) reading the questionnaire responses and highlighting the sections that were considered relevant to research objectives, (2) developing thematic categories relevant to the corresponding research questions, and finally (3) compiling the text within the thematic categories (Kuckartz, 2014).

7.7 Survey Results

7.7.1 Participants

Out of the total 25 surveys that were distributed, six were completed and returned. All participants were female, with a mean age of 64.5 (range 56-72). The family members' educational levels ranged from minimal formal education (no formal education since secondary school) to university and post-graduate levels, with the majority (n=4) having received no education since school. Consistent with research conducted by Braga, Junior and Ylvisaker (2004), the family members' educational levels were used as a reference for the family's social economic status due the lack of reliable data about classification of this variable. Participant demographics are presented in Table 7.1.

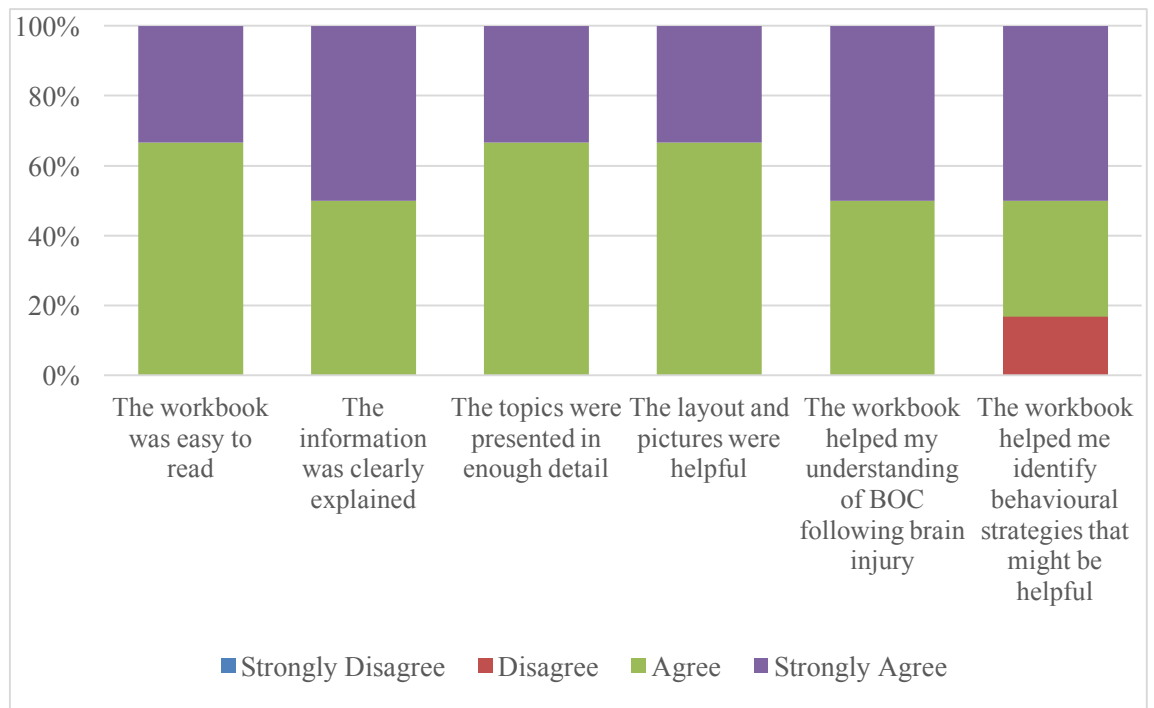
Table 7.1 *Participant demographics*

Gender	Age	Education since school	Main language spoken at home
F	56	TAFE CERT III	English
F	62	None	English
F	67	Post-Graduate University Degree	English
F	58	None	English
F	72	None	English
F	72	None	English

7.7.2 Workbook feedback

All respondents felt the workbook was presented in an accessible manner and was helpful in increasing their understanding of BOC following brain injury and in identifying useful management strategies; all respondents either agreed or strongly agreed with these items (see raw data in Appendix 47). The items with the highest positive rating were those relating to information presented clearly, and the workbook's usefulness in increasing knowledge and providing helpful strategies. The percentage of responses according to each of the Likert-type items is presented in Figure 7.1.

Figure 7.1. Survey responses - Likert-Type data



7.7.2.1 Positive feedback

Respondents provided a range of positive feedback regarding the workbook, emphasising (a) its simple and clear presentation of information, (b) the use of the illustrations and examples, (c) the focus on proactive strategies with strengths focus, and (d) usefulness of information presented. Responses have been categorised under these four themes, presented in Table 7.2.

Table 7.2 *What family caregivers liked about the FDBM Workbook*

Simple and clear presentation

- *I found the workbook very informative, but also like the simplicity of the workbook. Very educational*
- *Like how each module has a clearly defined aim and expected outcomes*
- *Great to incorporate simple explanations as to why behaviours change after injury. This helps carers to understand challenging behaviours and to not personalise them.*
- *Liked the defining of challenging behaviours and how it was done concisely and in a respectful context*
- *The program is very well written and presented in clear, ethical, manageable steps... I think it will work very well*
- *The explanation of words and how to understand clearly of each module. I also feel the workbook is well presented and was not as long as I thought it was going to be*
- *Like how, here and there, you reassure the reader with 'try not get overwhelmed by... or 'we will work on this next week' etc.*
- *I like the explanation of how the brain functions*

Use of illustrations and examples

- *Really liked the illustration, their humour and aptness, the way they lighten issues, the way they give space and visual summary*
- *Liked the diagram of the brain and the notations around the function of each area of the brain showing how an injury can cause a vast and diverse range of changes*
- *Anecdotal examples are always a brilliant teaching tool. Can't have too many of them*
- *My ABI daughter loves the drawing as well as she can relate to them*

Preventative and strengths focus

- *The strengths tree was a great way to start. Really important to hold the person as a loved human being with a history and with valued qualities (not just a person with challenging behaviours). I see that the manual picks this up again very well on p15*
- *Really like the emphasis placed on meaningful activities being incorporated into an individual's routine...*
- *Like how the manual encourages carers to focus on a proactive rather than a reactive approach*

Usefulness

- *Excellent list of changes that may occur as a result of brain injury- important for the carer so that he or she can, as truly as possible, appreciate the difficulties from their family members' perspective and work realistically within their capacities*
- *Great to provide opportunity for group members to identify a difficulty to focus on with the*

support the group leader and the group members too

- The module on anger is respectful, empathetic and helpful. Certainly in my daughter's case, she cannot articulate where an anger outburst comes from. Sometimes there is a potential trigger. However, sometimes a slight touch, even with a gentle warning, seems to suddenly overstimulate her brain. While such outbursts are rare and short lived there's a real 'primal flash' of rage. It's distressing for us to experience. A brief period of space and solitude works best along with the other tips you've outlined and which I always use. I feel trepidation about the lack of training given to some support workers and thus I hope very much that eventually you will use this manual in a range of support settings- to train workers, not just family members*
 - Good to identify triggers as on p26 and to use the exercises*
 - Liked the emphasis on positive reinforcements – always important and can be potent*
 - Make it available for everyone with an ABI. It will assist them with their recovery*
 - I thought it covered most of the behaviour I have encountered with my son with his ABI*
-

7.7.2.2 Suggested changes

Families provided limited feedback in this section. However, responses did indicate the need for an illustration that presented the left and right hemisphere brain function. It was also suggested that the importance of structured routine could have been included before discussing possible triggers. One participant also suggested that it could be helpful to include an additional module on effective communication. Responses regarding these themes are presented in Table 7.3.

Table 7.3 *Aspects families felt could be improved in the FDBM Workbook*

Illustration of both hemispheres and related functions

- *I would have liked to see the left and right side of brain function*
- *Maybe another view of the brain showing more of what the left side of the brain does and the right side of the brain*

Emphasising structured routine before discussing possible triggers of behaviour

- *having a son that was in Hampstead for a year the one thing they emphasised was structured routine. This solves a lot of anger issues and frustrations. I felt this could have been discussed a bit more before getting into the trigger points. It would be difficult when to mention this as I guess understanding or observing the person with ABI has to be learnt first. What I am saying module 5 perhaps could have been discussed first*

Module on effective communication

- *Perhaps a module on simple effective communication could be included although this may overcrowd it*

Workbook title

- *I think that the title of the manual needs to be a bit different*

7.7.2.3 Additional feedback

When provided with the opportunity to provide additional feedback, respondents further commented that the content was easy to understand and helpful. Respondents also expressed a wish that they had had such a resource earlier in their journey following their family member's brain injury. These comments are presented in Table 7.4.

Table 7.4 *Additional feedback regarding the FDBM Workbook*

Easy to understand and helpful content

- *I wish I had this workbook when my son had his accident. It has simplified and condensed the information in this one workbook*
- *It is so heartening to witness the commitment of caring professional in supporting ABI survivors and their often devoted and hard working families. Thank you*
- *I think everyone that has a family member with brain injury should have one of these books*
- *I found the workbook easy to understand, having the simplest pictures was also a great way to help understand how brain injury works. I also feel I can explain to others a little bit better of my son's injury*
- *Apart from the problem with attention and distraction a lot of this was not relevant for my relative*

7.8 Discussion

The aim of this study was to seek feedback from family members regarding the accessibility of the FDBM Education Workbook, specifically whether information was understandable, clearly presented and useful to family members in understanding behaviour changes following brain injury and identifying useful management strategies. The workbook was developed to guide the education component of the FDBM program; however, in this study families have provided feedback regarding this workbook as a standalone educational resource.

7.8.1 Positive feedback

The preliminary findings from this survey indicate that family caregivers find the workbook understandable, clear and engaging, with positive responses to the narrative illustrations and case examples. This reflects the need for information to be

presented in layperson language (Gan et al., 2010; Grader & Bateman, 2017; Newby, 2013) and recommendations for professionals to tailor complex information about neurological mechanics and cognitive function to the individual's level of understanding (Newby, 2013; Grader & Bateman, 2017). However, it has also been suggested that written education materials alone may not be sufficient (Oddy & Herbert, 2003). Indeed, Wade and colleagues (Wade, Michaud, & Brown, 2006) developed written training materials that required less than a high school level of reading, with this level proving difficult for some families. It has been further suggested by Braga and colleagues (Braga et al., 2005) that individualised and illustrated manuals may be more accessible for families with varying education levels and socio-economic status.

The FDBM workbook is not individualised in its entirety, however, emphasis is placed on the unique experiences faced by families following brain injury, with the inclusion of activities that prompt families to reflect on and apply newly learnt knowledge to their individual situations. Furthermore, a novel component of the FDBM workbook is the narrative illustrations, which further engage family members, summarise content and break up the content, avoiding dense information that may be overwhelming for readers. As one respondent stated, “[I] really liked the illustrations, their humour and aptness, the way they lighten issues, the way they give visual space and visual summary”.

Although family educational resources generally appear to be presented in clear and simple language, information is often text-heavy. One of the very few standalone educational resources specific to supporting family caregivers with behaviours of concern is written by Iverson and Osman (1998). This simple and

clearly written article includes: an introduction to the causes of human behaviour; methods for identifying BOC; tracking behaviour over time; strategies for increasing desired behaviours and behaviours of concern (Iverson & Osmon, 1998). However, being a journal article, there may have been restriction with the layout (which is text heavy) and content (i.e. no illustrations), which the current study suggests to promote further family engagement.

There are also helpful resources (although not specific to family members) developed by Brain Injury Association of Queensland Inc. (now Synapse), relating to understanding and responding to BOC following ABI. However, in skimming through these resources, families may become overwhelmed by wording such as *framework for understanding behaviour, measurement records, and evaluation*, which may contribute to a preconception that material is technical and information-heavy, and therefore more applicable to clinical and academic audiences. The researcher suggests that such resources may be better suited to educational programs/sessions in which a professional can guide families through the information presented, prompting them to stop and reflect on the content, breaking up the information and providing space to digest the information presented. This is in consensus with recommendations that information should be provided in both written and verbal form (Oddy et al., 2003). One respondent in the current study also expressed that the workbook ‘*wasn’t as long as [she] thought it would be*’, which perhaps suggests this preconception that information would be dense and more technical (taking longer to process). Although the workbook is 82 pages in length, it is well spaced and information is broken up with the illustrations.

The FDBM workbook attempts to take the family on an educational and visual journey, presenting information and activities in a logical and manageable

manner, scaffolding knowledge and explaining the logic throughout the process. This is reflected in the feedback, with respondents reporting the workbook to be *simple*, and *clearly presented in manageable steps* (see Table 7.3). The workbook also begins with a strengths focus, encouraging family members to identify the skills, talents, achievements and things that they love/admire about their family member with brain injury. This is to encourage families to separate the individual with brain injury from the ‘problems’; the behaviour of concern is the problem, not the individual (Ponsford et al., 2013). In response to this activity, one respondent stated,

“[This] was a great way to start. [It is] really important to hold the person as a loved human being with a history and with valued qualities (not just a person with challenging behaviours). I see that the [workbook] picks this up again very well..”

The workbook acknowledges the challenges faced by the family member following the brain injury, including the grieving process and role changes (Larøi, 2003; Turner et al., 2007). It is important families have their expertise and experience acknowledged (Hostler, 1999; Lefebvre et al., 2005); therefore, starting the book with this empathetic approach may further contribute to families’ engagement with the content.

There is a lot of focus on the importance of building trusting and empathetic professional-family relationships in family collaboration (Briggs, 1997; Hostler, 1999; Lucyshyn, Albin, & Nixon, 1997; Sohlberg & Mateer, 2001), however, to the authors knowledge, there appears to be very little about how this therapeutic trust and rapport may be developed through written information. In the current study, respondents found the illustrations helped them engage with the information presented, but also found the informal and supportive language reassuring. For

example, one respondent stated “[I] like how.. you reassure the reader with ‘try not get overwhelmed by...’ or ‘we will work on this next week’ etc”. This prompts the need for further research in determining how best to promote caregiver engagement in educational resources, with accessible and meaningful information being more useful to caregivers, and thus more efficient in their purpose to increase the capability of families in their support roles.

One respondent liked how the workbook promoted family members to focus on a proactive rather than a reactive approach to managing behaviours, and another liked the emphasis placed on meaningful activities incorporated into the individual’s routine (see Table 6.3). This is in line with the PBS framework utilised, which emphasises the use of antecedent-based strategies (e.g. choice making, meaningful activities, positive routines) for individuals with brain injury, emphasising prevention in proactively addressing BOC (Gardner et al., 2003; Ylvisaker & Feeney, 1998). It is also likely that such strategies are not only easier for families to implement with no specialised training (rather than technical contingency based procedures), but also reinforces the strong link between behaviours and environmental factors.

Family members may also feel that they are somehow the cause of the behaviour. It is therefore important to provide information on common behavioural changes following brain injury and explanations as to why these may occur, with psychoeducation being suggested to reduce caregiver concerns regarding common sequelae following brain injury (Ponsford et al., 2001; Wade et al., 2008). This was also reinforced by one respondent who stated that the simple explanations included in the workbook “helps carers to understand challenging behaviours and not to personalise them”. Furthermore, Gagnon and colleagues (2016) suggest that developing a clear understanding of functional implications following brain injury

contributes to a greater understanding and adjustment to changes following brain injury and the ability to effectively educate others about the individuals support needs. This was highlighted by one of the participants, who felt that the FDBM workbook enabled her to better educate others about her son's injury (see Table 7.2).

7.8.2 Suggested changes

The FDBM workbook provides basic information regarding the function of various regions in the brain, and information on common cognitive and behavioural changes following brain injury. This is in response to family reports of dissatisfaction with the amount of information they have received specific to ABI (Braine, 2011, Turner et al., 2011, Biester et al., 2016). Although respondents liked the diagrams of the brain, which identify a vast range of possible changes following injury, it was suggested that an image presenting both the left and right hemispheres of the brain and different functions may be helpful (see Table 7.3). This will be included in the updated version of this workbook.

One participant also felt that an additional section could be added regarding effective communication, but also acknowledged that this information may overcrowd the workbook. Effective communication and interpersonal skills are emphasised as key factors in building rapport (Berven & Bezyak, 2015) and implementing behavioural strategies (see Kreutzer, Gan, & Marwitz, 2017), and although the workbook does discuss the importance of this, this feedback has prompted the development of an additional section in the back of the book that outlines some basic yet important strategies for communicating effectively.

It was also suggested that Module 5 (concerning antecedent strategies) could be placed before Module 4 (which introduces the basics of behaviour analysis). This feedback has contributed to a statement in Chapter One that highlights the importance of environmental strategies. However, these Modules have not been swapped because Module 4 introduces the concept of Antecedent-Behaviour-Consequence (ABC) analysis, which is important for understanding the reason why antecedent strategies may be effective for individuals with brain injury, and these strategies are then outlined in Module 5.

One participant also suggested that the title of book should be changed; however, no suggestions were provided. The researcher also felt a change was necessary, given her changing views regarding terminology (i.e. behaviour support vs behaviour management, behaviours of concern vs challenging behaviours), and the underpinnings of PBS in *supporting* behaviour change. It is therefore suggested that the title is changed to: *Positive Behaviour Support following a Brain Injury: A Family Education Workbook*.

7.8.3 Delivery format and recommendations

The proactive focus of the FDBM workbook places importance on when such resources should be distributed to families. Indeed, the emphasis is on promoting positive behaviours in the first instance through the development of positive communication, reasonable expectations and supportive environments. Families should therefore be provided with this information early in their journey post-brain injury. Furthermore, simply making this information ‘available’ may not be sufficient, as this presumes that all families have the resources to seek such information/support in a timely manner. Families should be given this information at

a time when the insight and strategies provided may be helpful in promoting positive behaviours and avoiding established patterns of learnt BOC. For example, unrealistic expectations of the individual with brain injury over subsequent years may contribute to established patterns of BOC (Gardner et al., 2003), which may then be further reinforced by the family's response to the behaviour. Families should therefore be given information at a time that increases their chances of pre-empting such a situation, rather than being given the resources at a time of desperation when they may not have the reserves to engage in such material. Furthermore, the timing of family intervention is critical considering the grieving process and adjustment for families following brain injury, which may impact their ability to take on information (Mongomery et al., 2002; Oddy & Herbert, 2008). Therefore, providing families with a hardcopy of the educational resource may be better than providing verbal information or expecting families to initiate involvement in educational sessions in these early stages. Such a resource, which acknowledges the experiences of families, in a simple and respectful manner, may also improve the likelihood of families engaging with the information presented.

The FDBM workbook was developed to guide the four-week education phase of the FDBM program, which was designed as face-to-face group sessions. Although group sessions have many benefits, with families being able to draw support from, and share experiences with other families in similar situations (Foster et al., 2012; Sinnakurappan, Downey & Morrison, 2005), there are also perceived benefits from this workbook being utilised as a self-study resource. With the importance of individualised support widely acknowledged (Newby, 2013; Ponsford et al., 2013; Sohlberg & Turkstra, 2011), this format allows families to focus on relevant information without being overloaded with all information presented in a group

session. For example, the layout of common cognitive difficulties followed by helpful management strategies for each, gives families the opportunity to be selective about what information they deem relevant to their individual situations. Indeed, the activity in Module 1 encourages families to reflect on which specific cognitive difficulties they are faced with and which strategies presented may be helpful to their situations. The aim here was to develop information that caters to a wider audience of families with varying needs, but also individualise the focus dependent on their unique experiences. This is in consensus with findings from the FDBM feasibility study, in which one participant reported feeling quite overloaded with the content presented in the educational phase. The issue with this, however, is the key role that may be required of professionals in motivating families to engage in educational material and activities in a self-study format (ensuring a timely and sensitive approach). Therefore, if the workbook were to be utilised in this way, scheduled follow-up texts and phone contact may be useful in prompting families to complete the modules and ask questions relating to their progress and activities. This may be a more feasible format for families in rural areas with reduced accessibility to support services (Mitsch, Curtin, & Badge, 2014).

The benefits of having a hardcopy of the workbook also means that families are able to revisit information to refresh their knowledge about why behaviours occur and what strategies may be helpful. Of course, this is possible with online information available; however, it may be argued that having a physical copy of the information in a visual place would further prompt families to engage with the material. This was certainly true for one of the participants of the FDBM program, who kept the workbook in a place frequently visited by her and the support workers to prompt them to refer to the information when needed. Furthermore, it has been

suggested that providing families with appropriate resources may minimise the time they spend on researching, which allows them to prioritise other aspects of care (Gagnon et al., 2016).

In the initial stages of development, an online educational resource was also proposed by the researcher, however informal feedback from family caregivers' (during a family peer support group), emphasised the importance of having hard copies of resources and not to presume family caregivers are computer literate. This may have reflected the age of families in this group, who were generally older (60 years or older) and were the caregivers of adult children with ABI.

In saying this, however, the benefits of online resources and communication technology in supporting families should not be underestimated. With the increasing use of communication technology, researchers are successfully utilising video clips and web-based resources to provide education to families (Wade et al., 2008). Such methods may also enhance families' engagement, providing video clips of skills being modelled and providing practical skill-building exercises. Online education and video conferencing may also enable support to be provided to those living in remote areas (see Johnsson, Lincoln, Bundy, & Costley, 2016). This may be further explored in the development of a web-based version of the FDBM workbook, which is now also under development as a Mobile App. This will provide the ability to include further interactive resources. Furthermore, the more formats in which the information is available (i.e. group sessions/ self-study modules, hard copy resources/ web-based workbook and online resources), the more accessible it is for a broader audience with different preferences and abilities in accessing different modes of information.

7.8.4 Limitations

The small sample size (n=6) limits the generalisability of the findings, however provides valuable additional feedback on the acceptability of the workbook from family caregivers with varying levels of education.

Further feedback could have also been obtained through more open-ended questions relating to each module. However, surveys are recommended to take less than 20 minutes to increase the response rate (Tverador et al., 2016). Interviews with participants may have also provided more in-depth feedback; however, again this added time commitment may have impacted families desire to participate, thereby further reducing the sample size.

All respondents also reported English as a first language. Gathering further feedback on the accessibility of content for individuals from culturally and linguistically diverse (CALD) communities is now required. All respondents also completed a minimum of high school education, therefore providing no indication of the accessibility of information to individuals with more limited formal education.

7.9 Conclusion

The findings of this study suggest that the FDBM Family Workbook may be accessible to families with a variety of education levels. The feedback was predominately positive, with all respondents reporting the workbook to be presented in a clear manner and helpful in increasing their understanding of BOC and identifying useful management strategies. Respondents also provided positive feedback regarding the use of illustrations, which were suggested to promote further

engagement in the content provided. Family members also liked the strengths focus and emphasis on proactive strategies, with further appreciation for the simple, reassuring and respectful manner in which information was presented. This has also emphasised the importance of information being provided to families in a timely manner. This gives them the opportunity to gain increased insight regarding the impact of brain injury and apply preventative strategies in the manner they have been intended, rather than waiting for families to seek such support when negative patterns of behaviour may already be established.

Respondents also provided helpful feedback in informing the further development of the workbook, suggesting an additional image including different hemispheres of the brain with related functioning, and some more specific guidelines for effective communication. These suggestions will be incorporated into the updated version of the workbook. In the next stages of development, different modes of delivery should also be examined, such as web-based resources, and the use of the workbook in guiding group sessions in comparison to a self-study format.

This chapter has presented the final study in the multiphase mixed-method design adopted for this thesis, with each study advancing towards the core research aim: to examine how to enhance the capability of families to better manage BOC in the community following ABI. Within the following chapter these studies are synthesised and examined according to research questions.

CHAPTER EIGHT

IMPLICATIONS, RECOMMENDATIONS & CONCLUSIONS

Related publications:

Fisher, A., Bellon, M., Lawn, S., Lennon, S., & Sohlberg, M. (2017). Family-directed Approach to Brain Injury (FAB) model: A Preliminary Framework to guide family-directed intervention for individuals with brain injury. *Disability and Rehabilitation, Under Review*

Fisher, A., Bellon, M., Lawn, S., & Lennon, S. (2017). Brain Injury, Behaviour Support and Family Involvement: Putting the Pieces Together and Looking Forward. *Brain Injury, Under Review*

8.1 Introduction

This thesis has examined how to enhance the capability of family caregivers in managing BOC presented by relatives with ABI in community settings. Current knowledge on this topic has been examined, with a multi-phase mixed methods design utilised to gain a current SA perspective regarding community-based neurobehavioural support and family involvement, and to develop and evaluate the FDBM program. Within this chapter, the implications of this research are presented, with findings synthesised to inform a theoretical framework for facilitating a Family-directed Approach to brain injury (FAB). In particular, recommendations for future practice are listed, followed by directions for future research, the strengths and limitations of the thesis, and a concluding statement.

8.2 Implications

8.2.1 The development of a new theoretical framework

The results of this multi-phase thesis have informed and shaped a new framework for facilitating family-directed support. Findings of the systematic review and Delphi process have emphasised the importance of educating family caregivers within a strength-focussed and person-centred approach. These findings are in line with principles of FCC, which espouse the importance of professionals working collaboratively with families, and utilising family expertise within a family-centred approach (Hostler, 1999; Rosenbaum, King, Law, King, & Evans, 1998). The pilot intervention then revealed additional active ingredients when working with families,

including providing hope, legitimising the challenges of their caregiving role and providing regular reinforcement for their efforts and the strategies they are using (whether they are newly learnt techniques or already existing strategies).

The PBS framework has provided an evidence-based approach for educating and training family caregivers, who demonstrated their ability to engage with material and effectively ‘direct’ and implement strategies. The structure and empirical foundation of this framework appeared to provide reassurance and positive direction for the participants, which was emphasised by participant feedback.

The findings from this thesis have influenced the preliminary development of a Family-directed Approach to Brain Injury (FAB) model. Although this thesis specifically focuses on enhancing the capability of family caregivers in implementing behavioural interventions, the theoretical foundation of this model is presented below within the broader context of brain injury rehabilitation with a focus on evidence based practices specific to behaviour management. The theoretical foundations of the FAB model are then followed by recommendations for guiding professionals in this process.

8.2.1.1 Background – family involvement

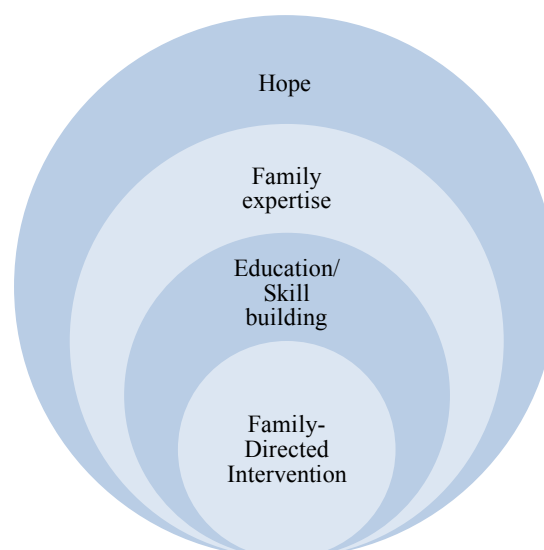
Although the importance of family collaboration and FCC is widely acknowledged, there appears to be limited literature concerning *how* to facilitate the increased competence of family caregivers as active members of the rehabilitation process. To address this issue, Sohlberg and colleagues (Sohlberg, McLaughlin, Todis, Larsen, & Glang, 2001) developed a theoretical model for guiding family

collaboration, and researchers began examining the concept of empowering families to maximise their participation in the delivery of rehabilitation services following brain injury (Man, Lam, & Bard, 2003). Others have also explored the involvement of families in goal-planning during the rehabilitation process (Levack, Siegert, Dean, & McPherson, 2009). Findings from this thesis build upon this foundation, enabling the development of a model to guide professionals in facilitating family-directed intervention.

8.2.1.2 Family-directed Approach to Brain Injury (FAB) model

The FAB model is presented in Figure 8.1. In simple terms, the FAB model provides an integrated framework for educating and training family members in implementing interventions within a hope-focused and family-centred approach. The overarching components of the model will be discussed below, which will then be followed by an outline of how these components are interrelated within recommendations for practice.

Figure 8.1 *The FAB model*



Hope

Although the importance of ‘hope’ has been noted in the positive psychology approach to brain injury rehabilitation (Evans, 2011), this topic appears to have gained little attention in the ABI literature. ABI research mentioning hope rather seems to concern avoiding ‘false hope’ for unrealistic recovery (Kuipers et al., 2014). However, hope has been identified as a key element in the recovery process (Bright, Kayes, & McPherson, 2011) and important in family members’ experience of involvement in brain injury rehabilitation across all stages of care (Kuipers et al., 2014). Family members have suggested hope could be fostered further by presenting realistic information regarding prognosis, but also acknowledging that, with work, things could improve (Kuipers et al., 2014). This was emphasised by the researcher throughout the FDBM pilot, with hope-focussed language also adopted within the education workbook. Although the importance of facilitating ‘hope’ was not explicitly identified as a critical concept by participants in the pilot study, the researcher noted that hope and optimism were reflected in their engagement in the program.

Furthermore, looking beyond the area of brain injury, hope has been recognised as a critical component in coping and adjustment (Dorsett, 2010; Keenan & Joseph, 2010), linked with life satisfaction, and identified as a protective factor for stress and depression (Strom & Kosciulek, 2007). Hope is therefore proposed to be critical in effective family collaboration. It is consequently an important and overarching component of the FAB model, providing family with a realistic optimism towards rehabilitation outcomes. Hope may be fostered through adopting a strengths-focused approach, emphasising the person’s abilities rather than disabilities. Secondly, families should be informed of the brain’s capacity to learn

and adapt following injury (Kolb et al., 2011; Raskin, 2011). With this as a foundation for family-directed interventions, family caregivers should be encouraged to maintain a realistic but optimistic outlook. As stated by Feeney (2010b);

It is the charge of all clinicians to help people create meaning in their lives – meaning is hopeful, meaning is positive, meaning requires us to believe and to communicate our hopefulness and to remember that “there’s always something that works” (p 146).

Family expertise

The FAB model draws on the theoretical framework of family-centred care (FCC). As mentioned earlier, FCC espouses the idea that family should work collaboratively with professionals to maximise rehabilitation outcomes, and that family members’ expertise should be acknowledged and utilised in the decision making process (Hostler, 1999). As suggested by Sohlberg and Mateer (2001), professionals must be willing to “release” their role as the only expert on the team.

The importance of family expertise was illustrated in the FDBM pilot. For example, early in the development of Angus’ behaviour support plan, Kate spoke about him becoming agitated. The researcher then asked Kate how she knew Angus was agitated, to which Kate responded “oh..., he gets that look in his eye”. Kate also offered practical strategies for responding to behaviours, which drew on Angus’ interests and support needs, with this insight also proving invaluable to this process.

Family-centred and community-based support plans should reflect family goals and values, build on family strengths and incorporate available resources,

which requires listening to and learning from family members (Lucyshyn et al., 1997). The involvement of family is beneficial in gaining a holistic ‘picture’ of the individual, including the ecology of his or her family, home life, and natural environment. The researcher could gain information on Angus’ living situation, revealing that he lived in his own home with the environment physically adapted to his needs; however, Kate shared the pride Angus had in being a ‘home-owner’, and the history in purchasing and setting up his ‘home’, which has greatly impacted his positive sense of independence. Kate also identified a number of successful support strategies that she was already using, which could be built upon during the intervention process.

It seems likely that utilising the family caregiver’s expertise would not only result in more effective interventions that cater to the unique needs of the individual, but would also assist in a more cost-effective intervention approach. However, in the current health care climate, where there is little time or infrastructure for interactions with significant others, the challenge is to facilitate such a process. The FDBM program may offer one way to address this issue, by providing group education sessions, individualised sessions, and ongoing peer-support (minimising time and resources).

Health professionals are striving to master not only the technical aspects of health care, but also to cultivate compassionate and humanistic interactions that are commonly believed to improve the experience of clients and result in better health outcomes (Gaufberg & Hodges, 2016; Kelley, Kraft-Todd, Schapira, Kossowsky, & Riess, 2014). It is likely that utilising pre-existing family relationships that are

grounded in a mutual understanding of events, family experiences, cultural values, and trust, will provide solid groundwork for successful family-centred rehabilitation.

In the context of the FAB model, family expertise therefore refers to acknowledging and utilising the knowledge and insight family caregivers can offer regarding the individuals' situation, but also their existing rapport and familial bond with the individual.

Education and skill building

The importance of information (Coco et al., 2011; Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015; Kuipers et al., 2014; Lefebvre & Levert, 2012), practical support, and hands-on collaboration with health care professionals has been widely reported by family members following ABI (Bellon, Crocker, et al., 2015; Coco et al., 2011; Kuipers et al., 2014; Lefebvre & Levert, 2012). Furthermore, as discussed previously, research emphasises the need for more accessible information regarding ABI presented in 'layperson's terms' (Gan et al., 2010; McDermott & McDonnell, 2014) and embedding information within a strengths-focussed and person-centred approach (Fisher et al., 2017a; Ponsford et al., 2013). These themes were also identified during the Delphi process as key components in programs aimed to support family caregivers in managing BOC.

In order to implement intervention strategies, family members must be provided with the necessary information to develop their 'toolbox' of knowledge, with education based on context-relevant and evidence-based practices. This was central to the current study.

It is also important that family members are given the opportunity to practice learnt strategies, to further develop the skills needed to not only to understand the theoretical base for intervention, but develop the practical skills in implementing these.

Therefore, within the FAB model, ‘education’ refers to providing information to promote understanding and tools for facilitating positive change, and ‘skill building’ refers to developing the practical skills needed to implement this change.

Family-directed intervention

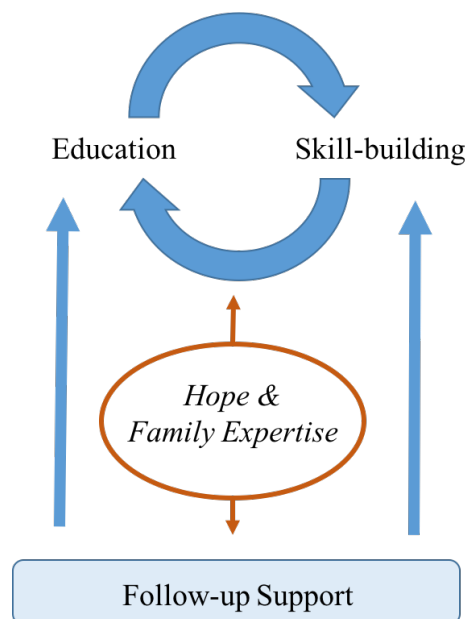
The FAB model aims to provide a framework that empowers family members as *facilitators* of change. The researcher refers to this notion of family-directed (or family-driven/family-led) intervention as professionals working in collaboration with family caregivers, with an emphasis on educating and guiding family members to develop and implement intervention strategies. Family members are encouraged to utilise their ‘toolbox’ of strategies (provided within the educational component) in making educated decisions about what strategies are appropriate, and in monitoring the progress of the intervention. As stated by Foster et al. (2012), this shift of responsibility from professionals to family members aims to equip the family with the necessary techniques to support their family member with ABI whilst also increasing their sense of mastery and confidence. These in turn enhance self-efficacy– the family caregivers’ sense of competence (Berry & West, 1993) in their caregiving role. From a theoretical perspective, a high sense of caregiver efficacy is advantageous as family members are more likely to persist with their support roles/involvement if they feel competent (Bandura, 1982). Changes in family

caregivers' sense of self-efficacy in their behaviour support role should be further explored in future studies.

As suggested by this thesis, family-directed intervention gives families the opportunity to play a key role in shaping their environment, and to feel valued and respected in this process (Petr & Walter, 2005).

The relationship between each component of the FAB model is depicted in Figure 8.2. Hope and family expertise underpin each stage of the delivery process, which initially focuses on education and skill-building. These components are represented in an iterative manner, with education providing the knowledge base for each stage of practical training.

Figure 8.2 *The interrelational components of the FAB model*



Follow up support is an important part of this process, giving families the opportunity for revision and further skill-building. The need for ongoing family support is widely acknowledged in the literature (Dillahunt-Aspillaga et al., 2013;

Gagnon et al., 2016; Klonoff, 2014; Kratz et al., 2017; Oddy & Herbert, 2008; Ponsford et al., 2013). Families should have the opportunity to revisit relevant education and practice techniques learnt, but also reflect on whether strategies are working/not working, whether they feel competent in implementing techniques, and to reflect on what changes might be needed. As an individual's support needs and environment continually evolve over time, management approaches also need to be continually modified and updated. This places importance on providing families with a range of strategies to draw from and the ability to monitor techniques and problem-solve. However, follow-up support is also essential in providing families with new education regarding changing needs, but also updated information regarding current evidence-based practices, which are also continually evolving.

Recommendations for practice

It is not sufficient to present the theoretical basis and significance of such a model, without considering its practical application. How can we guide professionals to adopt this optimistic, hopeful (but realistic), compassionate (yet professional), and family-centred approach in practice?

The recommendations presented in Table 8.1 are suggested to guide professionals in facilitating family-directed intervention utilising the FAB model. These recommendations are drawn from results from this thesis in addition to the literature regarding family support needs following brain injury (Foster et al., 2012; Klonoff, 2014; Kratz et al., 2017; Piccenna et al., 2016; Sohlberg & Mateer, 2001), and constructive guidelines for promoting professional-family collaboration (An et al., 2016; Blue-banning, Summers, Frankland, Nelson, & Beegle, 2004) and

developing essential relationship-building and empathetic listening skills (Berven & Bezyak, 2015). These recommendations reflect family caregiver feedback that there is still need for better communication and engagement, and provision of appropriate information to families (Piccenna et al., 2016). They are also in consensus with service recommendations made by Foster et al. (2012) for facilitating family engagement, which promote the importance of: early engagement; culturally appropriate practice; active listening; and providing education and skills training. Emphasis is also placed on the uniqueness of each family, which requires staff to “demonstrate a higher level of receptiveness, flexibility, and creativity that may be delivered in a more medical model of rehabilitation” (Foster et al., 2012, p. 1860).

Table 8.1 *Recommendations for professionals facilitating family-directed intervention*

<i>Promoting hope</i>
<ul style="list-style-type: none"> • Inform the family member that the brain <i>always</i> has the capacity to learn and adapt (<i>even</i> beyond the acute phase of recovery, although this may be slower). • Present realistic information, but acknowledge that improvement is possible. • Encourage the family member to focus on the individual’s strengths, rather than only disabilities. • Provide positive and hopeful examples that are meaningful to the family, while at the same time remaining aware that everyone’s experience is unique (e.g. share observations, experiences that relate to that’s individuals experience, with consideration of ethical and confidentiality issues). • Be positive; let them know that you are confident that you will find something that will help (remembering that we feel more positive when we are surrounded by positive people). • Acknowledge all the things they are doing well (there is always something). • Remember that you have the capacity to bring hope to this family; it is not only your technical knowledge that will made a difference, but also your positive attitude.

Acknowledging family expertise

- Families' are experts of their experience, and this should be acknowledged and utilised in the rehabilitation process.
- Acknowledge that the caregiving role is not always easy, and emphasise the things they are doing well.
- Listen and offer your time; you may need to guide this process, but do not rush or dismiss the families' experience.
- Remember that families will already have lots of strategies in their 'toolbox', you are simply helping them develop more.

Providing education and training

- Educate families regarding evidence-based intervention strategies. Inform them that research has been done to show that these strategies can be effective, and let them know if you have used these strategies before.
- Communicate in a positive manner: smile, have a relaxed and welcoming posture (e.g. do not cross arms), and give eye contact (unless culturally inappropriate). Be genuine and true to yourself: this will help you develop trust and rapport, which is key to promoting positive engagement. Share your practical experiences where appropriate.
- Present information using language that the family member understands (e.g. avoid professional jargon and ask them if they understand concepts presented).
- Provide practical and meaningful examples, with opportunities to practice new skills. Give opportunities for them to provide their experiences and strategies; this is also an opportunity for you to learn.
- Praise their efforts and help them recognise progress (you may need to remind them of what they have achieved).
- Monitor the rate at which you present information (ask them to paraphrase information or provide examples to demonstrate their understanding, and ask whether the pace of delivery is ok for them).

8.2.1.3 Summary

In summary, the FAB model provides a theoretical framework for supporting family caregivers as facilitators of change. With the current shift towards greater family collaboration, the FAB model defines potential active ingredients that have emerged from this research, and provides a theoretical framework to guide treatment

implementation. This model emphasises a focus on promoting family competence in supporting behavioural changes following ABI, rather than a dependency on service systems currently unable to meet the demand for support.

8.3 Future direction

This research adds to the mounting evidence supporting PBS approaches for individuals with ABI in community settings, and the importance of utilising family expertise in this process. With the shift towards greater involvement of family as active members of the rehabilitation team, this thesis presents an important step forward in guiding family involvement in community-based neurobehavioural support. However, there is considerable research still needed to inform an optimal community-based neurobehavioural support model that addresses family needs and is economically viable. The following recommendations are suggested by this thesis:

- To examine the concept of ‘transfer-of-training’ with family members of relatives with ABI specific to PBS strategies: what training methods are most effective and accessible, and what are the longer term outcomes for families?
- To examine how the FAB model can be used to guide the increased involvement of family members. In particular, to explore the value of hope and the way in which self-efficacy may be promoted and enhanced within the FAB model.
- To further examine and define the concept of ‘Family-Directed’ intervention in comparison to clinician-lead or clinician-supported approaches.

- To conduct a large scale feasibility study of the FDBM program, including extensive follow up to examine the families' ability to modify and implement new strategies with changing support needs, and an examination of its impact on levels of service utilisation specific to behavioural issues.
- To explore the long-term outcomes of training non-specialised caregivers in basic PBS strategies: does this reduce dependency on specialised services?

8.4 Strengths and limitations of this thesis

The research presented in this thesis has a number of strengths. Firstly, the multi-phase research design followed an iterative process, with each study building on and informing the previous study. This was a novel component of this program, with the FDBM program co-produced by key stakeholders (family caregivers and rehabilitation professionals). This thesis therefore incorporated elements of participatory research (Cargo & Mercer, 2008), ensuring the relevance of the research at the community level. It is recommended that a steering committee representing key stakeholders be established to guide further development of the FDBM program and future research to evaluate its outcomes.

An additional strength was the mixed-methods approach utilised, which provided triangulation of data. The addition of qualitative data provided important insight into family caregivers' experiences and outcomes of their participation in the FDBM pilot beyond purely object (quantitative) measures, which revealed areas recommended for further examination in future studies (i.e. generalisation of problem solving skills).

A significant limitation of this research program was the small sample size in each study, which limits the reliability of conclusions drawn. This has informed recommendations for additional methods of recruitment; however, limited sample sizes may also reflect time restrictions presented by this 3.5 year PhD program. During this time, the FDBM was developed through a multi-stage design, including design, ethics approval, recruitment and implementation of these separate studies. The time restrictions also impacted on the pilot study design, not allowing for a preferred six-week baseline measure and six or nine-month follow-up.

8.5 Concluding statement

This thesis has shed light on the importance of family involvement within behavioural interventions for relatives with ABI, but also the barriers faced by families in accessing the specialised supports required. The limited services available in addition to the unmet family support needs, presents great risk within our communities. Although families often become the primary caregiver in the long-term following ABI, they are often not sufficiently equipped to support behavioural changes. This may have detrimental implications for individuals, families, and society at large.

There is growing emphasis on involving family members in behavioural interventions, and the importance of family collaboration in maximising rehabilitation outcomes. However, there appears to be very little focus on *how* to increase the capability of families and guide this process within community-based settings.

This issue was central to this thesis. The multi-phase design has informed the development of the FDBM program, which presents an individualised and context-sensitive approach to supporting behaviour change in individuals with ABI. The culmination of findings from the multiple studies has also influenced the development of a Family-directed Approach to Brain injury (FAB) model for subsequent studies and clinicians to test and use. In light of these developments, the FDBM program has been renamed the FAB-*PBS* program, and subsequently used in related publications and research.

The preliminary work presented in this thesis will now be extended in a two-year research study (2017-2019) funded by the Lifetime Support Authority (Bellon, Fisher, Lawn, Sohlberg, & Douglas) examining the feasibility of the FAB-*PBS* with a larger sample. There is still considerable work needed to inform an optimal community-based neurobehavioural support model that addresses family support needs and is economically viable; however, this research provides an important step in this direction.

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APPENDIX 1. Systematic review - database search terms

Subject Themes	Database Subject Headings/ Key Word Searches			
	CINAHL (Subject Headings)	PsycINFO (Subject Headings)	MEDLINE (Subject Headings)	Informit/ PEDro/ Cochrane (key Work Searches)
Brain Injury	Brain Injuries Head Injuries	Brain Damage Traumatic Brain Injury Head Injuries	Brain Injuries (<i>subheadings; -rehabilitation, -therapy, -nursing, -complications</i>) Brain Damage (<i>chronic. subheadings; -psychology, -rehabilitation, -therapy</i>)	Brain injury/injured Brain damaged Head injury/injured ABI TBI
HITS	19,889	28,923	23,996	3,339
Behavioural Problems	Disruptive Behavior Social Behavior Disorders Social Behavior Behavior Therapy Behavioral Changes Mental Disorders Behavior Modification Community Violence	Behavior Therapy Behavior Disorders Behavior Change Behavior Problems Behavior Modification Mental Disorders Anger Control Anger	Mental Disorders Social Behavior Disorders Behavior Therapy Self-Injurious Behavior Aggression (<i>subheadings; -complications, -psychology, -therapy</i>) Behavior Control Sexual Behavior (<i>subheading; -psychology, -therapy</i>) Compulsive Behavior (<i>subheading; -psychology, -therapy</i>) Violence (<i>subheading; -psychology, -therapy</i>)	Challenging behavio(u)r Aggression Anger Behavio(u)r/al disturbances Behavio(u)r/al management Behavio(u)r/al modification Behavio(u)r/al intervention Behavio(u)r support Sexual Behavio(u)r Inappropriate Behavio(u)r Harmful Behavio(u)r Violent/violence Repetitive Suicide/al Irritable Agitated Neurobehavio(u)r/al Maladaptive Non compliant/compliance Mental illness/ disorders psychiatric

HITS	291,675	585,829	171,635	100,204
Family Involvement/ Context	Family Centered Care Community Programs Caregiver Support Family Coping Family Attitudes Communities Home Nursing Rehabilitation, community-based	Family Family Members Family Therapy Family-Centered & Parent-based models Caregiver Burden Parental Attitudes Significant Other Caregivers Family Intervention Family Support Communities Social Integration Community Services	Family (<i>subheadings; -education, -psychology</i>) Caregivers (<i>subheadings; -Education, -Psychology</i>) Home Nursing (<i>subheadings; -education, -methods, -psychology</i>) Social Support Family Therapy Family Health Community Health Services (<i>subheadings; -education, -methods</i>) Mentors (<i>subheadings; -education, -psychology</i>) Peer Group Social Environment Spouses (<i>subheading; -education, -psychology</i>)	Home In-home Community/ies Family/families Carer Care giver/caregiver Significant other Partner Spouse Mother Father Husband Wife Daughter Son Parent Friend Support Relative
HITS	48,594	243031	252428	327088
subject themes combined using 'AND'/ limited to 1980-2013, English language, participants ≥16 years of age	N=75	N=147	N= 66	N=91



Approval Date: 13 September 2014

Ms Alinka Fisher
Faculty of Medicine, Nursing and Health Sciences
Flinders University

Dear Ms Fisher,

HREC reference number: **HREC/14/RAH/398**

Project Title: **“Behaviour management following acquired brain injury (ABI) in Community settings: A family perspective.”**

RAH Protocol No: 140906.

Thank you for submitting the above project for ethical review. This project was considered by the Chairman of the Royal Adelaide Hospital Human Research Ethics Committee. I am pleased to advise that your protocol has been granted full ethics approval and meets the requirements of the *National Statement on Ethical Conduct in Human Research*. The documents reviewed and approved include:

- **LNR Application: AU/1/888A116**
- **Research Protocol, Version 1, 3 September 2014**
- **Letter of Delphi Introduction & Consent, Version 2, September 2014**
- **Letter of Support, Dr Miranda Jelbart, 9 September 2014**
- **Cover Letter to Professional/Family Caregiver, Round 1, Version 2, September 2014**
- **Instructions on how to complete Delphi Round 1, September 2014**
- **Questions, Delphi Round 1, September 2014**
- **Demographics Round 1, September 2014**

Please quote the RAH Protocol Number allocated to your study on all future correspondence.

GENERAL TERMS AND CONDITIONS OF ETHICAL APPROVAL:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
 - (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
 - (b) changes to the protocol,
 - (c) premature termination of the study.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is valid for **5 years** from the date of this letter, after which an extension must be applied for. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each anniversary of the above approval date, within 10 working days, using the Annual Review Form available at: <http://www.rah.sa.gov.au/rec/index.php>
- The REC must be advised with a report or in writing within 30 days of completion.

Should you have any queries about the HREC's consideration of your project, please contact Ms Heather O'Dea on 08 8222 4139, or rah.ethics@health.sa.gov.au.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a SA Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

This Committee is constituted in accordance with the NHMRC's *National Statement on the Ethical Conduct of Human Research* (2007). The HREC wishes you every success in your research.

Yours sincerely,

A/Prof A Thornton
CHAIRMAN
RESEARCH ETHICS COMMITTEE

Subject: OH-00109 - SBREC Acceptance Notice (6 September 2016)
Date: Tuesday, September 6, 2016 at 3:11:19 PM Australian Central Standard Time
From: Human Research Ethics
To: Alinka Fisher, Michelle Bellon
Priority: High
Attachments: OH-00109 application .eml

Dear Alinka,

Your request for ethics approval from the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University based on the ethics approval already granted by the SA Health Human Research Ethics Committee has been received.

As outlined on the [Social and Behavioural Research Ethics Committee \(SBREC\)](#) website ethics approvals conducted by Flinders University staff and students (including those with adjunct status), for social and behavioural research, granted by another Australian NHMRC Human Research Ethics Committee (HREC) will be accepted by the SBREC without further review or scrutiny. This approach is in line with Chapter 5.3 of the *National Statement on Ethical Conduct in Human Research*, which encourages the minimising of ethical review duplication. On that basis, the research project listed below has been accepted by the SBREC.

Important Note

The application submitted (SBREC Project OH-00109) has been accepted by the SBREC on the condition that:

1. the research is not clinical in nature (as per the guidelines on the SBREC website); and
2. no participants will be recruited from any organisations under the banner of the [Southern Adelaide Local Health Network \(SALHN\)](#) which includes the Flinders Centre for Innovation in Cancer (FCIC).

ACCEPTANCE OF ETHICS APPROVAL

Granted by other NHMRC Registered HREC

SBREC Project
Number:

OH-00109

Other HREC
approval number:

HREC/14/RAH/398

Ethics approval
granted by:

SA Health Human Research Ethics Committee

Project Title:

Behaviour Management following Acquired Brain Injury (ABI) in
Community Settings: A family perspective

Flinders University
Researcher:

Ms Alinka Fisher

School / Dept

Disability and Community Inclusion

Email:

alinka.fisher@flinders.edu.au

Date approval
accepted:

6 September 2016

Conditions of Acceptance

As the ethics approval granted by the SA Health Human Research Ethics Committee has been accepted by the Social and Behavioural Research Ethics Committee (SBREC) it is a requirement that the following conditions be met:

1. Flinders University Letterhead

- a) If the Flinders University researcher is the principal researcher on the accepted application it is a requirement that all documentation and/or information to be distributed to potential participants is placed on the Flinders University letterhead. Please ensure that these changes are submitted to the original approving Human Research Ethics Committee (HREC) as a modification request and are approved by them prior to implementation. Please also submit a copy of the modification request (and any relevant attachments) along with the modification approval notice from the other HREC to the SBREC. This information will just be saved onto your electronic project file.
- b) If the Flinders University researcher is not the principal researcher on the project; then documentation to be provided to potential participants does not need to be placed on Flinders University letterhead.

2. Modifications / Amendments

With the exception of modifications that may be required in number 1 above, the research project will continue being monitored by the other HREC that granted ethics approval; and on that basis copies of modification requests and approvals do not need to be submitted to the SBREC.

3. Submission of Other HREC Reports

Copies of all reports (i.e., annual progress and final) submitted to the Human Research Ethics Committee that originally approved the application need to be submitted to the Social and Behavioural Research Ethics Committee (SBREC). The reports will be reviewed by the SBREC Chair and then placed on your project file (i.e., a report approval notice will not be emailed to you). When reports are emailed to the SBREC please ensure that the SBREC project number the report relates to is listed in the subject line of the email.

For Future Reference

If you need to contact the SBREC in relation to this email in the future please ensure that you quote the project number allocated by the SBREC (OH-00109).

Kind regards
Andrea

Mrs Andrea Fiegert and Ms Rae Tyler

Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday
Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au

Web: [Social and Behavioural Research Ethics Committee \(SBREC\)](http://Social and Behavioural Research Ethics Committee (SBREC))

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au
[Research Services Office](#) | Union Building Basement
Flinders University

APPENDIX 3



Alinka Fisher
PhD Candidate

Flinders University
Sturt Campus
GPO Box 2100
Adelaide SA 5001
Telephone +61 8 8201 5956
Email: Alinka.Fisher@flinders.edu.au
Facsimile +61 8 8201 3646
www.flinders.edu.au

Date

Addressee Name
Position
Company Name
Address 1
Address 2
Suburb State Postcode

Dear Sir/Madam,

I am a PhD student in Disability and Community Inclusion, School of Health Sciences, at Flinders University.

I am undertaking research entitled "Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective."

Individuals often experience significant behavioural changes following brain injury, which can present a fundamental problem in their management. Behavioural changes can also cause significant distress for families within their homes and communities.

This projects aims to identify what supports and services are currently available in South Australia that specifically address issues of behaviour management following ABI for family caregivers, what strategies family caregivers are currently using to manage problem behaviours, and how family caregivers can be better supported to manage problem behaviours in community settings.

This project also seeks feedback regarding the development of an informed Family-Directed Behaviour Management (F-DBM) program for individuals with an ABI in community settings.

There is little research to date which examines community-based behaviour management following ABI with an emphasis on family involvement. This research therefore presents an important step towards the development of an optimal SA service model which empowers family to better manage problem behaviours in the community.

You have been identified as a key stakeholder who may meet inclusion requirements for this study, which are as follows:

- A professional or family caregiver who is (and have been for a minimum of two years) involved in the management of behavioural problems exhibited by individuals with ABI living in community settings
- 18 years or above
- Willing to participate

Involvement

This research will be carried out using a Delphi technique consisting of three questionnaires (known as rounds) aiming to reach consensus. The questions will be distributed to participants via SurveyMonkey, a web-based survey program. Simple and specific instructions will be provided for each questionnaire.



The amount of time necessary for completion of each questionnaire (or rounds) will vary with each participant, but should range from approximately 30-45 minutes for Round 1, 10-15 minutes for Round 2, and 10-15 minutes for Round 3. There are no right or wrong answers to the questions, as this study is seeking expert opinion.

Information provided will be confidential and participants will remain anonymous to the other participants.

The Delphi method will be presented in two parts. The aim of Part A will be to reach consensus regarding an optimal service model, and Part B will be used to refine the intervention protocol relating to a Family-Directed Behaviour Management (F-DBM) program.

If you feel you do meet inclusion criteria outlined above and would like to participate, please complete the consent form attached and return it using the postage-paid envelope provided by the (insert date).

If you have any questions please contact Alinka Fisher at Alinka.Fisher@flinders.edu.au or by telephone on (08) 8201 5956.

I do think participants will find this process interesting, and that this research will have important implications.

Thank you for your time,

Yours sincerely,

Alinka Fisher

PhD Candidate
Disability and Community Inclusion
School of Medicine,
Flinders University

APPENDIX 4

Dear (Professional/ family caregiver name)

Re: *Behaviour Management Following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective*

Thank you for returning your consent form indicating that you meet the inclusion criteria for this study and that you are willing to participate.

The following link will direct you to the first round Delphi questionnaire.

<https://www.surveymonkey.com/s/FDBM-Delphi>

The aim of this study is to come to agreement on the current supports and services available, and come to an agreement on the priorities for empowering families to better manage problem behaviours in the community following ABI.

Please read the instructions carefully and complete the Delphi questionnaire as fully as you can. It is also important that you complete the demographics sheet at the end of the questionnaire as this will enable the researcher to provide you with feedback throughout the process. Return of completed Delphi rounds implies consent to participate.

Please complete and submit the Round 1 questionnaire by the 9th of January 2015. It would be greatly appreciated if you could complete the questionnaire before you go on Christmas break. However, I do appreciate this is a difficult time, and if this is not possible I would be most grateful if you could meet the above deadline.

If you wish to discuss any aspects of this further, please contact Alinka Fisher at Alinka.fisher@flinders.edu or phone on (08)8201 5956

Thank you for agreeing to participate in this study

Yours Sincerely,

Alinka Fisher
PhD Candidate
Disability and Community Inclusion
Flinders University

Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

Instructions on how to complete Round 1

Dear Participant,

This Delphi questionnaire is the first stage of a research project entitled “Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective”.

This project aims to identify what supports and services are currently available in South Australia that specifically address issues of behaviour management following ABI for family caregivers, what strategies family caregivers are currently using to manage challenging behaviours, and how family caregivers can be better supported to manage challenging behaviours in community settings.

This project also seeks feedback regarding the development of an informed Family-directed Behaviour Management (FDBM) program following ABI in community settings. A preliminary study will then be conducted to examine the effectiveness of this program using a Randomised Controlled Trial.

There is little research to date which examines community-based behaviour management following ABI with an emphasis on family involvement. This research therefore presents an important step towards the development of an optimal SA service model which empowers family to better manage challenge behaviours in the community.

The first round of this Delphi will be conducted in two parts:

Part A will ask you two questions about what strategies family caregivers are using to manage challenging behaviours in adults with ABI (18 years or above), and what services and supports are currently available.

Part B will outline the Family-directed Behaviour Management (FDBM) program and will ask you eight questions regarding the proposed content and methods.

Where there are 10 spaces for you to detail your answers, you are encouraged to identify a minimum of five and a maximum of 10 items.

This round of the Delphi is expected to take you between 30-45 minutes to complete. Please be assured that the following rounds will not be so lengthy, and should only take a maximum of 20 minutes to complete.

Please provide your demographic details at the end of this questionnaire. This will enable the

researcher to identify your responses so we can provide individual feedback to each panel member. Please note that you will remain anonymous to other panel members.

Please complete and submit this questionnaire by the 9th of January It would be greatly appreciated if you could complete the questionnaire before you go on Christmas break. However, I do appreciate this is a difficult time, and if this is not possible I would be most grateful if you could meet the above deadline.

Thank you for agreeing to participate in this study.

If you have any questions please contact Alinka Fisher at alinka.fisher@flinders.edu.au or phone (08) 8201 5956.

Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

PART A

What are challenging behaviours?

Behaviours deemed 'challenging' will vary between individuals, but may include:

- Physical and verbal aggression
- Sexually inappropriate behaviour
- Socially inappropriate behaviours
- Absconding (wandering off)
- Lack of initiation
- Reduced social skills
- Irritability
- Mood disorders

Current management strategies

There is very limited research identifying what strategies family caregivers use to manage challenging behaviours in community settings following ABI. However, the literature has reported the use of avoidance and distraction. In one case, the mother of her 20-year-old son with ABI would often avoid altercations that might precipitate angry episodes, try to divert his attention or change the topic of conversation, and withdraw from situations and lock herself in her bedroom when her safety was at risk (Willis & LaVigna, 2003).

Family caregivers may also use the promise of desired activities/objects to encourage more positive behaviour, or use negative consequences following challenging behaviour with the hope of decreasing its frequency. Family caregivers may also contact psychologists and psychiatrists to seek advice on how to manage specific situations, or call on family members/friends for urgent support.

If possible, please list a minimum of five and a maximum of 10 items for the following question. Your answers do not have to be in any particular order.

* 1. What strategies are used by family caregivers you know to manage challenging behaviours in community settings following ABI?

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Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

Services and supports for managing challenging behaviours

In South Australia there are a number of organisations that offer support to individuals with ABI and families in community settings (such as South Australian Brain Injury Rehab Services, Brain Injury Network South Australia, Families4Families). However, there are very limited supports that specifically address issues of challenging behaviour following ABI.

If possible, please list a minimum of five and a maximum of 10 items for the following question. Your answers do not have to be in any particular order.

- * 2. Are you aware of any services and supports regarding challenging behaviours following ABI that are available in S.A for individuals and family caregivers? Or (if applicable) can you identify what services and supports are available in your current state?

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- * 3. In which state do you reside/work?

Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

PART B

Appropriate terminology

There are a variety of terms used throughout the literature that make reference to “challenging behaviours” following brain injury. These include, problem behaviours, neurobehavioural disturbances, maladaptive behaviours, and behavioural challenges. You may also be aware of alternative terminology used.

- * 4. The term 'challenging behaviours' has been adopted throughout this research. Do you think this term is appropriate? If not, please specify an alternative

Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

Identifying an appropriate intervention model

The literature suggests that education plus individualised intervention is an appropriate model for supporting family caregivers in managing challenging behaviour following ABI. Education components often include common behaviour changes following brain injury and general principles of behaviour management. The individualised intervention may involve professionals working in collaboration with family members to develop behaviour management strategies specific to their individual situations.

If possible, please list a minimum of five and a maximum of 10 items for the following question. Your answers do not have to be in any particular order.

* 5. What intervention components do you think should be included in a behaviour management program aimed at supporting family caregivers of individuals with ABI?

1	<input type="text"/>
2	<input type="text"/>
3	<input type="text"/>
4	<input type="text"/>
5	<input type="text"/>
6	<input type="text"/>
7	<input type="text"/>
8	<input type="text"/>
9	<input type="text"/>
10	<input type="text"/>

Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

Education Component

Behaviour management interventions often include an education phase, and may include the following components: identifying common challenging behaviours following brain injury; identifying specific challenging behaviours according to the families' individual situations; introducing common behaviour management strategies; and strategies for recording and monitoring challenging behaviours.

If possible, please list a minimum of five and a maximum of 10 items for the following question. Your answers do not have to be in any particular order.

* 6. What topics do you think should be included in an education component for a behaviour management program aimed at supporting family caregivers of individuals with ABI?

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Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

PART B

The literature shows that education plus intervention is an appropriate model. A systematic review (Fisher et al., Submitted) has informed the development of a Family-directed Behaviour Management (FDBM) program.

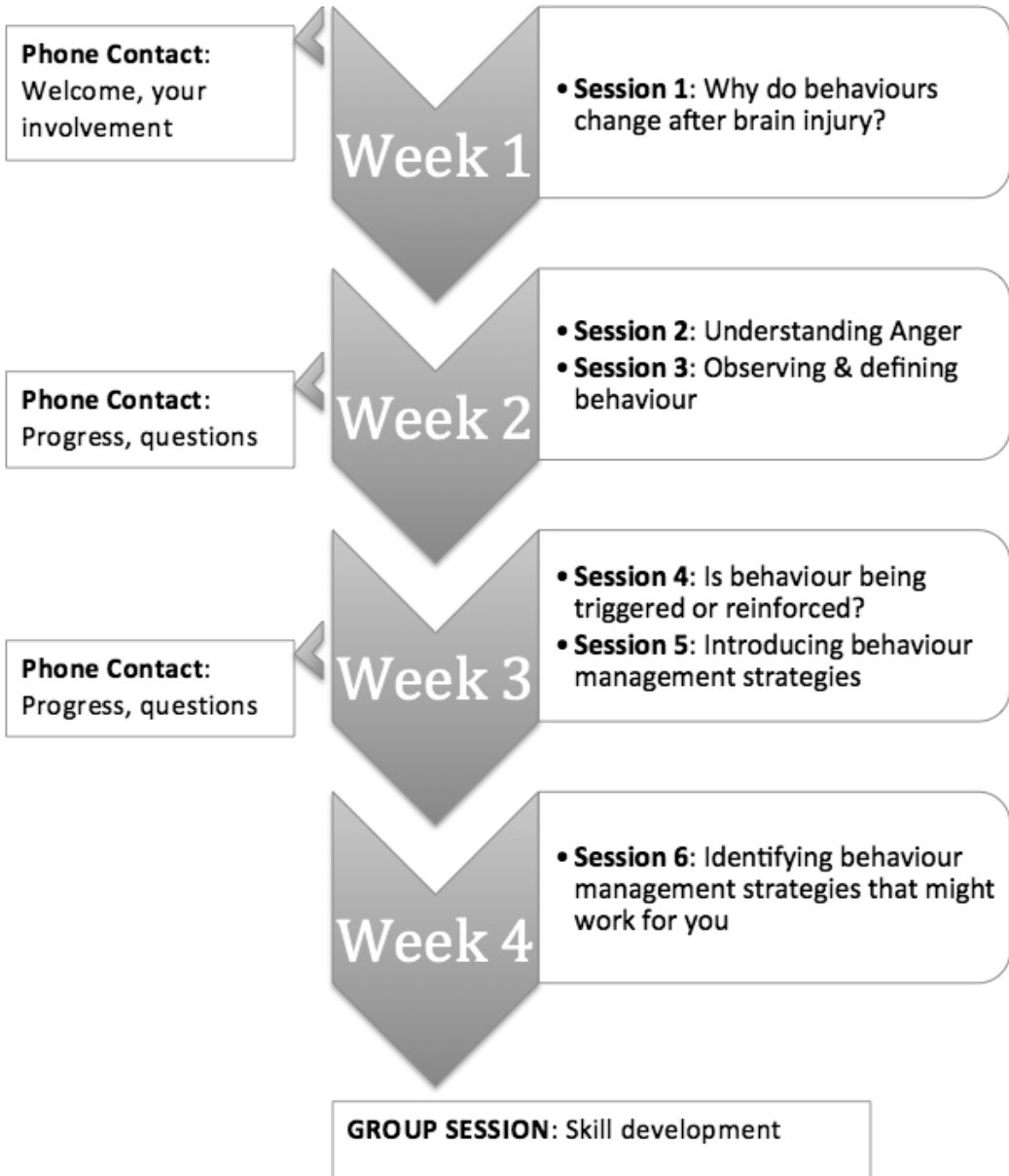
Please review the outline of the FDBM below and answer the following questions.

The FDBM program consists of both an education phase and an individualised intervention.

Education Phase

During the education phase, family caregivers will be guided using a 'Family Education Booklet' titled 'Understanding & Managing Challenging Behaviours following Brain Injury'. The booklet consists of six sessions providing information about common neurobehavioural sequelae following brain injury and behaviour management techniques (see below)

Weekly Overview



The sessions will consist of self-study modules so participants do not have to commit to physically attending weekly sessions. Participants are encouraged to set aside 2 hours per week to complete the required sessions. The primary researcher will make initial phone contact with participants to discuss the details of their involvement and answer questions (the researcher will have already had face-to-face contact with participants to complete intake assessments and collect baseline data). Phone contact will also be made during week two and three of the program to offer further support where needed and guide participants through self-directed activities, which are an important element of the education program.

As new information is introduced, activities are encouraged to help participants apply knowledge to their individual situations. For example, participants will be asked to define challenging behaviours in observable terms, and later try and identify possible triggers or events that may be reinforcing these behaviours.

Behaviour management strategies included within the FDBM program will focus on antecedent based techniques (understanding the purpose/triggers of behaviours and looking at environmental factors), with less emphasis on contingency based strategies (consequence focussed) due to the cognitive difficulties often associated with brain injury. There will also be a strong focus on creating a positive environment and structure within the persons daily life.

The final session will be held in a group format, in which the content covered throughout the six sessions will be summarised and behaviour management strategies will be further discussed in relation to individual situations.

* 7. Do you think the major themes covered in the education sessions are relevant in supporting family caregivers to manage challenging behaviours following ABI? If not, please specify

* 8. Do you think the self-guided (rather than face-to-face) study sessions are appropriate given the nature of the study? If not, please specify

Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

Individualised Behaviour Management Plan

Family caregivers will continue to meet with the research team for approximately 1.5 hours weekly for an additional eight weeks. The research team will work with the family caregiver in a collaborative manner to develop and implement an individualised intervention focusing specifically on the target behaviours identified.

This phase will include interactive sessions to elicit problem solving regarding modification of the target behaviour. Family caregivers will also be further educated around the role of antecedents and consequences in eliciting and maintaining challenging behaviours.

As the focus of this intervention is on training family caregivers in the management of behaviours, family caregivers will be given the responsibility to implement intervention strategies independently between sessions and report on their progress in the following session.

A preliminary study will be conducted evaluating the effectiveness of the FDBM program in community settings using a Randomised Controlled Trial (RCT), with an education plus intervention (full FDBM) group being compared with an education only group.

This study aims to answer the following research questions:

Does participation in the FDBM program (a) decrease frequency of challenging behaviours by people with ABI, (b) improve caregiver confidence in managing challenging behaviour, and (c) improve levels of burden in caregivers?

Data will be collected from the following sources:

- The Overt Behaviour Scale (OBS), which will be completed by a family caregiver
- The Care and Needs Scale (CANS), which will be completed by a clinician who has directly provided support to the participant with ABI
- The Sydney Psychosocial Reintegration Scale (SPRS), which will be completed by a family caregiver
- The Caregiver Appraisal Scale (CAS), which will be completed by a family caregiver
- A purpose-designed survey to collect data regarding the family members perceived confidence in managing challenging behaviours pre and post intervention.

The OBS (Kelly et al., 2006) will be used to measure frequency of target behaviours, but will also be used as a screening instrument to determine the presence of challenging behaviours for inclusion in the study. Other measures will be used to collect additional information about each participant with ABI and family caregivers, including levels of support needs and psychosocial functioning and levels of burden experienced by the family caregiver.

Detailed demographic information will be gathered concerning both the participants with ABI and family caregivers.

- * 9. Do you think meeting with the family caregivers for 1.5 hours weekly over eight weeks seems like an appropriate length of time given the nature of this study? if not, please specify and justify an appropriate length for this intervention.

* 10. Do you think the outcome measures are relevant to the research questions? If not, please specify

11. Any further comments/ suggestions:

Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

DEMOGRAPHIC INFORMATION

Please be assured that you will remain anonymous to other panel members. The demographic information you provide below will only be visible to the primary researcher. It is important that the researcher can identify your responses as the Delphi has individual feedback for every panel member built into the process.

* 12. Current Role

Name:

Role (e.g. family caregiver, psychologist, etc):

Department (if applicable):

Employing organisation (if applicable):

* 13. Are you...

Male

Female

14. If applicable, please list your qualifications:

* 15. How many years experience do you have in the management of challenging behaviours following ABI in community settings?

16. If applicable, do you work in the health service or in private practice?

Health Service

Private Practice

Disability Service

Other (please specify)

Behaviour Management following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective

Thank you for taking the time to complete the first round questionnaire. Alinka Fisher will email you a summary of participant responses with the Round 2 questionnaire. You will receive this by the 23rd of January 2015.

We sincerely value your participation.

APPENDIX 5

Dear (Professional/ family caregiver name)

Re: *Behaviour Management Following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective*

Thank you for completing the first round Delphi questionnaire. The following link will direct you to the second round questionnaire:

<https://www.surveymonkey.com/s/ABIdelphiround2>

This questionnaire is completed differently to the first round and instructions are included which will guide you through this process.

This questionnaire includes a summary of your responses from Round 1. The aim of Round 2 is for participants to rate the importance of items that have been raised within Round 1 regarding the current supports and services available and priorities for empowering families to better manage challenging behaviours in the community following ABI.

Please read the instructions carefully and complete the Delphi questionnaire as fully as you can. Return of completed Delphi rounds implies consent to participate.

Please complete and submit the Round 2 questionnaire by Monday the 9th of February 2015.

If you wish to discuss any aspects of your involvement further, please contact me at Alinka.fisher@flinders.edu or phone on 0433 682 281. Please note that you may not be able to contact me using my office number previously provided.

Thank you for agreeing to participate in this study

Yours Sincerely,

Alinka Fisher
PhD Candidate
Disability and Community Inclusion
Flinders University

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

Instructions on how to complete Round 2

Dear Participant,

Thank you for completing the first round Delphi Questionnaire.

The second round of this Delphi lists the responses from participants in Round 1. These responses have been content analysed and similar responses grouped together to ensure that the questionnaire is not repetitive and easily completed. The meaning of the responses has not been changed.

Please note that although the full detail of some of your responses have not been included for the purpose of this Delphi, the information you have provided will make a valuable contribution to this research project.

Within this questionnaire you will be asked to rate items using a Likert scale numbered 1 to 5. These numbers correspond to a response as below:

- 1. Very Important**
- 2. Important**
- 3. Neither important or not important**
- 4. Not important**
- 5. Unimportant**

Please complete and submit this questionnaire by Monday the 9th of February 2015.

Thank you for participating in this study.

If you have any questions please contact Alinka Fisher at alinka.fisher@flinders.edu.au or phone 0433 682 281

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

PART A

Participants have identified the following strategies to be used by family caregivers to manage challenging behaviours in community settings following ABI. Please rate each according to how much you feel family caregivers depend on/use these strategies (1=Very often, 5=Not at all).

1. Distraction (e.g. change topic/ shift persons attention/ make a joke)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Attempt to ignore behaviour (e.g. walking away/not engaging with or commenting on challenging behaviour)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. Negative consequences following challenging behaviour (e.g. threats to withdraw personal items, food, money, and possible eviction)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Reward positive behaviour (e.g. use tokens, food rewards, verbal praise)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. Agree with person's demands to avoid challenging behaviour

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Reason with the person (e.g. try discuss the situation/ ask them to 'stop' & try make them understand behaviour is inappropriate/ understand what is wrong)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. Avoid triggers (e.g. environments/ conversations/ situations that may trigger challenging behaviours)

1

2

3

4

5

8. Identify and manage triggers (e.g. if person is tired (trigger) ask if they need a rest, noticing mood changes and responding appropriately)

1

2

3

4

5

9. Access support services for education/ information/ support to develop behaviour plans (e.g. Psychologists, BIRCH, Counsellors, GPs)

1

2

3

4

5

10. Call on others to help and give emotional support (e.g. family and friends)

1

2

3

4

5

11. Call on police or ambulance to assist in managing behaviours

1

2

3

4

5

12. Medication

1

2

3

4

5

13. Timeout (e.g. leave person alone, remove from activity, or invite them to take a break)

1

2

3

4

5

14. Use of respite (finding ways for family caregiver and person with ABI to have regular time apart)

1

2

3

4

5

15. Creating meaningful routines (keeping them busy with meaningful activities/ creating predictability and variety)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Setting realistic goals

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Physical activity

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Being dominant/ directing person with ABI

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Do not leave them alone (24 hour supervision)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. Locking doors/ secure physical environment

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

Participants have identified the following services and supports in S.A to be available to family caregivers regarding the management of challenging behaviours following ABI.

Please rate each according to how specific they are to supporting family caregivers with managing challenging behaviours in people with ABI (1=Very, 5= Not at all). Please also indicate if you were aware of these services in relation to supporting family caregivers in behaviour management following ABI in community settings.

21. BIRCH (Brain Injury Rehab Community & Home)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

23. BIRU (Brain Injury Rehab Unit)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

25. BINSNA (Brain Injury Network of S.A)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

27. Springboard

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

29. Disability SA (The Positive Behaviour Support Team)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

31. Families4Families (peer support and education)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

32. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

33. Private Specialists (e.g. [neuro]psychologists, [neuro]psychiatrists, OTs)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

34. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

35. CRP (Community Re-entry Program)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

36. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

37. Metro Options (Uniting Care Wesley)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

38. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

39. Uniting Communities Metro Project

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

40. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

41. Carers SA

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

42. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

43. Carers Respite Service

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

44. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

45. General Practitioners

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

46. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

47. Noarlunga Mental Health Services

1

2

3

4

5

48. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

49. Lifeline

1

2

3

4

5

50. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

51. DASSA (Drug and Alcohol Services S.A)

1

2

3

4

5

52. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

53. Secondary consulting with Diverge (Victoria)

1

2

3

4

5

54. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

55. Mens Health

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

56. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

57. Pananga (Christies Beach)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

58. Were you aware of this service in relation to supporting family caregivers in behaviour management following ABI?

59. Any further comments:

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

The appropriateness of the term 'Challenging Behaviours'

Six out of 11 participants feel the term 'Challenging Behaviours' is appropriate. However, some alternatives were discussed.

'Behaviours of concern' was preferred by some as it "tends to reflect the concept that there are behaviours that are either of concern to people around an individual or that there are some behaviours that the individuals themselves is coming to see are of concern".

Another participant stated that "'Challenging' now has a degree of stigma attached to it and people can then be labeled as 'challenging' which can affect some services, agencies and community groups' acceptance of them". It was argued that they are not challenging, but rather it's their behaviours that are the thing of concern.

One participant suggested 'harmful behaviours' may be more appropriate, being "inclusive of various behavioural issues including verbal and/or physical aggression, volatile behaviours, tantrums, swearing, threatening self-harm, a range of sexually inappropriate behaviours, loudness, intrusiveness etc". However, as another participant stated, behaviours of concern may include "fatigue, constant repetition, lack of insight, concrete thought, processing delays, emotional processing, etc".

The term 'neurobehavioural disturbances' was also suggested as it "seems to place blame back on the ABI and doesn't attribute the blame to the person".

Considering this new information, how comfortable would you be using the following terms? (1=Very, 5=Not at all)

60. Challenging behaviours

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

61. Behaviours of concern

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

62. Harmful behaviours

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

63. Neurobehavioural disturbances

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

Intervention components

When asked what intervention components participants thought should be included in a behaviour management program aimed at supporting family caregivers of individuals with ABI, the following key themes were identified.

Please rate each according to how important you feel it is within an intervention specific to behaviour management (1=Very, 5=Not at all).

64. Education regarding ABI (including common cognitive and behavioural sequelae)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

65. Information about the link between ABI and mental illnesses (e.g. depression and anxiety)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

66. Person-centred/ individualised approach (e.g. discussing issues with the family and individuals with ABI - what is their perspective? What is meaningful to them?)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

67. Behaviour management strategies (e.g. positive communication skills, antecedent behavioural approaches and Positive Behaviour Support [PBS] approaches, with a focus on positive reinforcement)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

68. Assessment/ observation of challenging behaviours (how and why - e.g. The importance of observing behaviours in natural settings, identifying triggers and reinforcers, and keeping track of what works and what doesn't)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

69. Ongoing counselling/ support for families (e.g. peer support and support groups for family members, phone support when needed)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

70. Respite (regular and emergency respite provided in specialised units with well-trained staff)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

71. Strengths focus (identifying strengths and challenges of the individual, and where possible building on strengths)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

72. Accessing emergency support (clear guidelines on how/who/when to access support, ability to contact ABI trained professionals 24/7 in crisis)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

73. Support from (neuro)psychologist and/ or (neuro)psychiatrist (early, regular and responsive support)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

74. Information on current systems (e.g. how to obtain support when needed, how to work through government and non-government support systems, list of helpful resources in the community)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

Education components

When asked what education components should be included in a behaviour management program aimed at supporting family caregivers of individuals with ABI, participants identified the follow themes.

Please rate each according to how important you feel it is within an education component specific to behaviour management (1=Very, 5=Not at all).

75. What is an ABI? (basic biology of ABI)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

76. Possible cognitive and behavioural changes following ABI (including common changes and possible reasons for behaviour, including physical, social, emotional, and psychological)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

77. Role changes after ABI (e.g. changes in family dynamics and how that impacts on the person with ABI and caregivers)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

78. Grieving (understanding that individuals with ABI and families may be grieving their losses)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

79. Case studies/ examples (examples of strategies that people have found helpful in managing common challenging behaviours following ABI)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

80. Behavioural, cognitive and communication sequelae that can be prone to misattribution errors (e.g. reduced initiation = "they're just being lazy")

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

81. Identifying triggers (potential physical, environmental and social triggers)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

82. Behaviour management strategies (e.g. positive communication skills, developing meaningful routines, information regarding Antecedent Behavioural approaches and Positive Behaviour Support (PBS) approaches, with a focus on positive reinforcement)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

83. Person-centred approach (importance of understanding individual with ABI, involving family - 'doing with' the family rather than 'doing to' or 'doing for')

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

84. Self-care strategies (importance of family looking after themselves, strategies to keep safe and sane)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

85. Information on support agencies (what support and services are available, knowing when and how to access these services)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

86. What to do in a crisis (developing an emergency behaviour plan - knowing where to go and who to contact)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

PART B

Feedback regarding the FDBM program

The Family-Directed Behaviour Management (FDBM) program consists of both an education phase and individualised intervention to support family caregivers in managing challenging behaviours following ABI. The education sessions consist of six self-study modules to be completed over four weeks, with telephone support and a final group session.

The education component includes information on common cognitive and behavioural changes following ABI (including the 'less mentioned behaviours' such as fatigue, constant repetition, delayed processing etc), why behaviour changes, the importance of observing behaviours, and behaviour management strategies.

Only two out of 11 participants agreed with the self-guided study format of the education component, with most participants indicating that face-to-face sessions were more appropriate. The following suggestions were made. Please rate how effective you think each format is likely to be (1=Very, 5=Not at all).

87. A mix of face-to-face and phone calls (e.g. Face-to-face at the start of session 1 and then follow up phone calls, with one more face-to-face session held in week 2 of the 4-week program) to guide family caregivers through self-study modules.

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

88. Face-to-face sessions every week plus follow up phone calls, supporting participants to work through the self-study modules. The issue identified with this format is the time commitment, and less flexibility in completing the workbook.

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

89. Group sessions every week, allowing brain storming and listening to others' experiences. The issue identified with this format is being able to organise times when all participants are available.

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

90. Any further comments:

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

Individualised Behaviour Management Plan

Following the education component, family caregivers will continue to meet with the research team for approximately 1.5 hours weekly for an additional eight weeks to develop an individualised behaviour management plan. The research team will work with the family caregiver in a collaborative manner focussing specifically on the target behaviours identified.

Nine out of 11 participants feel that that meeting with family caregivers for 1.5 hours weekly over eight weeks seems like an appropriate length for this intervention. However, it was suggested that due to individual situations, some families may need longer and that the program should be reviewed after a few weeks. There was also concern that on top of a four-week theoretical model this adds up to a heavy time commitment by family.

The following suggestions were made. Please rate how important you feel these changes are to the FDBM program (1=Very, 5=Not at all)

91. The intervention should be reviewed at week 10, 14 and 18 to stretch out the time for monitoring and adjustment

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

92. There should be a two hour follow up two months post intervention, allowing time to practice newly learnt skills and some feedback with fine tuning

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

93. The intervention should instead be held for 1.5 hours fortnightly for six visits. This lessens the time commitment required by families, and a less intensive, longer lasting program might be better received

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

94. Any further comments:

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 2)

Thank you for taking the time to complete the second round questionnaire. Alinka Fisher will email you a summary of participant responses with the Round 3 questionnaire. You will receive this by Friday the 27th of February.

We sincerely value your participation.

APPENDIX 6

Dear (Professional/ family caregiver name)

Re: *Behaviour Management Following Acquired Brain Injury (ABI) in Community Settings: A Family Perspective*

Thank you for completing the second round Delphi questionnaire. The following link will direct you to the second round questionnaire:

<https://www.surveymonkey....>

The purpose of this Delphi process is to reach consensus (75% agreed response rate) regarding the topics/items you have been involved in identifying and rating in relation to importance.

The third round questionnaire will include those items that have not yet reached agreement. You will also find a list of the priorities/items that have already reached consensus on their importance. This does not mean that they are the most important priorities, only that they have reached consensus at an early stage.

This questionnaire is completed differently to the first and second round and instructions are included which will guide you through this process.

Please read the instructions carefully and complete the Delphi questionnaire as fully as you can. Return of completed Delphi rounds implies consent to participate.

Please complete and submit the Round 2 questionnaire by Friday the 13th of March 2015.

If you wish to discuss any aspects of your involvement further, please contact me at Alinka.fisher@flinders.edu or phone on 0433 682 281.

Thank you for agreeing to participate in this study

Yours Sincerely,

Alinka

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

Instructions on how to complete Round 3

Dear Participant,

Thank you for completing the second round Delphi Questionnaire.

The third round of this Delphi only includes questions that are close to reaching consensus. You will also be presented with items that have already reached consensus in Round 2. Scores from the upper (e.g. 'very important' and 'important') and lower bands (e.g. 'not important' and 'not at all important') have been collapsed to provide a group consensus as either 'important' or 'not important'. Where there was not consensus in either the upper or lower bands, the item has been omitted from the 3rd round questionnaire.

For each question you will be provided with the group consensus rate from Round 2 (this will appear as a percentage), and be asked to reconsider your original response in the context of the group response. Please note that you do not have to change your original response if you do not wish to.

Please complete and submit this questionnaire by Friday 13th of March 2015.

Thank you for participating in this study.

If you have any questions please contact Alinka Fisher at alinka.fisher@flinders.edu.au or phone 0433 682 281

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

In Round 1 participants identified a number of strategies to be used by family caregivers to manage challenging behaviour in community settings following ABI.

Agreement was reached in Round 2 that the following strategy is used OFTEN:

-Identifying and managing triggers (e.g. if the person is tired (trigger) ask if they need a rest, noticing mood changes and responding appropriately).

Consensus has almost been reached regarding the following strategies. In brackets following each strategy the group consensus rate has been provided from Round 2. Please consider your response in the context of this group response.

Please rate each according to how much you feel family caregivers depend on/use these strategies (1=Very often, 5=Not at all)

1. Distraction (e.g. change topic/shift persons attention/ make a joke)

(GROUP CONSENSUS - 73%= often)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Agree with person's demands to avoid challenging behaviour

(GROUP CONSENSUS - 73%= often)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. Reason with the person (e.g. try discuss the situation/ ask them to 'stop' & try make them understand behaviour is inappropriate/ understand what is wrong)

(GROUP CONSENSUS - 64%= often)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Avoid triggers (e.g. environments/ conversations/ situations that may trigger challenging behaviours) -

(GROUP CONSENSUS - 55%= often)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. Access support services for education/ information/ support to develop behaviour plans (e.g.

Psychologists, BIRCH, Counsellors, GPs)

(GROUP CONSENSUS - 55%= often)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Medication

(GROUP CONSENSUS - 73%= often)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. Setting realistic goals

(GROUP CONSENSUS - 55%= often)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Physical activity

(GROUP CONSENSUS- 55%= often)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Being dominant/ directing person with ABI

(GROUP CONSENSUS - 64% = rarely)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Locking doors/ secure physical environment

(GROUP CONSENSUS - 64%= rarely)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

In Round 1 participants identified a number of services and supports in S.A to be available to family caregivers regarding the management of challenging behaviours following ABI.

Consensus has almost been reached according to how specific the following services are to supporting family caregivers with managing challenging behaviours in people with ABI.

In brackets following each strategy the group consensus rate has been provided from Round 2. Please consider your response in the context of this group response.

Please rate each according to how specific these services are in supporting family caregivers with managing challenging behaviour in people with ABI (1= very specific, 5=not at all specific)

11. BINSAs (Brain Injury Network of S.A)
(GROUP CONSENSUS - 55% = not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. Springboard
(GROUP CONSENSUS - 55%= not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. Families4Families (peer support and education)
(GROUP CONSENSUS - 55%= specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. Private Specialists (e.g. [neuro]psychologists, [neuro]psychiatrists, OTs)
(GROUP CONSENSUS - 64%= specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. Uniting Communities Metro Project
(GROUP CONSENSUS - 55%= not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Noarlunga Mental Health Services

(GROUP CONSENSUS - 64%= not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Lifeline

(GROUP CONSENSUS - 64%= not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. DASSA (Drug and Alcohol Services S.A)

(GROUP CONSENSUS - 55%= not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Secondary consulting with Diverge (Victoria)

(GROUP CONSENSUS - 64%= not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. Mens Health

(GROUP CONSENSUS - 73% = not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. Pananga (Christies Beach)

(GROUP CONSENSUS - 55% = not specific)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

In Round 2 participants were asked how comfortable they would be using the following terms.

In brackets following each strategy the group consensus rate has been provided from Round 2. Please consider your response in the context of this group response.

How comfortable are you in using the following terms in relation to 'challenging' behaviours following ABI? (1=Very comfortable, 5= Not at all comfortable).

22. Behaviours of concern

(GROUP CONSENSUS - 73% = comfortable)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. Harmful behaviours

(GROUP CONSENSUS - 55% = comfortable)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. Neurobehavioural disturbances

(GROUP CONSENSUS - 64% = comfortable)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

In Round 1 participants identified a number of intervention components they thought should be included in a behaviour management program aimed at supporting family caregivers of individuals with ABI. You were then asked to rate each of these according to how important you feel it is within an intervention specific to behaviour management.

Agreement was reached in Round 2 that the following intervention components are IMPORTANT:

-Education regarding ABI (including common cognitive and behavioural sequelae)

-Person-centred/ individualised approach (e.g. discussing issues with the family and individuals with ABI - what is their perspective? what is meaningful to them?)

-Assessment/ observation of challenging behaviours (how and why - e.g. The importance of observing behaviours in neutral settings, identifying triggers and reinforcers, and keeping track of what works and what doesn't)

-Strengths focus (identifying strengths and challenges of the individual, and where possible building on strengths)

Consensus has almost been reached regarding the importance of the following intervention components. In brackets following each strategy the group consensus rate has been provided from Round 2. Please consider your response in the context of this group response.

Please rate each according to how important you feel it is within an intervention specific to behaviour management (1=Very important, 5=Not at all important).

25. Information about the link between ABI and mental illness (e.g. depression and anxiety)

(GROUP CONSENSUS - 73% = important)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. Behaviour management strategies (e.g. positive communication skills, antecedent behavioural approaches and Positive Behaviour Support [PBS] approaches, with a focus on positive reinforcement)

(GROUP CONSENSUS - 73% = important)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. Ongoing counselling/ support for families (e.g. peer support and support groups for family members, phone support when needed)

(GROUP CONSENSUS - 73% = important)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. Respite (regular and emergency respite provided in specialised units with well-trained staff)

(GROUP CONSENSUS - 64% = important)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. Accessing emergency support (clear guidelines on how/who/when to access support, ability to contact ABI trained professionals 24/7 in crisis)

(GROUP CONSENSUS - 73% = important)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. Support from (neuro)psychologist and/ or (neuro)psychiatrist (early, regular and responsive support)

(GROUP CONSENSUS - 64% = important)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

31. Information on current systems (e.g. how to obtain support when needed, how to work through government and non-government support systems, list of helpful resources in the community)

(GROUP CONSENSUS - 73% = important)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

In Round 1 participants identified a number of education components they thought should be included in a behaviour management program aimed at supporting family caregivers of individuals with ABI. You were then asked to rate each of these according to how important you feel it is within an education component specific to behaviour management.

Agreement was reached in Round 2 that the following intervention components are IMPORTANT in a behaviour management program:

-Possible cognitive and behavioural changes following ABI (including common changes and possible reasons for behaviour, including physical, social, emotional and psychological).

-Behaviour management strategies (e.g. positive communication skills, developing meaningful routines, information regarding Antecedent Behavioural approaches and Positive Behaviour Support (PBS) approaches, with a focus on positive reinforcement).

-Role changes after ABI (e.g. changes in family dynamics and how that impacts on the person with ABI and caregivers)

-Case studies/ examples (examples of strategies that people have found helpful in managing common challenging behaviours following ABI)

-Behavioural, cognitive and communication sequelae that can be prone to misattribution errors (e.g. reduced initiation = "they're just being lazy")

-Information on support agencies (what support and services are available, knowing when and how to access these services).

-What to do in a crisis (developing an emergency behaviour plan - knowing where to go and who to contact).

-Identifying triggers (potential physical, environmental and social triggers).

-Person-centred approach (importance of understanding individual with ABI, involving family - 'doing with' the family rather than 'doing to' or 'doing for')

-Self-care strategies (importance of family looking after themselves, strategies to keep safe and sane)

Consensus has almost been reached regarding the importance of the following education components. In brackets following each component the group consensus rate has been provided from Round 2. Please consider your response in the context of this group response.

Please rate each according to how important you feel it is within an education component specific to behaviour management (1=Very important, 5=Not at all important)

32. What is an ABI? (basic biology of ABI)
(GROUP CONSENSUS - 73% = important)

1

2

3

4

5

33. Grieving (understanding that individuals with ABI and families may be grieving their losses)

(GROUP CONSENSUS - 64% = important)

1

2

3

4

5

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

Feedback regarding the FDBM program

The Family-Directed Behaviour Management (FDBM) program consists of both an education phase and individualised intervention to support family caregivers in managing challenging behaviours following ABI.

Consensus has almost been reached regarding the suggested study format for the education phase. In brackets the group consensus rate has been provided from Round 2. Please consider your response in the context of this group response.

Please rate how effective you think the following format is likely to be (1=Very effective, 5=Not at all effective).

34. Face-to-face sessions every week plus follow up phone calls, supporting participants to work through the self-study modules. The issue identified with this format is the time commitment, and less flexibility in completing the workbook.

(GROUP CONSENSUS - 64% = effective)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

Individualised Behaviour Management Plan

Following the education component, family caregivers will continue to meet with the research team for approximately 1.5 hours weekly for an additional eight weeks to develop an individualised behaviour management plan. The research team will work with the family caregiver in a collaborative manner focussing specifically on the target behaviours identified.

Meeting with family caregivers for 1.5 hours weekly over eight weeks was agreed to be an appropriate length for this intervention. However, it was suggested that due to individual situations, some families may need longer and that the program should be reviewed after a few weeks. There was also concern that on top of a four-week theoretical model this adds up to a heavy time commitment by family.

Agreement was reached regarding the following suggestions:

-The intervention should instead be held for 1.5 hours fortnightly for six visits. This lessens the time commitment required by families, and a less intensive, longer lasting program might be better received

Consensus has almost been reached regarding the following suggestion. In brackets following each suggestion the group consensus rate has been provided from Round 2. Please consider your response in the context of this group response.

Please rate how important you feel this change is to the FDBM program (1=Very important, 5=Not at all important)

35. The intervention should be reviewed at week 10, 14 and 18 to stretch out the time for monitoring and adjustment

(GROUP CONSENSUS - 73% = important)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Behaviour Management following ABI in Community Settings: A Family Perspective (Round 3)

Thank you for taking the time to complete the second round questionnaire. Alinka Fisher will email you a summary of participant responses once they have been analysed.

You may be surprised that some of your suggested items were not included in this final round. When the Delphi process is complete you will have the opportunity to provide feedback regarding this. This information has also been included in the analysis, and will be represented in the thesis.

We sincerely value your participation.

APPENDIX 7

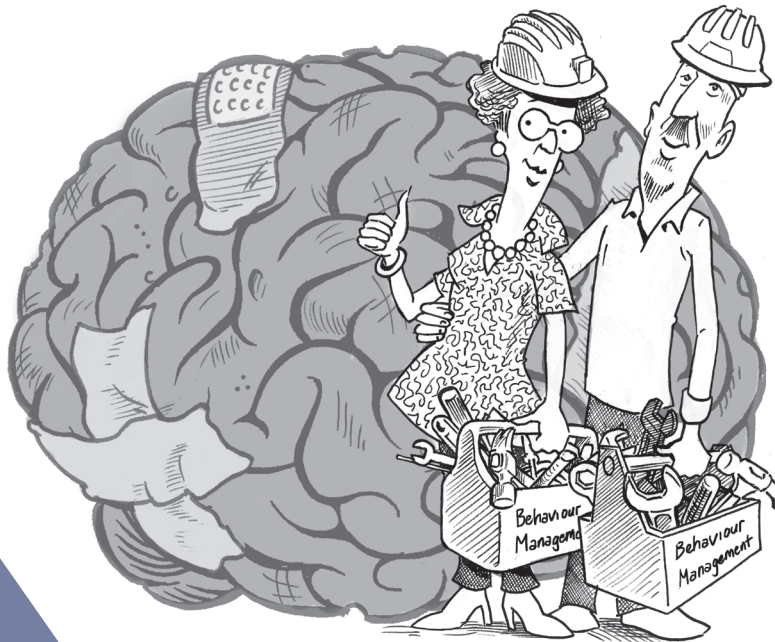
FDBM EDUCATION WORKBOOK



Flinders
UNIVERSITY



UNDERSTANDING & MANAGING CHALLENGING BEHAVIOURS FOLLOWING BRAIN INJURY



Alinka Fisher

The purpose of this workbook is to provide family caregivers with information regarding common behaviour changes following brain injury, and to introduce general principles of behaviour management that can be utilised within community settings.

This workbook is the educational resource for the **Family-Directed Behaviour Management (FDBM)** program. The FDBM program consists of an education component and individualised behaviour intervention, which together aim to empower family caregivers to better manage challenging behaviours following ABI in community settings.

The development of the FDBM program makes up part of the Primary Researcher's PhD project.

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Flinders University, Adelaide SA

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Medical Illustrations and Media
Flinders Medical Centre, Adelaide SA

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This research has been conducted according to the *NHMRC National Statement of Ethical Conduct in Human Research, 2007*, and has been approved by the **Royal Adelaide Hospital Human Research Ethics Committee** (Project Number R2015116). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on **8222 4139** or by email rah.ethics@health.sa.gov.au

IMPORTANT NOTE

If you are being confronted with high-risk behaviours, where the behaviour is presenting danger to you or your family member with ABI, please seek help immediately:

Domestic Violence Helpline (24 hours): 1800 800 098

Lifeline (24 hours): 13 11 14

Crisis Care (4pm-9am): 13 16 11

CRANA Confidential Support Line (for rural families) (24 hours): 1800 805 391

THANK YOU!

Thank you for participating in this program. We do hope you find the sessions helpful and look forward to your feedback.

YOUR INVOLVEMENT

You will be guided through this workbook over four weekly education sessions. These sessions will run for two hours, during which we will discuss common behaviour changes following brain injury and introduce general principles of behaviour management. You will be given the opportunity to apply this information to your individual situation, with the completion of activities being an important part of this process.

The time and location of these sessions will be finalised during your initial meeting with the Primary Researcher.

Follow-up phone calls will also be provided to discuss your progress. This will give you further opportunity to ask any questions you may have about the program and your involvement.

Once you have completed this four-week program you will continue to meet with the Primary Researcher for approximately 1.5 hours each fortnight for six visits to develop and implement an individualised behaviour management plan.



WEEKLY OVERVIEW

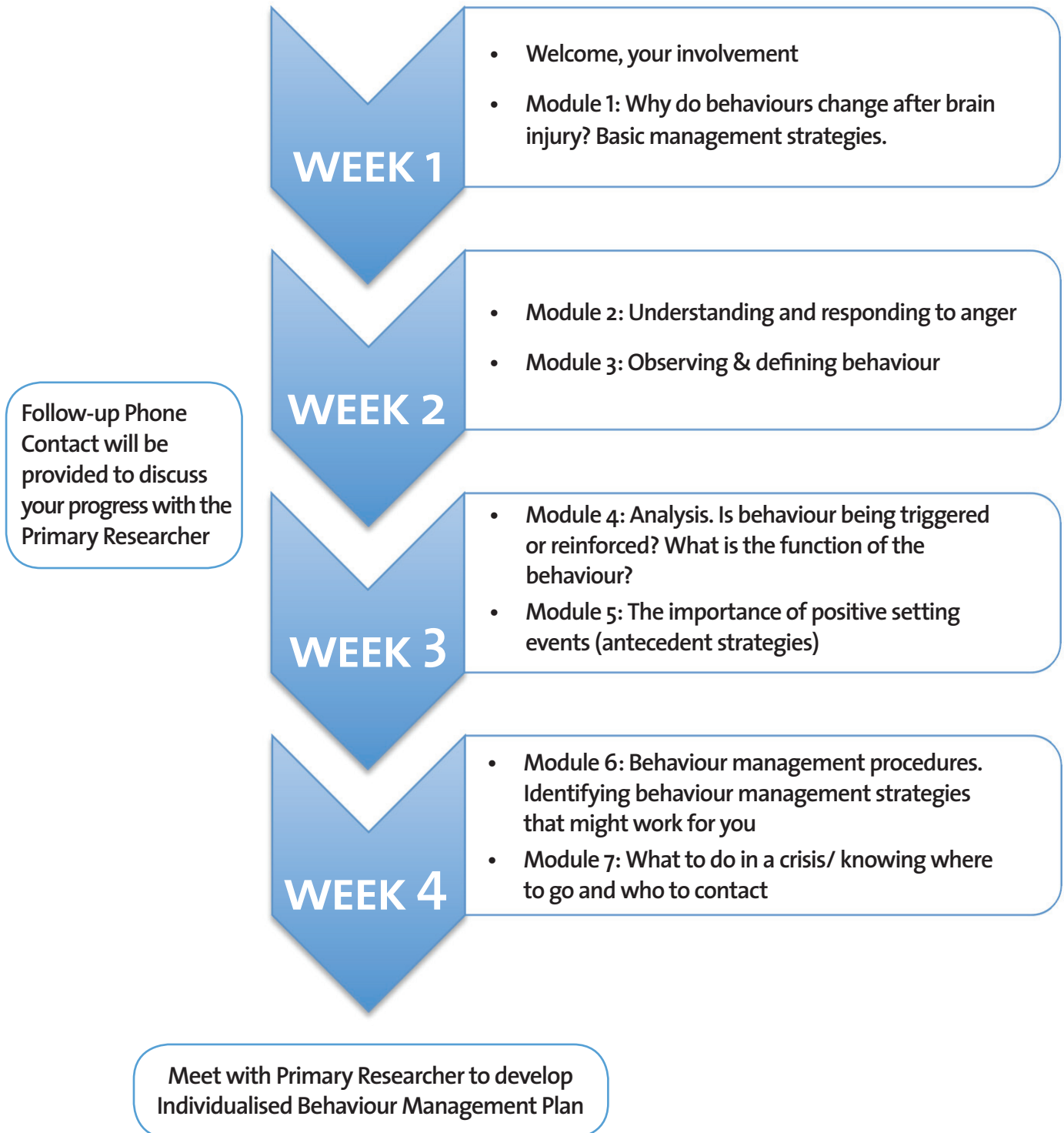
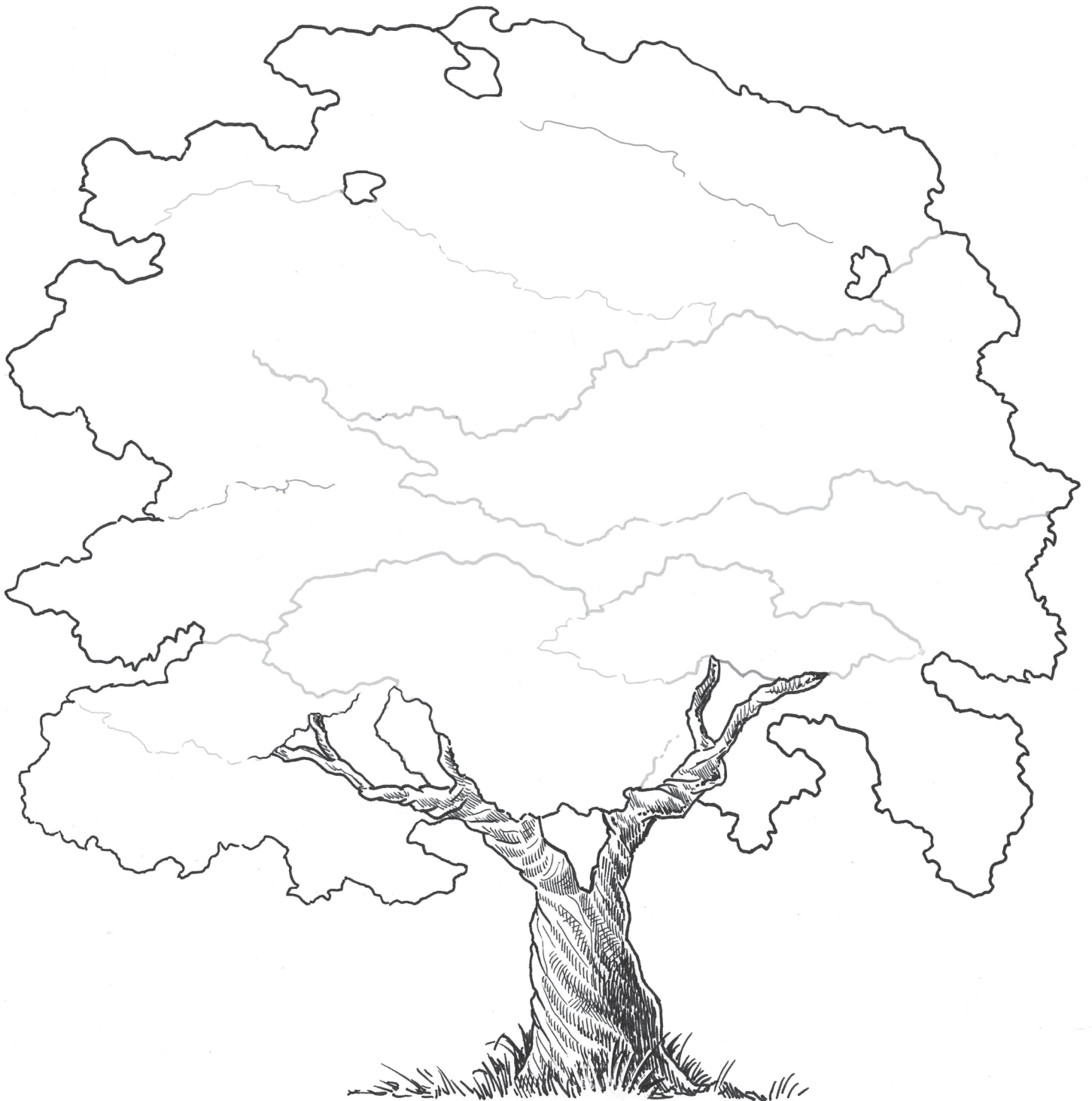


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THE STRENGTHS TREE

Let's first think about the strengths of your family member with ABI. What are their skills, talents and achievements? What is it about them that you love/admire?



MODULE 1

Why do behaviours change after brain injury?



Aim

During this module we will identify common behaviour changes after brain injury. We will also explore how damage to the brain and environmental factors may influence these behaviours.

Outcomes

On completing this module you should be able to:

- understand that behaviour is a product of physiological processes and external factors
- identify what behaviours you find challenging in your current situation, and what factors may be contributing to these behaviours

What are 'challenging behaviours'?



Behaviours deemed 'challenging' will vary between individuals, but may include:

- physical & verbal aggression (e.g. hitting, verbal abuse)
- sexually inappropriate behaviours (e.g. suggestive touching, flashing, sexual propositions)
- socially inappropriate behaviours (e.g. staring at others, using foul language, urinating in public)
- absconding (wandering off)
- apathy (lack of interest or concern)
- lack of initiation
- reduced social skills
- irritability
- mood disorders

Behaviours often become challenging when they are perceived to be of such intensity, frequency or duration that personal safety is at risk, or if the behaviour negatively influences relationships or community participation.

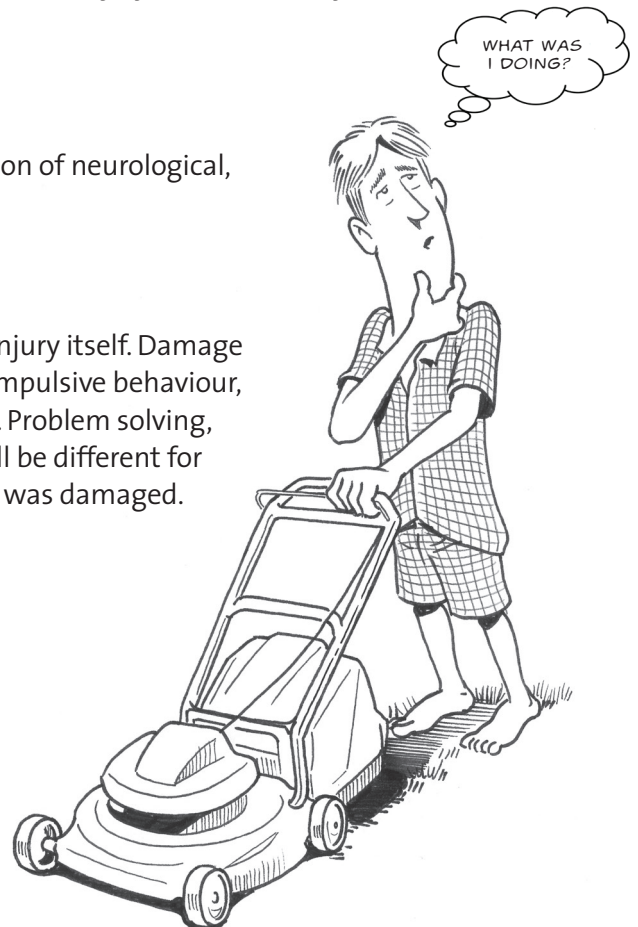
These behaviours may have been present before the brain injury, or only appeared afterwards. Coming to terms with and managing these can present unique difficulties for the individual with brain injury and their family.

Why do challenging behaviours occur?

Challenging behaviours often occur as a result of a combination of neurological, reactive and premorbid factors (from before the injury).

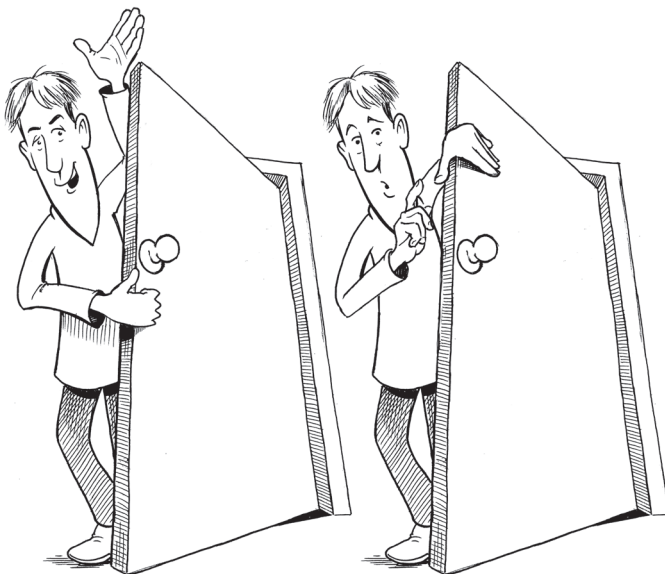
Neurological factors

Challenging behaviours are often a direct result of the brain injury itself. Damage to the brain can result in a wide range of changes, including impulsive behaviour, reduced tolerance, distractibility and cognitive difficulties (eg. Problem solving, learning, memory, decision-making and reasoning). These will be different for each individual, and will depend on where and how the brain was damaged.



What changes might occur as a result of the brain injury?

- Slowed information processing (delayed responses)
- Difficulty following a sequence of events (not knowing what happens next)
- Mental fatigue
- Short attention span
- Poor concentration
- Easily distracted
- Difficulty learning new things or remembering new information
- Difficulty working out how to do things (problem solving)
- Unable to think of a new solution (flexible thinking)
- May repeatedly refer to the same topic or keep returning to that topic
- May start something without considering options or consequences
- Thinking might be rigid and concrete
- Reduced empathy
- May take things literally
- May not pick up on social cues (e.g. understanding non-verbal cues – ie; someone hinting to finish the conversation)
- May be unaware of own limitations and have unrealistic expectations



The information provided here is a guide only. Each individual will display a different pattern of changes, with varying severity. One person may, for example, have a poor memory, minor problem-solving difficulties, but no change in their personality.



What changes have you noticed in your family member since their brain injury?

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Reactive factors

Apart from the brain injury itself, there are other factors which may affect the person's behaviour.

These may include:

- feelings of loss and frustration
- spending a lot of time attending appointments
- less contact with friends
- reduced income and the financial uncertainty of the future
- difficulty returning to work or finding work
- physical changes
- reduced independence and the need to rely on others for day-to-day activities
- pain
- fatigue
- other health issues (e.g. seizures, mental health)

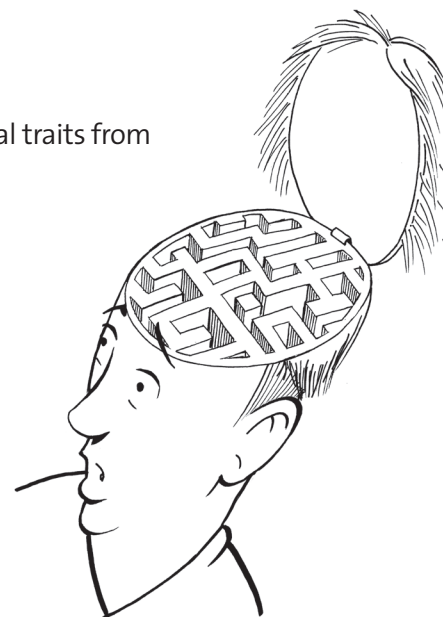


Premorbid factors

It is also important to consider the person's cognitive, social and behavioural traits from before the brain injury. These can also influence current behaviours.

For example what were their previous:

- problem solving skills
- personality and coping style
- interpersonal and communication skills
- levels of motivation
- experiences of substance use
- cultural factors



What specific behaviours do you have difficulty understanding or managing?
Please identify one of these to focus on during the following modules.

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Did these behaviours start occurring after the injury, or were they present before the injury?

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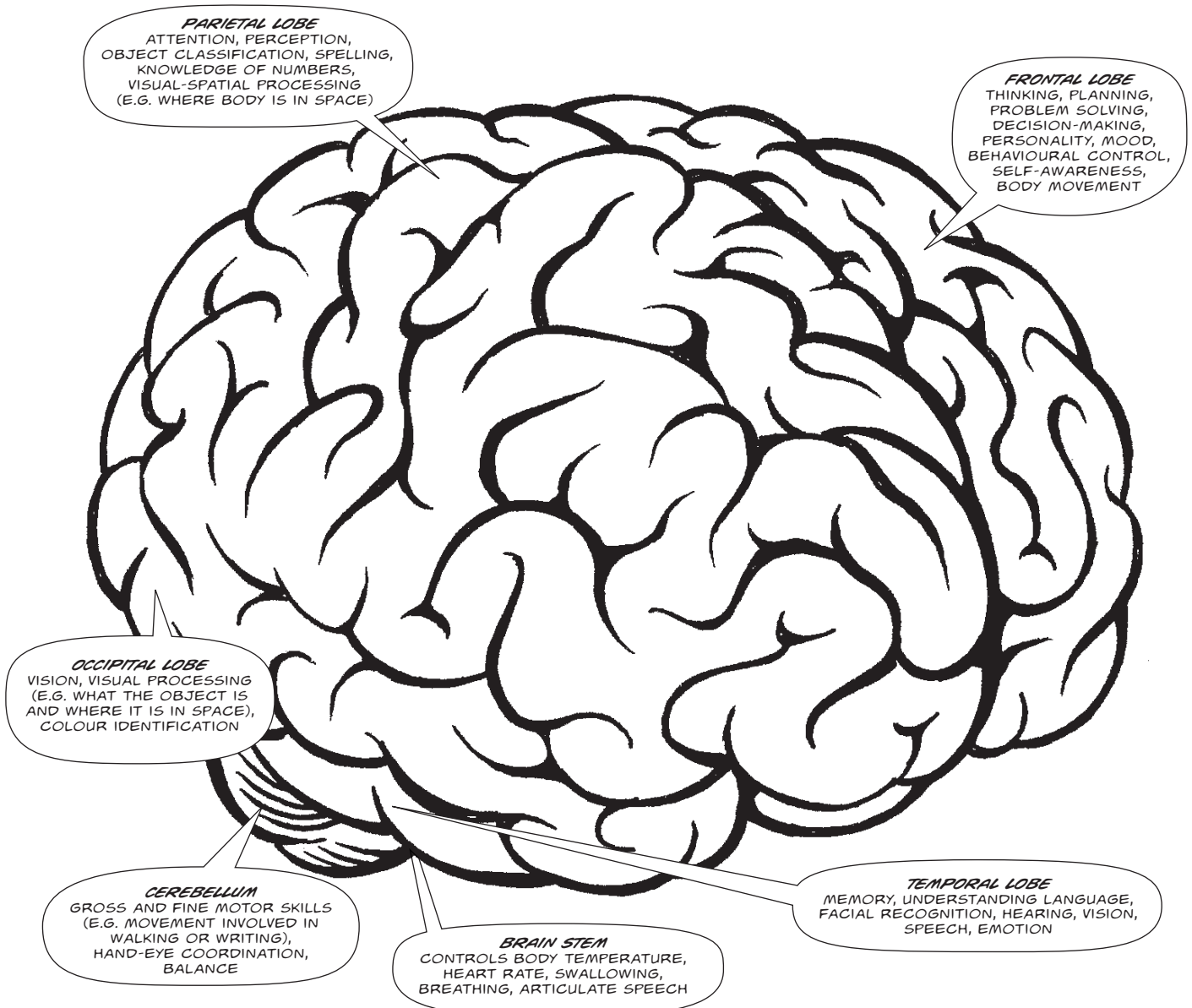
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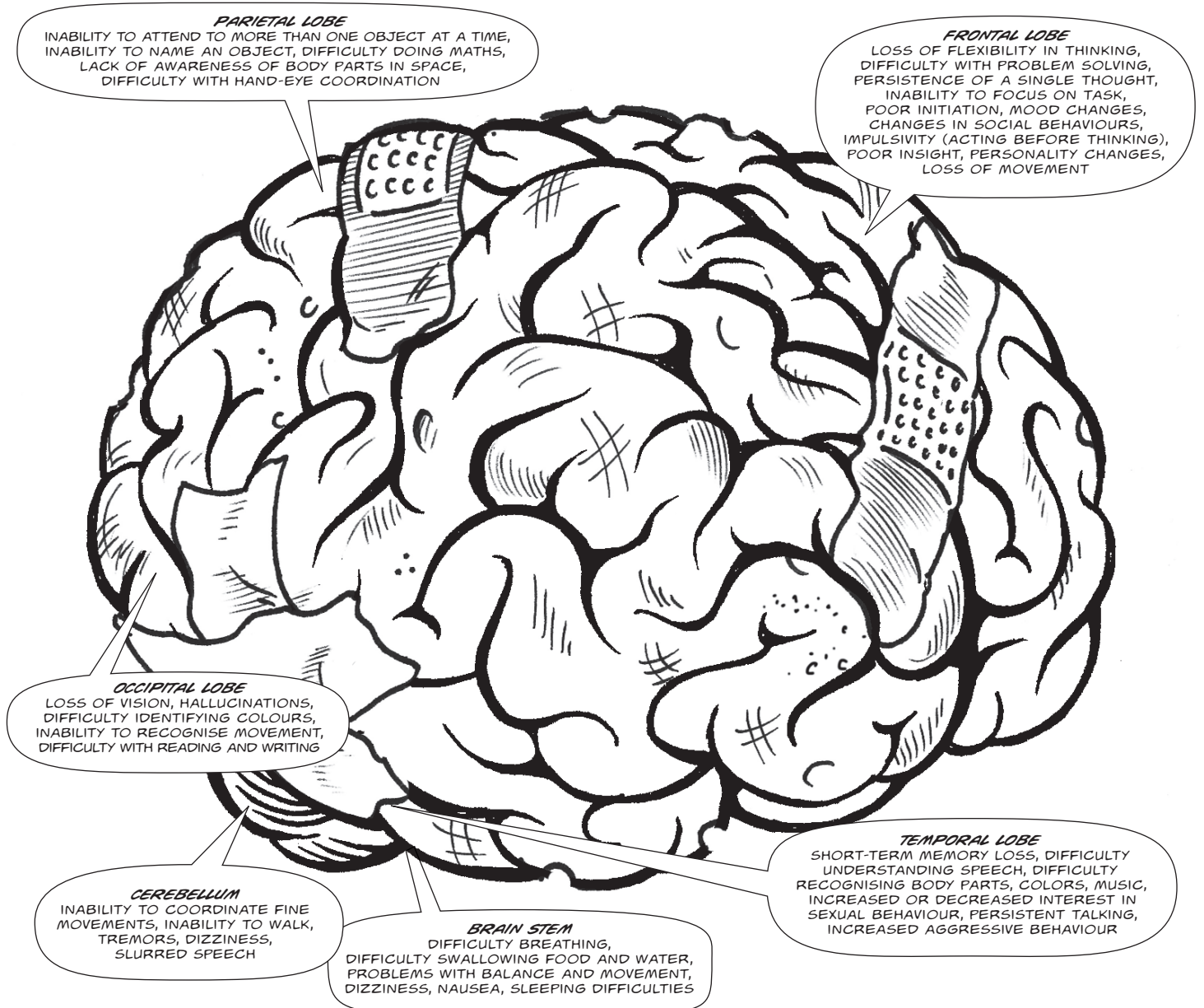
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The brain and its functions

This picture describes the main functions of different parts of the brain.



When the brain is damaged we may see the following changes:



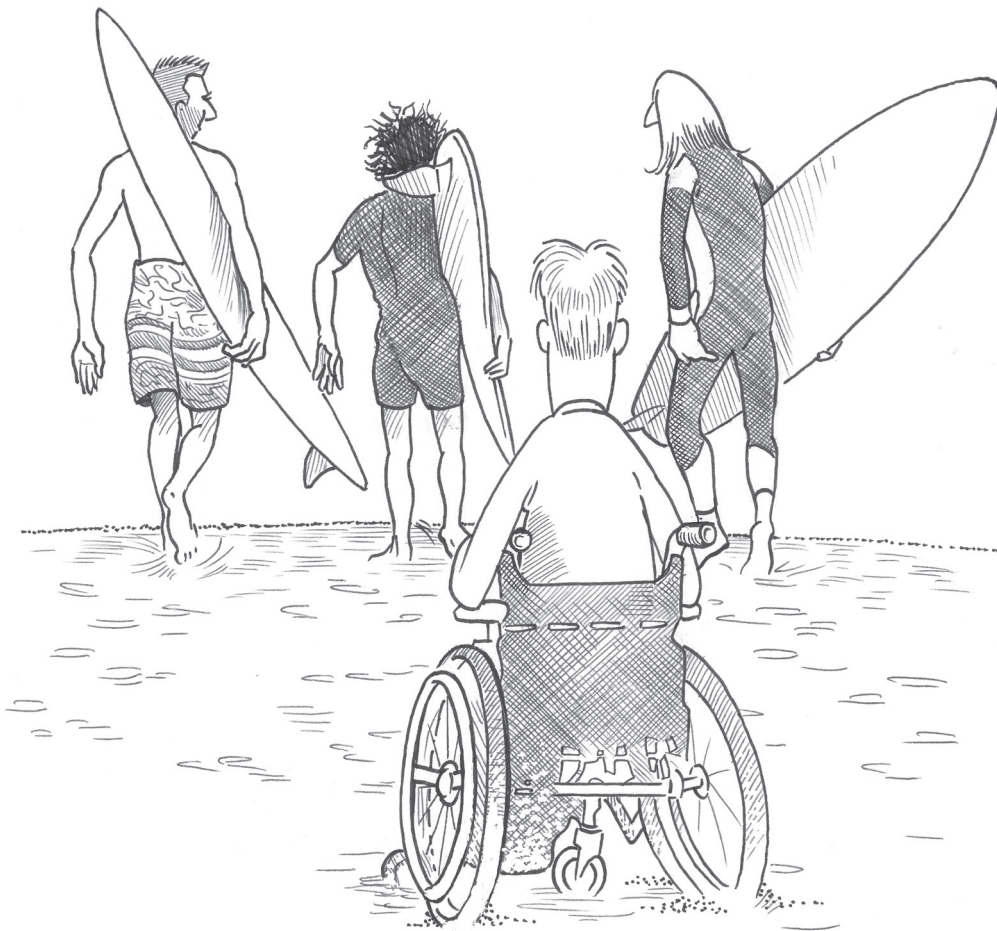
Temporary confusion and disorientation

In the early stages of recovery the brain may be severely damaged, causing the individual to be confused and disoriented. This can result in significant challenging behaviours.

In some cases long-term brain damage occurs. The frontal and temporal lobes, which play an important role in behaviour and emotions (see image on page 10), are particularly vulnerable to damage in traumatic brain injury (e.g. vehicle accidents and sporting injuries).

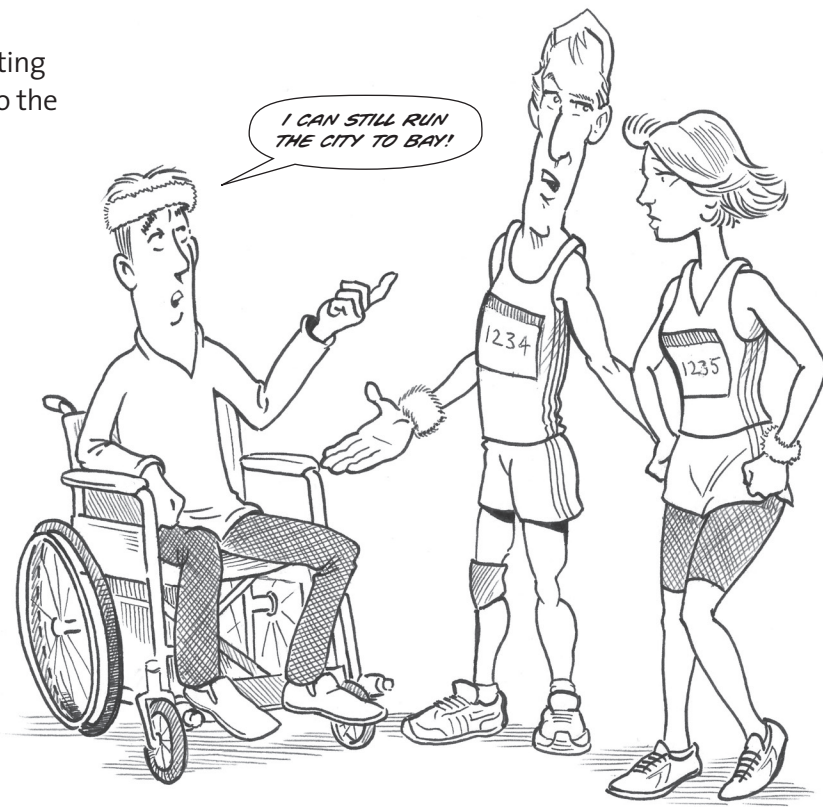
Adjusting to change after brain injury

A person with brain injury often has to adjust to cognitive and/or physical disabilities following the injury. They often go through a grieving process for the person they were and for what they have lost. As a result they may experience anger, resentment, depression, emotional lability (constant changing emotions), withdrawal, or loss of self-confidence.



Some people with brain injury try to cope by denying their problems.

This may lead to problems in accepting rehabilitation and reintegration into the community.



Other people may have difficulty with insight, and are unaware of their changed behaviour and the effects this has on those around them. This is due to damage to the frontal lobe, which affects their ability to monitor behaviour. This can improve overtime.

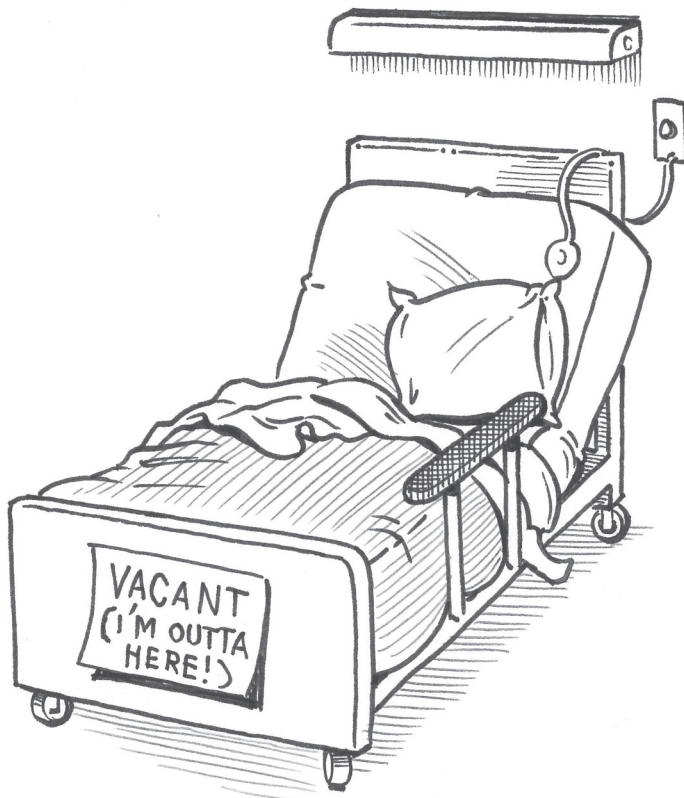
The person with brain injury may be unaware of their tactlessness or inappropriate behaviour.

People may not be able to monitor their behaviours and learn from their mistakes after brain injury due to reduced insight and memory difficulties.

And what about your adjustment?

Families also go through an adjustment and grieving process. This process will be different for every family, as you come to terms with the brain injury and are then faced with the challenges of managing changed behaviour within your home and community.

Your family dynamics before the injury will have an impact on how your family cope and adjust to changes following the brain injury. Your role in the family may change. Perhaps you will take on a more leadership role, taking on extra responsibilities. This may include increased pressure on your income, responsibility for transport, managing finances, making decisions and providing emotional/ practical support. Your loved one may also find it difficult coming to terms with this reduced responsibility and increased dependency. As you both learn to adapt to your new roles, there will be a period of adjustment.



The transition home may not be all that you'd hoped...

Although the transition home may be exciting, the person with brain injury may find it difficult to transition from the structured hospital setting to the less structured home environment. They may be slow to respond to change due to cognitive difficulties, and may be more easily disturbed by change to their routine.



The person with brain injury may become overwhelmed in crowded environments and may not tolerate noise.



Friends and family might find it difficult to understand and accept the changes in the person with brain injury (especially where there is not visible evidence of disability).

They may stop visiting, and the person with brain injury may feel isolated. This places further burden on family relationships.

We have discussed why behaviours might change after brain injury... so now what?

It is easy to become consumed with 'the problems'. Let's think of the positive attributes you identified in the 'Strengths Tree' at the beginning of Module 1, and separate the person with brain injury from their challenging behaviours

Whilst a particular behaviour may be undesirable or offensive, it's important not to make negative judgments about the whole person. Remember to focus on the individual's strengths, as well as their difficulties, and believe that there is capacity to replace the challenging behaviours you have identified with more adaptive ones.



Basic management strategies

There are a few strategies that we can use to minimise the impact of some of the common cognitive changes after brain injury.

We can:

- speak clearly, using short and simple sentences
- repeat information if necessary
- keep activities and instructions short and uncomplicated
- prompt individuals to the next step in a task (or before moving to the next activity)
- limit distractions
- identify achievable outcomes, ensuring there is a purpose
- keep the environment organised
- keep calm and in control, and avoid using emotional undertones (check that you are in the right head space when doing activities - is this the best time for *you* to be supporting behaviour?)
- allow plenty of time to do things - limit rushing

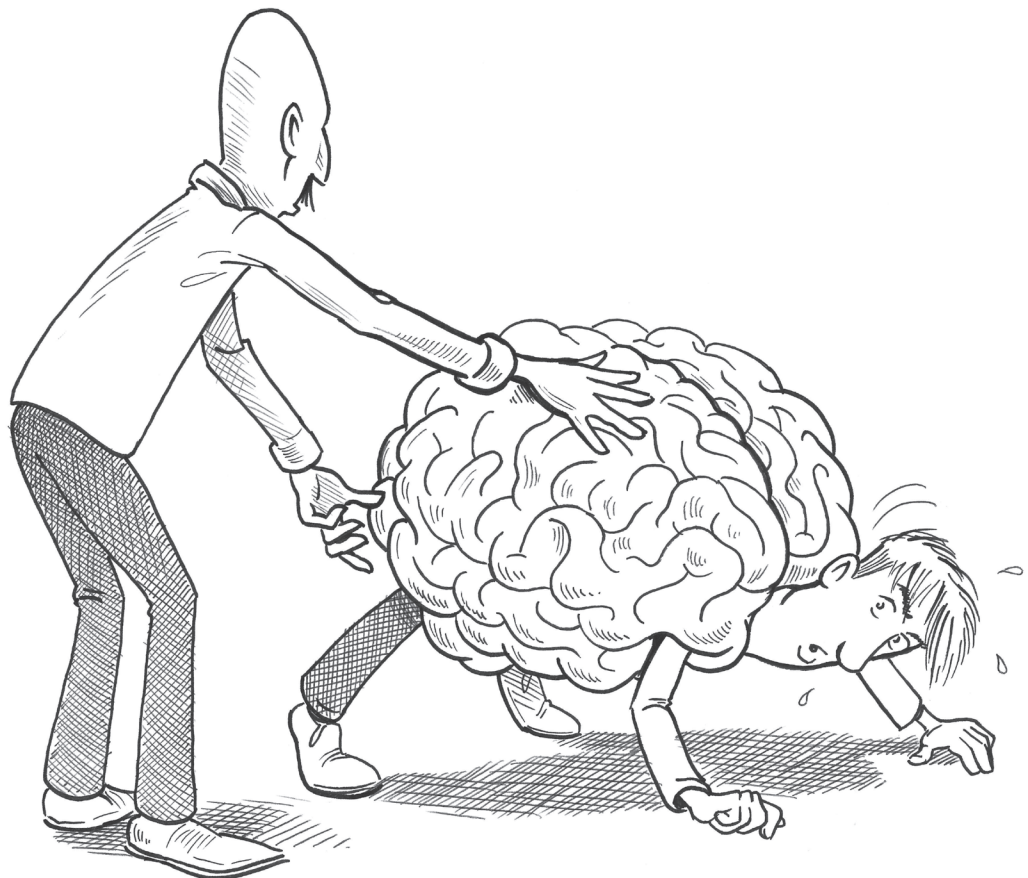


Overleaf is a more comprehensive list of management strategies that apply to specific cognitive changes after brain injury. Try not get too overwhelmed by all the strategies presented here, but rather see if any of these might be helpful in your situation.

Sometimes small changes in the way we respond and interact with a person may significantly change their behaviour. These strategies place importance on allowing time, setting achievable goals/tasks, reducing distractions and communicating in a clear manner (and repeating if necessary). This is not always easy and can take a lot of patience, however, if you keep calm and in control you will more likely see these behaviours reflected in the individual with brain injury.

It might help to circle the strategies that you think could be applied to your situation.

Remember you need to work together to better manage brain injury!



Speed of information processing

The person may:

- take longer to complete tasks
- take longer to answer questions

You can:

- give them extra time
- speak clearly
- present only one thing at a time
- try not to interrupt or answer questions for them
- check that they are keeping up with the conversation



Difficulty following a sequence of events

The person may:

- have difficulty following instructions
- lose track of what they are thinking/doing
- get information mixed up or become confused

You can:

- keep activities and instructions short and simple
- ask specific or direct questions
- provide prompts to the next step in a task



Fatigue

The person may:

- get tired quickly
- have reduced tolerance and ability to cope
- become irritable easily

You can:

- encourage them to take rest breaks
- schedule more demanding tasks when they are at their best (often in the morning)
- keep activities short



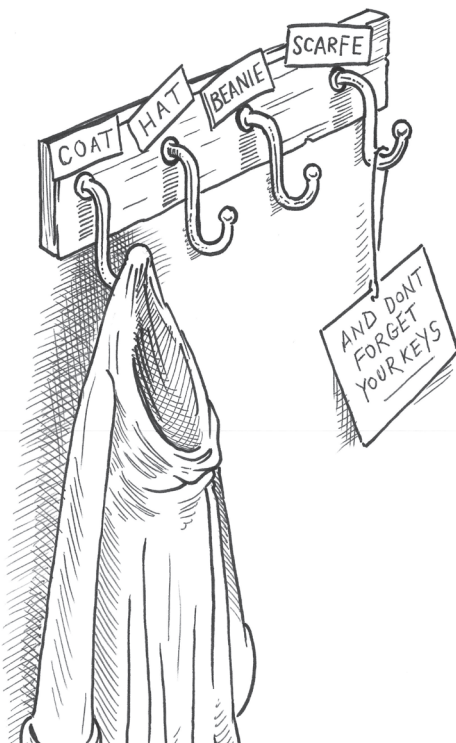
Attention

The person may:

- appear not to be listening
- miss details
- forget what people have said
- have difficulty concentrating
- be unable to cope with more than one thing at a time
- be easily distracted
- often change the subject
- get bored easily

You can:

- use short and simple sentences
- keep activities short
- ensure they write down important information
- encourage them to focus on one activity at a time
- reduce distractions (noise, other people)
- bring their focus back to task if they get distracted
- use different activities to maintain interest
- carefully select *when* you will ask for their attention (e.g. the time of day when they are most engaged)



Memory

The person may:

- have difficulty learning new things
- be forgetful (what people say, names, appointments)
- lose things
- have difficulty recalling what they have learnt

You can:

- repeat information as necessary
- encourage rehearsal of new information
- encourage them to use diaries, calendars, and timetables
- have 'special places' for belongings
- give reminders and prompts

Problem Solving

The person may:

- have difficulty working out solutions to problems
- be unable to generate new ideas

You can:

- help identify an achievable outcome for the task, making sure there is a purpose
- avoid giving open-ended tasks
- help them approach tasks in a more systematic way
- assist them to break tasks down into smaller components
- introduce one thing at a time – start simple



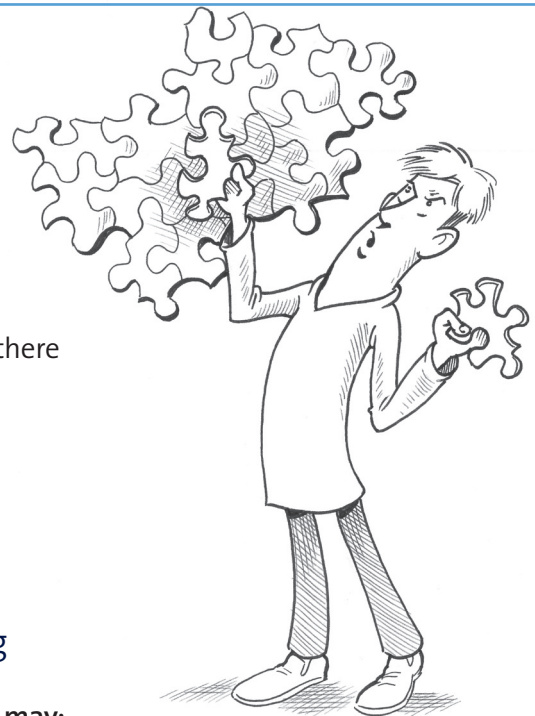
Flexibility

The person may:

- be unable to adapt to change
- become 'stuck in a rut' unable to develop new strategies
- persist with incorrect/ inefficient methods despite feedback
- repeatedly refer to the same topic or return to that topic

You can:

- help them to identify initial signs of frustration and recognise that this is a time to stop what they are doing
- provide alternative ways of completing a task so a choice is available
- direct them to another activity if they are continually making errors
- if they are talking off topic, direct them back to task by asking a specific question



Reasoning

The person may:

- have rigid and concrete thinking
- take statements literally
- be unable to "put themselves in another's shoes"
- be resistant to change
- not understand complex emotions
- show poor judgment and decision-making skills

You can:

- use simple language and avoid abstract terms (e.g. using metaphors)
- explain changes in routine in advance, giving reasons
- if issues occur, think about timing and communication approach (e.g. talk about it later when they are calm)
- avoid using emotional undertones (e.g. say 'yes' but clearly mean 'no')



Planning and organising



The person may:

- have difficulty preparing for a task
- be unable to work out the steps or sequences involved in a task
- not consider the consequences of their actions
- have difficulty organising their own thoughts and explaining things to others

You can:

- encourage them to consider what they are about to do before starting an activity
- provide a written structure or guideline outlining the steps in order
- give them prompts
- help them to develop a timetable (weekly/daily) to establish a routine
- keep the environment organised so things are always in the same place
- encourage them to take time to think about what they want to say

Insight

The person may:

- be unaware of their cognitive and physical limitations
- set unrealistic goals and expectations

You can:

- provide explanation why a proposed action (not their own plan) is useful, and reason through the steps (small steps, start gradually, etc.).
- help to identify realistic goals – these might be smaller components of a larger plan, but more achievable

Self-monitoring

The person may:

- often break rules
- not realise they have made errors because they have not checked their progress
- 'hog' conversations
- keep talking when others are no longer interested

You can:

- reinforce specific requirements of an activity
- encourage the person to check over how they have performed
- immediately provide feedback when errors occur or when they talk too much
- use signals, which have been agreed to in advance, to let them know when they are talking too much
- encourage turn-taking in conversations





Did you see any strategies here that might be helpful in your situation?

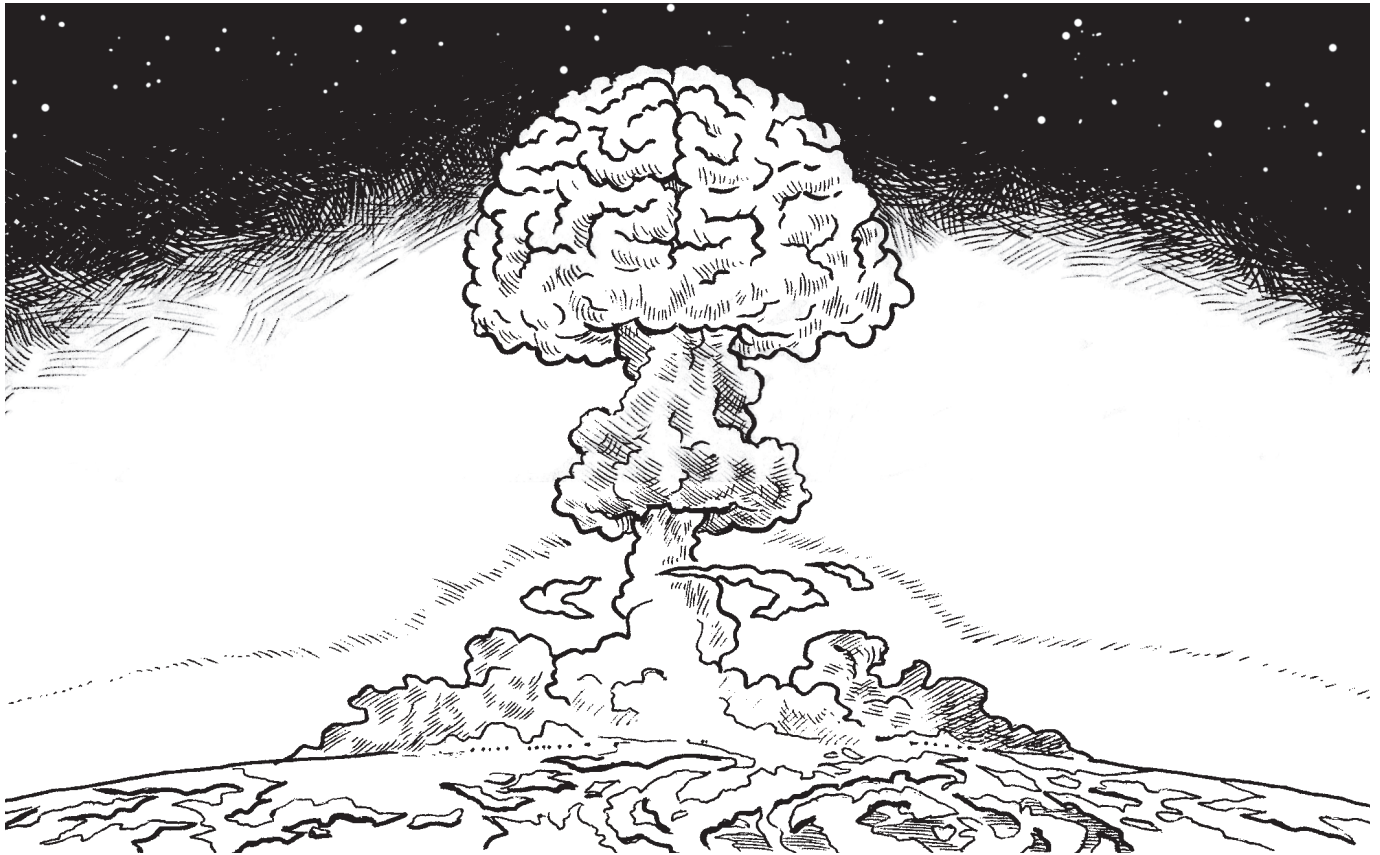
Reflect on how you currently manage challenging behaviours, and how you may be able to apply some of these strategies?

A series of 20 horizontal dotted lines provided for writing notes or reflections.



MODULE 2

Understanding and responding to anger



Aims

During this session we will identify important factors in understanding and managing anger.

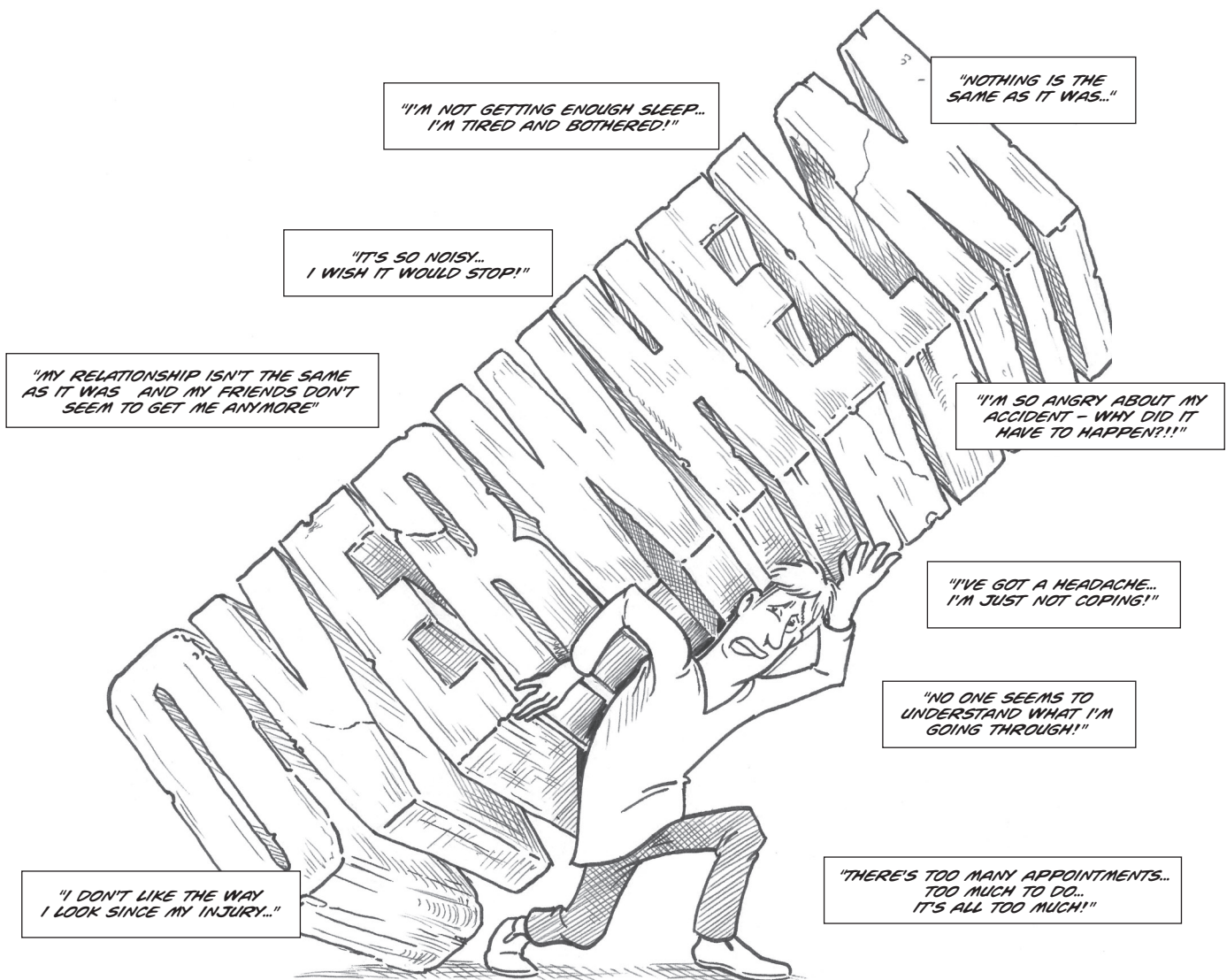
Outcomes

On completing this module you should be able to:

- identify early warning signals that an individual is becoming irritated/ angry
- recognise potential triggers of anger
- explain how your own behaviour can exacerbate a difficult situation
- understand the concept of 'anger as a secondary feeling'

Why do people get 'angry' after brain injury?

Anger problems may be a direct result of the brain injury itself, but may also be triggered by other cognitive changes including reduced self-control, impulsivity and lowered frustration tolerance. Issues of sleep deprivation, pain, changed image, changed routine and feeling misunderstood, may also trigger anger problems.



It is important to be able to:

- identify potential triggers of anger
- identify 'early warning signals'
- recognise your feelings and
- have strategies for managing anger

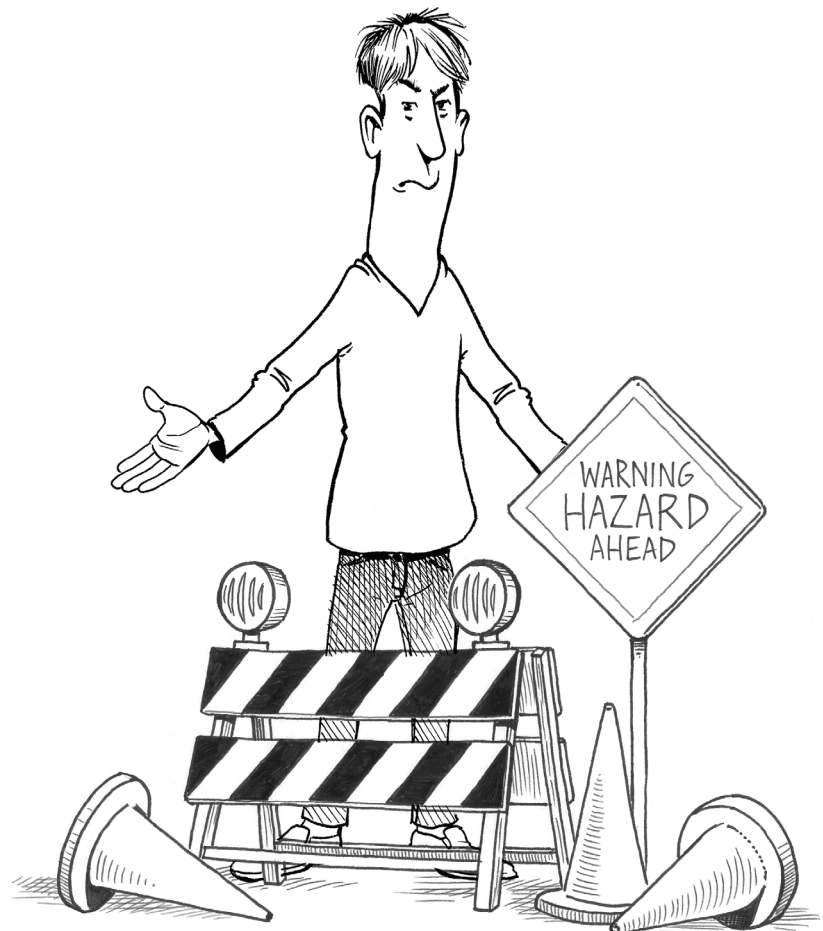
How do we identify the triggers?

Often visible changes occur as a person becomes angry (physical, emotional and/or cognitive). If we can identify these changes early enough (i.e. before the person loses their temper) we can use them as an 'early warning system'.

The following changes are often used as guideposts to alert a person that they are becoming angry.

Physical	Emotional	Cognitive
Muscle tension Temperature change Tremor/shaking Sweating Heart pounding Clenched fists	Irritated Frustrated Moody Unsettled Feeling upset	Changes to thoughts include: Racing Jumbled Irrational Jumping to conclusions

(TBI Staff Training: Martin, 2011)



Anger might be a secondary feeling

Anger can be a secondary feeling, and if so, dealing with the initial feelings may eliminate the 'anger response'.

- Pain
 - Frustration
 - Disappointment
 - Fear/ anxiety
 - Fatigue
 - Fear
 - Guilt
 - Embarrassment
 - Humiliation
- } Anger



When thinking about how people with brain injury can change from being calm to being angry or aggressive it is useful to think about triggers and responses.

A **trigger** is something that causes a reaction in the person (behaviour), and the **response** refers to the reaction to the behaviour.



We should intervene at this point before behaviour escalates

First check that you are in the right head space to intervene





Can you identify triggers of anger in your situation? And how you/or others respond to this behaviour?

<p>Triggers: e.g. being asked to have a bath</p>	<p>Behaviour →</p>	<p>Responses: e.g. let him keep watching t.v. and try asking again in the morning</p>
-------------------------------------------------------------	--------------------	--------------------------------------------------------------------------------------------------

If you can't think of any right now, don't worry. Perhaps this week you can try identify some of the triggers and responses to behaviours and fill this out then.

It is also important to recognise YOUR Feelings

Remember that the behaviour is not necessarily directed at you.

Why you?

Proximity (you are the closest person to them)

What are you feeling?

It is important to recognise and identify your feelings



How do you feel when your loved one becomes angry (if applicable)?

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.....

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.....

.....

What should you do about your feelings...?

- Accept your own feelings about the situation
- Talk to family, staff and friends and discuss how you are feeling
- Recognise that you are only human and that you can also be affected by stress, frustration and anger
- Use stress and anger management strategies yourself





How do we manage anger problems?

In any difficult situation it is important to maintain focus on the underlying issues, not the behaviour.

Below is a more comprehensive list of strategies for managing a situation that is escalating. These strategies place importance on:

- remaining calm
- walking away/removing yourself from situations temporarily (if safe/appropriate to do so) to regain composure
- using non-threatening/relaxed body language and tone
- taking slow deep breaths/using a deep breathing technique
- discontinuing a conversation/discussion that is causing a negative emotional reaction in you or the person
- avoiding making the problem worse with the use of alcohol or drugs to 'cope'

What if the behaviour is escalating...?

a) Keep calm and in control of yourself

- Avoid mirroring behaviour (e.g. yelling in response to someone being verbally aggressive)
- Controlled breathing (take deep slow breaths)
- Control voice (speak with a calm tone)
- Use non-intimidating body language

b) Maintain a safe distance

- Make sure you are standing outside of hitting and kicking distance (approximately 1 metre away from the person)

c) Use non-confrontational body language

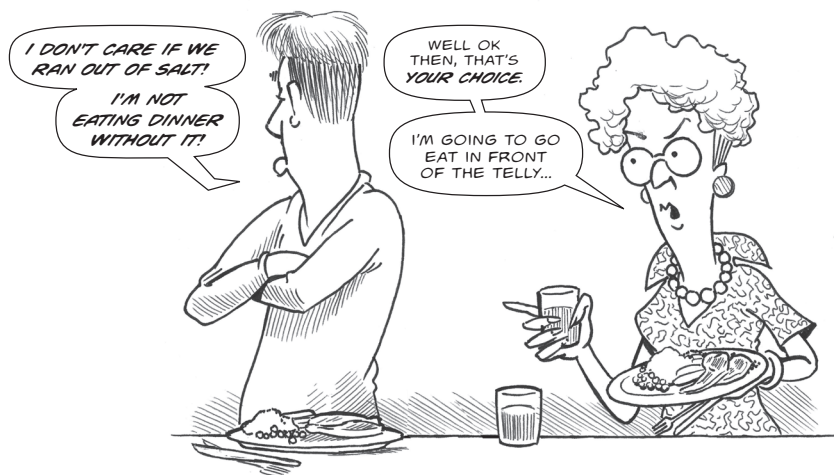
- Keep hands open and in full view
- Stand slightly at an angle to the person
- Avoid staring or standing with your hands on your hips
- Avoid making fast movements

d) Think about the situation

- Is there anything reinforcing the behaviour? (e.g. things in the environment or responses to the behaviour)
- Is there anything frightening the person?
- Is there anything frustrating the person? do they have any unmet needs?
- Are they being over or under stimulated?

e) Decide on an intervention (how to respond to behaviour)

- This might include negotiation, leaving, no action, surprise, distraction, humour, isolating individual, removal of other people from situation, asking for help and self defense (only to be used if under attack / as a last resort)



f) Is the intervention working? Decide on the next step

- If the intervention is not working, you might decide to modify or change your response (for example, if you try to negotiate without success you might feel it is best to remove yourself from the situation).

g) Managing after a crisis

The body's normal reaction to stress is a build up of tension. Tension can be released by:

- relaxation / breathing techniques
- physical activity (physical release)
- talking, laughter, crying (emotional release)

Things to avoid

- Self-administering drugs/ overuse of prescribed medication
- Using alcohol, caffeine or cigarettes
- comfort eating

Things to remember

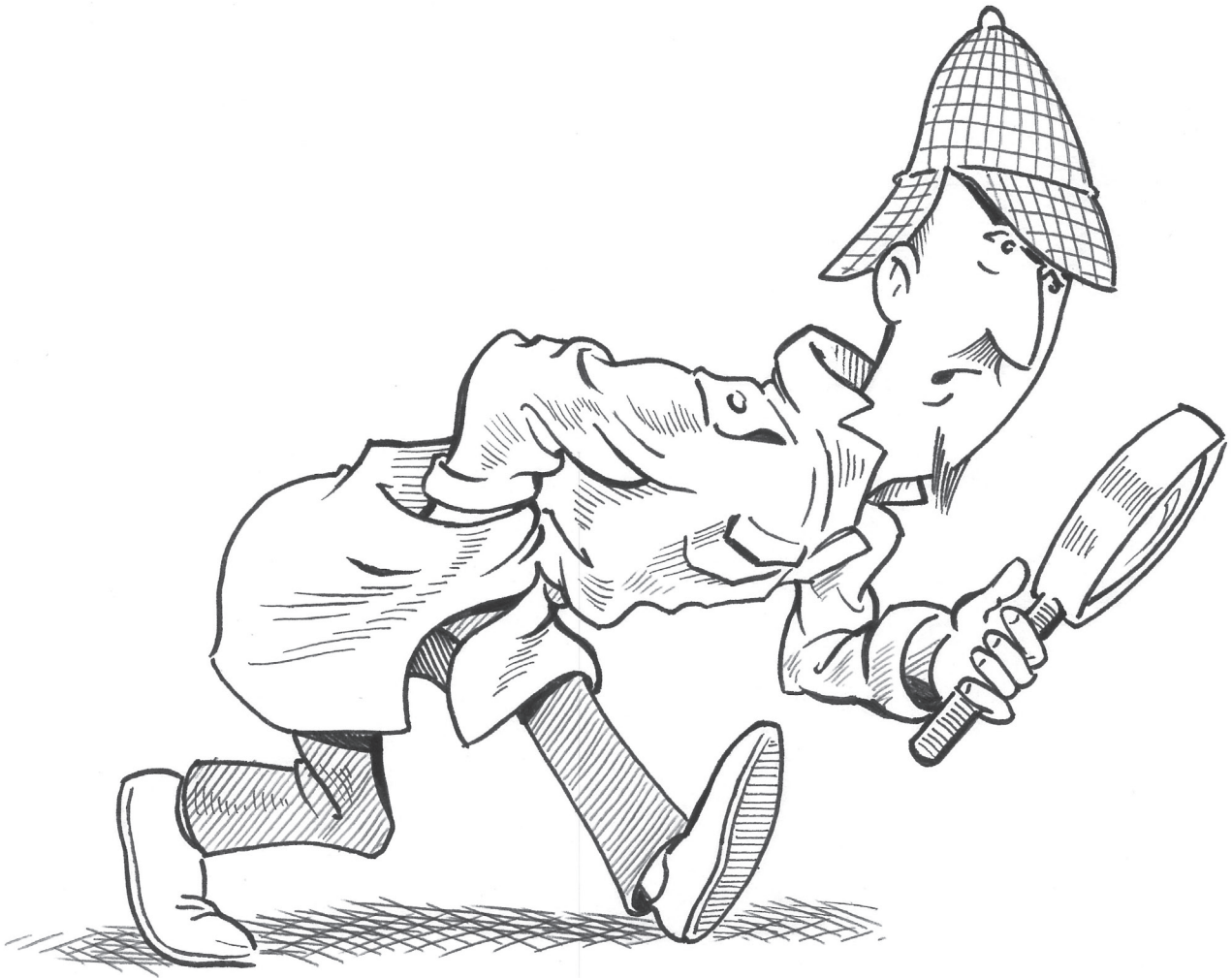
- After any crisis, it is normal for a person to experience an emotional or physical change
- don't label yourself as crazy
- avoid making life-altering decisions within a few weeks of the crisis



LOOKING FORWARD

MODULE 3

Observing and defining behaviours



Aim

During this session we will discuss the importance of observing and recording behaviours.

Outcomes

On completing this module you should be able to:

- understand the importance of clearly defining challenging behaviours
- know what to be looking for when observing behaviours
- describe the behaviours you identified in Module 1 in observable terms

We also need to think about:

- **environmental factors** (e.g. excess noise, over-crowding, appropriateness of environment)
- is the individual treated with **respect**?
Do they have **choices**?
- are they able to **communicate effectively**?
- would they benefit from being taught **coping skills** (e.g. relaxation etc)?



Many of these factors can be recorded through careful observation of the individual. This may reveal patterns of when the behaviours are most likely to occur, in which environment, and in whose company.

If possible, you should also make contact with others who may have been involved in managing challenging behaviour in your loved one (other family members and/or service providers), and find out what strategies have been tried in the past, and what *did* or *didn't* work.

So, what is the behaviour that needs managing?

Before planning an intervention, we need to clearly define the behaviour we want to 'manage'. An accurate and objective picture (not influenced by personal opinion) of the behaviour is best obtained by careful observation and recording.

A clear definition of the behaviour should be recorded in observable terms (exactly what you see).

Not helpful	Helpful
"Bill had an aggressive outburst"	"Bill punched his brother on the cheek with a closed fist"
"John was sexually inappropriate"	"John touched the breast of a female support worker"

When recording behaviours we should avoid ambiguous terms, such as "aggressive", "sexually inappropriate", or "disinhibited". This will ensure agreement as to the exact nature of the behaviour, leaving no room for interpretation.

Consider the following example:

Nathan was eating dinner at the dining room table. He bit his tongue and suddenly turned and grabbed the arm of his mother who was sitting next to him. His nails caused minor bleeding and the force of this action caused significant bruising.

What would best describe this behaviour?

- a) Nathan became aggressive towards his mother.
- b) Nathan firmly grabbed his mother’s forearm, causing minor bleeding and bruising.

Remember, it is important to describe behaviour clearly, leaving no room for interpretation.

The answer (a) above is too ambiguous, stating Nathan’s general mood, without explicitly stating what behaviour occurred.



Consider the behaviours you identified in Module 1: are these behaviours clearly defined? If not, try and think of a situation when these behaviours occurred, and describe them in observable terms.

You may need to observe these behaviours again to check that your description is accurate. If an episode of challenging behaviour has variations (e.g. sometimes the individual pulls their hair violently and kicks nearby objects, and at other times pulls their hair violently and then throws nearby objects), make sure you state this clearly.

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MODULE 4

Analysis... what it all means.



Aim

During this module we will discuss antecedents (what happens directly before a behaviour occurs) and consequences (what happens directly after a behaviour occurs), and start identifying whether challenging behaviours are being reinforced.

Outcomes

On completing this module you should be able to:

- start analysing behaviours by examining the role of antecedents and consequences
- be able to identify possible triggers of target behaviours

What is the purpose of the behaviour...? Why does it occur?

Throughout this module we will identify the function ('purpose') of the behaviour you have identified, and other reasons why the behaviour might be occurring. This might include antecedents and consequences.

Antecedents refer to what happens directly before the behaviour occurs, triggering a response. For example, you might observe that directly before the behaviour occurred there was a transition to a new activity. This 'transition phase', which might involve the individual being asked to change activities, would be referred to as the 'antecedent'.

By identifying the antecedent we can sometimes see what type of replacement behaviour may be appropriate. For example, if an individual becomes aggressive each time they are asked to try something new, it might be appropriate to teach them how to verbalise their concerns/ fears.

Antecedents are very important when designing interventions for people with brain injury, as individuals often have challenges in understanding and processing information.

Consequences refer to what happens directly after the behaviour has occurred. So, for example, Jane receives a phone call from her friend who says she can no longer come over for dinner (antecedent), Jane then becomes upset and begins crying and bangs her head against the wall (behaviour), which is followed by her mother giving her a hug and offering to take her out to her favourite restaurant instead. Jane calms down and is happy with this alternative (consequence). Also see the example below.



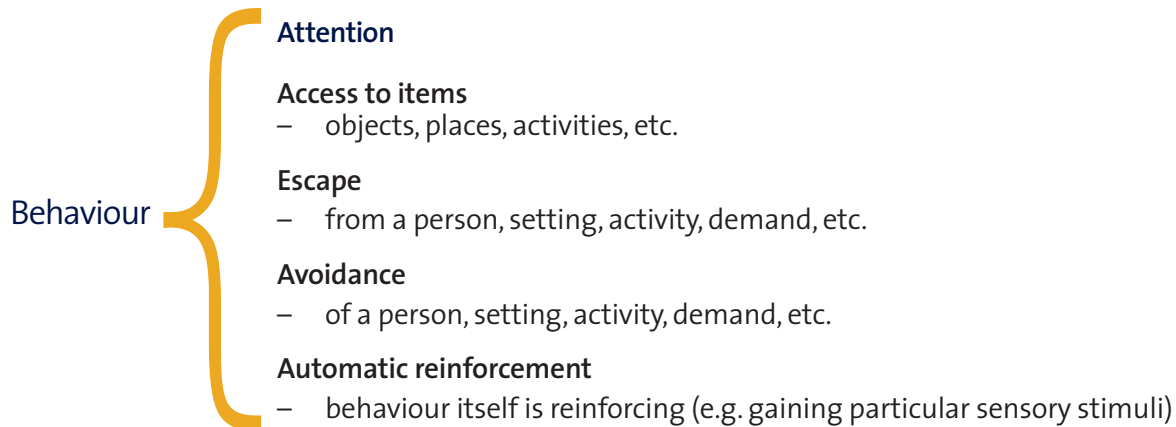
In this situation, the behaviour appears to serve an important function: to avoid having to stop playing his computer to have dinner. Its function in this situation is successful.

Identifying the 'function' of challenging behaviours is not always so easy; however, this example helps us to start thinking of behaviours as having a purpose.

Once we can identify the desired function of a particular behaviour, we can start looking at what might be reinforcing the behaviour. We may also see what more acceptable behaviours might serve the same purpose (e.g. an individual starts yelling when he gets bored, which results in a caregiver's attention the individual learns skills to request attention or change of activity without yelling).

This is an important first step in developing an effective behaviour management strategy.

Let's consider the different functions of behaviour below:



The two main causes of challenging behaviours after brain injury are:

1. Difficulty controlling (self-regulating) behaviour due to the direct result of a person's brain injury (e.g. reduced tolerance)
2. A learned response, which has been reinforced in a person's environment (e.g. If I yell I get what I want).

These factors will be discussed further in the following Modules.

Let's identify the antecedent, the behaviour, and the consequence in the following example:

Before her stroke, Jessica was a very good cook. She is still able to complete basic tasks in the kitchen but she now finds it difficult to get started. Her mother visits daily to assist her with everyday tasks such as cooking, cleaning and showering. Jessica's mother has particular difficulty getting her to help prepare dinner. One night, when her mother asked Jessica to peel the potatoes for her dinner, she swore at her and threw a potato across the room. Her mother became very upset and didn't know what to say to Jessica, so continued to peel the potatoes herself.

Antecedent: Jessica's mother has asked Jessica to peel potatoes for her dinner

Behaviour: Jessica swears at her and throws the potato across the room

Consequence: Jessica's mother finishes peeling the potatoes

Relevant information: Jessica is quite capable of doing this task but has poor motivation. Her mother is less likely to ask Jessica to do tasks. Jessica learns that she can avoid tasks by swearing and throwing objects.

Would you agree with the information presented here?

Let's now consider the following example.

Can you identify the antecedent, the behaviour, and the consequence?

Bill, aged 50 years, sustained a brain injury when he fell off a ladder while pruning trees in his garden. He lives at home with his wife Kate and they have a small group of friends who they see regularly. Since his injury, Bill does not like to visit friends as much, while Kate still enjoys socialising. On one occasion when they were invited to a friend's house for a BBQ, Kate and Bill had an argument due to Bill's reluctance to attend. Kate insisted that they go as she felt she needed to get out and talk to other people. During the course of the BBQ, Bill started to make inappropriate comments about their sex life. Kate was horrified and quickly made an excuse for them to leave early.

Antecedent:

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Behaviour:

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Consequence

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Once you have completed this activity, you can look at the suggested answers on the following page. If you do not feel confident in identifying antecedents, behaviours and consequences, please discuss this with the Primary Researcher.

Suggested answers – Identifying the antecedent, behaviour and consequence for Bill

Antecedent: Bill feels he has been ‘forced’ to attend the party. Kate is talking to their friends and enjoying herself

Behaviour: Bill begins to make comments about their sex life

Consequence: Kate makes an excuse for them to go home early

Relevant information: Bill did not feel like visiting their friends. He wanted to stay home with Kate.

Kate may become reluctant to visit friends with Bill and goes out less often herself. Bill learns he can spend more time at home with Kate and avoid seeing friends by talking about their sex life in public.

It is not always easy to identify what triggers behaviours, which highlights the importance of recording your observations. This will often show a pattern in behaviours, and possible triggers.

What to observe?

When observing behaviours it is important to take note of:

- the environment/ setting
- time
- who was present
- the antecedents and consequences (is something reinforcing the behaviour?)

This will be discussed in more depth in the following modules.

An **Observation Sheet** has been attached (page 45). This week, we will be using this checklist to identify when your identified behaviour/s are occurring.



LOOKING FORWARD

OBSERVATION SHEET

Name of person observed: _____ Observer: _____

Target behaviours: _____

Date	Time	What happens before the behaviour? (Antecedent)	Behaviour	What happens after the behaviour? (Consequence)	Possible Function (purpose of behaviour)/ Comments
15/10/15 (EXAMPLE)	10am	I asked Jane to help with the dishes	Jane picked up her plate and threw it on the floor. She then left the room to her bedroom	I gave her some time in her room and cleaned up the broken plate. We continued with daily activities when she returned we didn't speak of the incident	Avoiding helping with dishes. To let me know she was angry with me? I was irritable which she may have picked up on

Weekly Routine							
Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7:30-9:30am							
9:30-11:30am							
11:30am – 1:00pm							
1:00-3:30pm							
3:30-6:00pm							
6:00-8:00pm							
8:00-10:00pm							

In Module 5 we will discuss the importance of positive setting events (antecedent strategies) in behaviour management interventions for people with brain injury. We will also start identifying what management strategies might work for you.

Make sure you take note of any questions you have, as sometimes behaviour management strategies sound more difficult than they really are.

IMPORTANT NOTE

If you are being confronted with high-risk behaviours, where the behaviour is presenting danger to you or your loved one with ABI, please seek help immediately

Domestic Violence Helpline (24 hours): 1800 800 098

Call Lifeline (24 hours): 13 11 14

Crisis Care (4pm-9am): 13 16 11

CRANA Confidential Support Line (for rural families) (24 hours): 1800 805 391



MODULE 5

Creating a positive environment (antecedent strategies)



Aim

During this module we will discuss the importance of creating a positive environment (antecedent strategies) to manage challenging behaviours following brain injury.

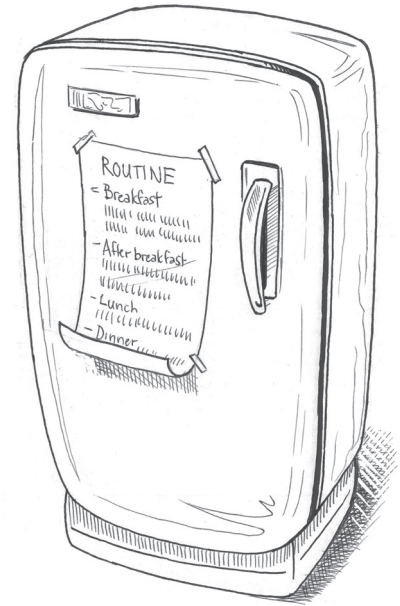
Outcomes

On completing this module you should be able to:

- understand the importance of creating a positive environment for your family member with brain injury, including environment changes, routines and meaningful activities
- start thinking about why your identified challenging behaviours are occurring and what antecedent strategies might be helpful

As discussed in previous modules, people with brain injury often face difficulty with information processing. It is for this reason that antecedent strategies (e.g. environmental changes and identifying warning signals/ triggers) are critical to behaviour management interventions for people with brain injury.

There are some basic antecedent strategies that can be helpful in creating a positive setting for your family member with brain injury. These strategies focus on creating a positive and organised environment – you may find by making small changes to your environment, challenging behaviours will decrease.



Environmental changes

During previous modules we have discussed the importance of an organised and structured environment following brain injury. An individual may find it difficult to transition from the structured hospital setting to the less structured home environment due to cognitive changes. Environmental modifications may also be required due to physical changes resulting from the brain injury.

Your observations may reveal a close link between challenging behaviours and environmental factors (e.g. frustration using particular door handles, or never knowing where the sugar bowl is!). These behaviours can often be resolved by making sure the environment is organised (having specific places for belongings and labeling cupboards) and appropriate to the person's physical abilities.

Even if you do not feel challenging behaviours are directly linked with environmental factors, it is likely that creating an appropriate and organised environment will result in positive outcomes for the individual. Rather than expending their cognitive energy trying to make sense of their surroundings, they can use it to focus on other tasks at hand.



Can you think of how you might make your environment more organised/ structured to suit the needs of your family member with brain injury?

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Routine

Routines are important for a person with brain injury. Following brain injury a person may have difficulty starting activities, planning how to do them, and maintaining concentration. Routines can help to prompt the person with brain injury with what needs to be done and in what order. Routines are also helpful if the individual has difficulty transitioning from one activity to the next.

Routine can give the individual with a brain injury a sense of control over his or her life.

Developing a routine allows your family member with brain injury and you, their caregiver, the opportunity to look at their weekly schedule and make sure activities are appropriate and reflect their interests. When you record their current routine, you might notice that there are certain parts of the week when there are no activities scheduled, which may directly relate to the occurrence of challenging behaviours.

Remember, it is important that the individual with brain injury helps in setting up their weekly routine, and choosing what activities/tasks should be included.

STRUCTURE and ROUTINE are the keys to independent functioning and success following brain injury.

How to set up a routine

Depending on the physical and cognitive abilities of your family member with brain injury, assistance may be needed with setting up a routine. It is important to first look at his or her current daily/weekly schedule and to incorporate their preferred routine – e.g. what time do they usually get out of bed? Do they like to have their shower before or after breakfast?

It is useful to have the routine displayed somewhere central (e.g. the fridge or dining room wall). You could laminate a large table (like the one on page 52) and use a white board marker to fill in the daily/weekly activities. This also enables you to make changes where necessary. You could also write your daily routine directly on to the fridge or window with a white board marker!



Look at your family member’s current routine on page 46. Is there anything that surprises/ concerns you? Can you think of how their routine might be adapted to better suit their needs? It might be helpful to develop a new routine using the table on page 52.

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Weekly Routine							
Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7:30-9:30am							
9:30-11:30am							
11:30am – 1:00pm							
1:00-3:30pm							
3:30-6:00pm							
6:00-8:00pm							
8:00-10:00pm							

Meaningful activities

So, how does this relate to behaviour management? Consider, how do you feel when you are doing something that you are enjoying or something that gives you a sense of purpose? Now compare that with how you feel when you do something out of obligation, or feel bored and uninspired by what you are doing or by your surroundings.

People who are engaged in meaningful activities are going to feel more positive, and when we are feeling positive, this is more likely to be reflected in our behaviour. Likewise, if we feel a sense of purpose or responsibility, we will feel more important and valued by others.

It is therefore important that meaningful activities are incorporated into the individual's routine. If an individual feels good about their routine, they will be more likely to cooperate when they are required to do necessary but less desired activities (e.g. showering, brushing teeth, dishes etc.).

It might help to consider the following questions:

What are the individual's interests? What do they like/dislike?

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What are their strengths? What are they good at?

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When do they seem most engaged?

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Can you think of any meaningful activities that could be incorporated into your family member's weekly routine?

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Consistency

In this context, consistency refers to all caregivers and family members having an agreed response to challenging behaviours and maintaining a structured environment. This is very important when implementing behaviour management strategies.

It is not always easy to maintain consistency within your homes. However, consider these two guidelines:

- responses following challenging behaviours (e.g. ignoring – discussed below) should be consistent amongst caregivers. If caregivers respond differently to target behaviours this will be confusing for the individual, and behaviour management strategies will most likely be ineffective.
- if you decide on specific places for belongings, it is important that all caregivers are aware of this system and understand the importance of maintaining an organised environment following brain injury

Let's consider the following example:

Andrew, 43 years of age, sustained a brain injury when he was hit by a car ten years earlier. He lives at home with his mother, Margret, and their pet dog, Alby. Andrew used to work as a graphic designer, but was unable to continue with this work due to cognitive changes following his brain injury.

Since his injury, Andrew has had difficulty with his short-term memory and relies on regular verbal prompts from his mother to complete daily activities. He would also become frustrated easily when he couldn't remember what he was talking about, locate items, or when things didn't go to plan. When this happened, Andrew would accuse his mother of hiding things from him, and become short-tempered, often throwing objects out of frustration.

It was suggested that Margret develop a daily routine with Andrew to display on the wall next to the clock, to help remind Andrew what activities were planned for the day. This routine included daily activities such as 'have breakfast', 'wash dishes' and 'brush teeth'. The process of developing a routine dramatically improved both Andrew and Margret's quality of life. Margret realised that much of Andrew's time was taken up with household activities and watching t.v, so they sat down together and discussed what it was that Andrew enjoyed doing. He said he would like to take Alby to the park and that he wanted to work on his computer.

Andrew's new routine included him walking Alby to the park three times a week, and spending time using a graphic design program (that Margret was able to obtain through his previous colleagues). Margret also labeled the clothes draws in his bedroom, and cupboards in the kitchen. This has helped Andrew locate items.

Andrew now independently carries out his morning routine, and prompts Margret that it is time to walk Alby to the park. Margret says Andrew seems more positive and in control. She has more time for herself and feels comfortable leaving the house in the mornings now that Andrew is confident with his daily activities. Andrew likes this added responsibility and independence.

Andrew rarely becomes frustrated anymore, but when he shows the early warning signs (irritability and swearing), Margret leaves the room and ignores this behaviour. When Andrew's sister visits, she is aware of the new systems in the house and also ignores these behaviours. Now when Andrew becomes frustrated he will often mumble to himself, but rarely directs his anger towards others.

Now let's apply the information we have covered so far to the following example:

Tim is a 21-year-old carpenter. He lives with his mother and father, and his German Shepherd dog, who he adores. Tim was a passenger in a motor vehicle accident. Neuropsychological assessment indicated an overall lowering of functioning, with mild learning/ memory problems, poor planning and poor problem solving skills. His attention and concentration were also below average.

Tim denies having any hobbies, but reported that he used to play indoor cricket on a regular basis. His other interests included rally cars and 'clubbing' with his mates.

Tim spent some time in the acute rehabilitation ward in hospital before transferring home to live with his mother and father. Tim frequently sits alone and appears lethargic. He occasionally becomes argumentative when prompted by his parents to attend appointments and social activities, and often retreats to his room. If his parents would allow it, he would prefer to lie in bed all day.

Questions

What is the main problem?

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What do you want the outcome to be?

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Is there anything currently reinforcing this behaviour?

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What potential reinforcers are available to you?

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How might you manage this behaviour?

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Are there other issues you need to consider?

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MODULE 6

Behaviour Management Procedures



Aim

During this module we will introduce some basic behaviour management procedures. These strategies can be used individually or in combination with other approaches as part of a more comprehensive behaviour management program.

Outcomes

On completing this module you should be able to understand and apply one or more of the following behaviour management procedures:

- Positive Reinforcement
- Extinction
- Differential Reinforcement
- Overcorrection

Managing challenging behaviours

Each case and challenge is unique and requires its own individualised approach. Not all individuals with brain injury – even those with similar challenges – will have the same response to the same approach. When appropriate to the situation, some of the behavioural procedures presented throughout this module may be useful. These procedures can be used to maintain or increase particular behaviours, or decrease behaviours.

Please note that these contingency management procedures should only be used with individuals who do not have difficulties with information processing and memory.

Try not to get overwhelmed by these procedures – they often sound more difficult than they really are! Make sure you take note of any questions you have so we can discuss these when we meet to develop your individualised behaviour management plan.

Positive Reinforcement

This is helpful when the aim is to maintain or increase behaviour. A positive reinforcer (reward) is presented immediately following the desired behaviour so the person will see the consequence of the behaviour as something positive. This results in the increased likelihood of this behaviour occurring in the future. Positive reinforcement can be tangible (If I work hard, I will get a raise) or social (praise or smile).

Example: Ted's mother cooked him dinner every evening. She wanted him to be more helpful with cleaning up after the meal. She made a point of praising him every time he took his plate to the sink (after prompting). As a result, Ted started taking all of the dirty dishes to the kitchen. He is now responsible for cleaning the table after mealtimes and doing the dishes.



Description:

Positive reinforcement is one of the most basic, effective, and easy-to-use behaviour management strategies. It is also one of the most popular procedures because it focuses on what a person is doing correctly rather than incorrectly.

The concept is simple: each time the person engages in the desired behaviour, you reward them, which increases the likelihood of this behaviour occurring again in the future. However, using this strategy requires attention to detail.

A reinforcer (reward) is most commonly, but not always, what the person likes, or what someone else thinks the person “should” like. For example, although a person may like chocolate, a block of chocolate is unlikely to be an appropriate reinforcer for someone who is trying to lose weight, or who has just eaten a large meal.

Sometimes the most preferred consequence may not be appropriate for use as a reinforcer. It may be too costly, inaccessible, or illegal. There are, however, many things that can act as reinforcers, including verbal feedback, praise, money, points, and so on. The opportunity to participate in preferred activities can also be an effective reward for doing less preferred activities. For example, we may be willing to clean out the shed if we can then go finishing, or eat our vegetables to get dessert.

Example: Erik liked to go to the cafe but refused to walk there. Telling him that he could go to the cafe whenever he walked there meant he got his desired trips to the café, but also the exercise that he needed.

Perhaps the most effective and most often overlooked reinforcers are verbal praise and attention. Think of how much we do for just a smile or some other form of acknowledgment from someone who is important to us. It is also important to note that what may be effective with one behaviour in one setting may not work in another.

It is also important for the value of the reinforcer to be equal to the effort that is required to perform the behaviour. A reward that is not worth the effort is unlikely to be an effective reinforcer. Would you mow the entire lawn and do all the weeding on Saturday for a dollar? How about for a thousand dollars? Finding a happy medium or balance between the value of the reinforcement and the behavioural effort is a skill that develops with time and experience.



What do you think would make effective reinforcers for your family member with brain injury?

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It is important to have control of the accessibility of the reinforcer. If the reinforcer is readily available to the person, it is unlikely that it will have much effect on the behaviour. For example, using crackers (food) as a reinforcer for putting the dishes away is unlikely to be very motivating after eating dinner. Using tokens that can be exchanged for time watching television, is also unlikely to be effective if the person has unrestricted access to his or her own television. It is also important that the reinforcer is age appropriate.

Example: Jason's mother could not understand why her token system was not working. She gave points to Jason when he helped with chores around the house that could be exchanged for dvds in the evening. However, Jason wasn't interested. It turned out that his mother selected "family style" movies to be watched by her 20-year-old son with significant frontal lobe damage and different interests. Jason could watch these "family style" programs on regular television at any time. He preferred more mature entertainment.

Controlling the accessibility of reinforcers presents important ethical issues. For example, it is blatantly unethical (and illegal) to deprive people of the basic elements required for life, such as water, food, clothing, shelter, and contact with others. However, these things are powerful motivators for all of us, so when used in any behaviour management plan should be carefully monitored and only used in a manner that does not violate personal rights and dignity.

For example, you may use certain types of food, such as special treats, or type of meals as reinforcers. You might also use food as a reinforcer during the early afternoon, between meals, rather than delaying an individual's lunch.

Finally, reinforcers may stop working. Too much of a good thing can be a problem, as it may no longer be an effective reinforcer. It is then important to think about the amount of reinforcer to provide following the desired behaviour.

It is also important to identify reinforcers that can be used within your natural environment, as they will be available and appropriate to the behaviour. In some situations, the changes in the person's behaviour will determine his or her own reinforcement. For example, although you may use praise and rewards to motivate a person to begin to walk again (considering the pain and confusion associated with this process), once they are able to walk, the ability to get around and access activities may be enough to maintain this behaviour.

When and how often do you reinforce the behaviour?

Generally, it is recommended that you reinforce (reward) the desired behaviour every time it occurs. However, once the behaviour is well established it is not necessary to reinforce it every time.

It is important that you reward the behaviour as soon as you can after it has occurred. If you wait for too long, other behaviours might occur in the meantime, and it may not be clear to the person exactly what behaviour is being reinforced.

Please note: Positive Reinforcement Programs that address *high-risk behaviours* should only be implemented by specially trained professionals.

When designing a Positive Reinforcement Program you should:

1. Identify the specific behaviour you want to target. The more specifically the behaviour is defined, the more focused the intervention can be.
2. State how often the behaviour currently occurs, so you can monitor whether the program is working or not
3. Consider other behaviour management techniques – do you think that positive reinforcement is the most appropriate procedure for the target behaviour?
4. Select a reinforcer (reward) that:
 - a) is “equal in value” to the behaviour to be reinforced
 - b) is readily accessible to you but not the individual
 - c) appears to be of interest to the individual
5. Carefully monitor the persons progress – is behaviour improving? Is the reinforcer still working effectively?

Example: Sally's mother tried to encourage Sally to chew with her mouth closed, but she had been unsuccessful. Sally really liked cats, so her mother set up a program in which they talked about cats during mealtimes as long as Sally kept her mouth closed while eating. When Sally opened her mouth, the conversation stopped and only continued when she closed her mouth again. As a result, Sally now chews her food with her mouth closed 95% of the time, compared to 30% of the time before the intervention

NOTES/QUESTIONS

A series of horizontal dotted lines for writing notes or questions.

Extinction

This is helpful when the aim is to reduce a behaviour. Extinction occurs when you do not reinforce a specific behaviour. For example, you may make a commitment to totally ignore inappropriate comments made by an individual. It is common when using extinction to see an initial increase in the behaviour. For example, ignoring inappropriate comments will initially result in the person becoming more vocal and explicit. However, if you continue to ignore this behaviour it should decrease/ cease over time.



Example: Allen tried to get his mum's attention by knocking his cup over during mealtimes. His mum would clean up the water, pick up the cup and refill it. This series of actions reinforced Allen's negative behaviour because he was getting the attention he was seeking. To address this problem, Allen's mum started ignoring Allen when he tipped over his cup. At first Allen tried to get her attention by throwing the cup on the floor, but then he stopped engaging in this behaviour because it was no longer resulting in the desired outcome (getting attention).

Description

This is one of the most basic and powerful behaviour management procedures to help decrease target behaviours. When we present a reward (reinforcer) following a behaviour, it can increase the likelihood of this behaviour occurring in the future. Therefore, by withholding this reinforcement, it is possible to decrease the likelihood of a behaviour occurring in the future. If someone does not receive reinforcement for his or her behaviour, they may be less likely to engage in that behaviour over time. In essence, when applied, this procedure follows the maxim of "ignore something and it will go away".

One of the biggest challenges in the use of extinction is to be consistent. For this procedure to be most effective, the reinforcer maintaining the behaviour must be consistently withheld whenever the behaviour occurs. However, it is very easy to slip and reinforce rather than ignore the target behaviour, as we have customarily reinforced this behaviour in the past. For example, when trying not to pay attention to someone so that he or she will remain focused on task, we may find ourselves inadvertently laughing at that person's jokes. When this happens, the person may learn that although the behaviour is not reinforced all of the time, it is sometimes reinforced. Intermittent reinforcement (sometimes reinforcing behaviours) can be very powerful in maintaining behaviour, and therefore when this occurs during an extinction procedure, it may take longer for the behaviour to stop occurring.

In other situations, all caregivers or family members/ friends may not be consistent in ignoring the behaviour and the person will simply learn who will and will not reinforce the behaviour. This is similar to a child knowing which parent to go to when they want something.

Finally, you may not be in control of the reinforcer (response) that is maintaining the behaviour, and the person may be able to find other avenues from which to be reinforced for the behaviour. For example, if you decided to no longer pay attention to a person's 'spitting' behaviour, they may be able to find a way for other community members to give him or her attention.

In such situations, extinction may not be effective because you are not able to fully control the reinforcer that is maintaining the behaviour.

Extinction procedures can take time to work, and it is possible that the target behaviour will increase in strength and frequency before decreasing. This is because the person may first try harder for the reinforcer before learning that it is no longer available. If the behaviour starts to increase, don't assume that the procedure is not working and "give in." The rule is to maintain the extinction program in full force unless you decide to abandon it completely. Otherwise repeated starting and stopping of the procedure may make the behaviour worse rather than solve the problem.

It is therefore important to think ahead when implementing this procedure, making sure that you (and your family) are able to manage the increased levels of the target behaviours. For example, a person who becomes too aggressive to handle during an extinction procedure may learn to manipulate others through this violence, and a person who initially engages in severe head-banging behaviour may accelerate to the point of potentially causing neurological damage. This does not mean that it is never appropriate to use extinction with these forms of behaviour, but that many considerations have to be taken into account before using this procedure for these types of challenging behaviours.

During an extinction procedure, it is important that the person is carefully monitored to ensure his or her safety as well as the safety of others. In addition, other strategies that reinforce appropriate behaviours and engage the individual in meaningful activities should continue.

Once the target behaviour has decreased to an appropriate level, it is important not to reinforce it again in the future. Otherwise there is an excellent possibility that the behaviour will come back.

Finally, extinction generally works best when it is used with positive reinforcement. This is a process known as differential reinforcement and is discussed below. In this procedure, one behaviour is targeted for decrease through the use of extinction, while more appropriate behaviour(s) are targeted for increase using positive reinforcement. Although differential reinforcement is preferred, sometime extinction procedures alone may be sufficient.

Please note: Extinction programs that address *high-risk behaviours* should only be implemented by specially trained professionals.

When designing an Extinction Program you should:

1. Identify the specific behaviour you want to target. Since many behaviours initially increase in frequency before they decrease, it is important to make sure that you and your family can control and manage the behaviour when it is at its extreme form.
2. State how often the behaviour currently occurs, so you can monitor whether the program is working or not
3. Consider other behaviour management techniques – do you think that extinction is the most appropriate procedure for the target behaviour?
4. Identify the reinforcer(s) (responses) that are currently maintaining the behaviour. Make sure you (and others involved) have full control of the reinforcers. If this is not the case, the extinction procedure is less likely to be successful.
5. Carefully monitor the persons progress – is the challenging behaviour decreasing?

Differential Reinforcement



This technique is not as complicated as it sounds. It is a combination of positive reinforcement and extinction procedures (discussed previously): it involves reinforcing desired behaviours, while inappropriate behaviours are ignored. For example, if your goal is to encourage an individual to socialise with others, you would reward them for just coming out of their room, even if they haven't yet reached the end goal (socialising with others). Basically, this technique involves reinforcing (rewarding) any desired behaviour rather than the inappropriate behaviour.

Example: John would prefer his mother to get him drinks of water, bring him fresh towels when he is perspiring, and meet other needs that he is capable of himself. His mother would like him to meet his own needs. As a result, his mother ignored requests that he is personally capable of meeting, while at the same time socially acknowledging (praising) his effort to help himself. John soon begins to take greater charge of his daily needs.

Description

Through using this procedure, the person changes a less desirable form of behaviour to a more desirable one. For example, Amy's sister is trying to teach Amy to introduce herself in a more gracious manner. She asks her family members and friends to ignore Amy when she says "hey you!" or "oi", and to only respond to her when she says "hello, how are you?" In most situations, a person will quickly change his or her behaviour to continue to receive the social reinforcement of your response.

As with other procedures, it is important to be consistent when using differential reinforcement to maximise effectiveness. Otherwise, the person may learn that with certain people they get away with the behaviour, or they may become frustrated/ confused with the lack of direction. It is also a good idea for the behaviours that are going to be reinforced to be of approximately equal (or less) effort as the behaviour you are trying to extinguish. Otherwise the person may not feel that it is worth the effort to engage in the new behaviour. Furthermore, if you reinforce both the positive and negative forms of behaviour, the person will learn that they can engage in either, rather than just the new and more desirable behaviour.

When using differential reinforcement it is generally recommended to attempt to replace the challenging behaviour with some other specific behaviour. Usually, you would choose to reinforce the person for a behaviour that is incompatible with the behaviour that you are trying to decrease. For example, it is difficult to pace around the room (the behaviour to be decreased) and sit at the dining room table (an incompatible and acceptable behaviour to be increased) at the same time. Or, you may choose to reinforce a wide variety of other acceptable behaviours, just as long as the targeted challenging behaviour is not reinforced when it occurs.

Please note: Differential Reinforcement Programs that address high-risk behaviours should only be implemented by specially trained professionals

When designing a Differential Reinforcement Program you should:

1. Identify the specific behaviour(s) you want to increase through positive reinforcement and the specific behaviour you want to decrease through extinction
2. State how often the behaviour currently occurs, so you can monitor whether the program is working or not
3. Consider other behaviour management techniques – do you think that differential reinforcement is the most appropriate procedure for the target behaviour?
4. Identify the reinforcer(s) (responses) that are currently maintaining the behaviour that you want to decrease.
5. Carefully monitor the persons progress – is the frequency of the challenging behaviour decreasing?

The specific procedures and requirements of differential reinforcement are the same as the combined procedures of positive reinforcement and extinction. For more detail, please refer to the individual descriptions of these procedures on page 62 and 66.

Example: George made inappropriate sexual comments whenever his mother had female friends visit. The more she tried to teach George that these comments were not welcomed, the more he said them. His mother asked her friends to ignore all the inappropriate sexual comments, but to readily engage him in conversation when he discussed other topics. At first George's behaviour became more vulgar, however, after a brief period of time he stopped all sexual comments towards females and talked about more socially acceptable topics.

Activity

How might you use a differential reinforcement procedure in the following situation?

As part of Mike's physical rehabilitation, he is required to walk for at least 15 minutes per day. However, Mike prefers to stay at home or go on outings in his wheelchair. Whenever it is time to leave the house for their walk, Mike says that he can't go because he has sore legs. Mike's mother examines his legs (and on several occasions has also taken him to the doctor for examination, which has ruled out chronic pain), but is unable to identify any physical problems with his legs that would prevent him from walking.

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Overcorrection

This is helpful when the aim is to reduce a behaviour. Overcorrection is based on the principle of 'overlearning'. Behavioural restitution follows the occurrence of a specific behaviour. This gives a person the opportunity to take responsibility for their behaviour/ or make amends with a logical consequence that is directly linked to the behaviour.



Example: Greg hates picking up his clothes and leaves a trail from the sofa to his bedroom each night. His father has encouraged him to pick up his clothes with points, verbal praise, and other approaches but has not been successful. His father uses a new program in which Greg has to clean up and wash all stray clothing each day that he does not pick up his own. Greg quickly learns that it is easier to pick up his own clothes than have to take responsibility for all stray clothing.

Description

Overcorrection can be considered as a form of behavioural restitution in which a person is required to make amends and/or repair the 'damage' that occurred because of his or her behaviour. For example, as a result of Jane scratching patterns in the kitchen table with her knife, she was required to sand and re-varnish that section of the wooden table. Overcorrection is considered a 'punishment' procedure, as it uses consequences to decrease the probability of a behaviour occurring again in the future. When using punishment procedures there is a stronger need to ensure the persons rights and to monitor ethical/ legal issues. Consequences should be ethically sound and relate specifically to the target behaviour. We will discuss this further below and within our group session.

Overcorrection is most commonly used when a person fails or refuses to participate in an activity/situation in which they are capable of, with the purpose of inconveniencing others. For example, this procedure might be appropriate for a person who is capable of eating neatly, but spills his or her food during mealtimes, thereby forcing his or her family caregiver to wash the floor each night. In this situation, the person might be required to clean the table and wash the floor around the table immediately after spilling food. It is hoped that he or she will learn that it is easier to eat neatly. In most cases, a positive reinforcement procedure would first be attempted in this situation, as a less restrictive procedure in which the behaviour of eating neatly (desired behaviour) is reinforced. However, sometimes it is not possible to gain access to the necessary reinforcers, or the behaviour is maintained by the ease of doing something poorly rather than engaging in the desired activity (think of how many times your dirty socks don't quite make it in the clothes basket, but you are content leaving them on the floor!).

Please note: overcorrection should never be used when a person does not have the required skills to perform the desired behaviour. For example, if the person in the previous example had problems with coordination, making it difficult to eat neatly (rather than choosing not to), an overcorrection procedure would not be acceptable. Instead, skills training or prosthetic methods may be more appropriate.

Overcorrection is most effective when the consequence for the target behaviour takes more time and energy than the desired behaviour. For example, eating neatly in the first place takes much less effort than having to clean the table and wash the floor. Similar to other procedures discussed, the consequence (response) should occur immediately after the behaviour occurs. The consequence should also directly relate to the behaviour, and of course cannot be malicious, abusive or vindictive. For example, it would not be acceptable or appropriate to make someone run ten laps around the block for leaving dirty clothes all over the floor. It would be more appropriate, to require the person to collect and wash all of the clothes in the house.

As mentioned, it is important that the consequence requires more effort than if the person had engaged in the desired behaviour in the first place. However, this should not be overly excessive and needs to be carefully considered. If you use a consequence that is overly burdensome, this may be resisted by the person or may even trigger aggression. When using an overcorrection program, it is also important that all caregivers (family members) are capable of consistently implementing the consequence, or it may not be effective. It is important to remain calm and directed, just stating the requirements the person should perform without using threats or other insinuations. This procedure shouldn't be used as a way to "get back" at a person for something they did. It may be helpful to discuss and practice your calm response to the behaviour with other family members, and make sure that you carefully monitor the program.

Positive reinforcement should always be used when implementing an overcorrection procedure, reinforcing alternative desirable behaviours. This ensures that you also focus on what the person is doing correctly rather than only focusing on their challenging behaviours.

PLEASE NOTE:

This procedure may be inappropriate for many forms of aggressive behaviours because it may trigger additional aggression.

Overcorrection can be easily misapplied and should be used carefully. Please seek advice from the Primary Researcher/ Trained Professionals before using this procedure.

Overcorrection Programs that address *high-risk behaviours* should only be implemented by specially trained professionals

When designing an Overcorrection Program you should:

1. Identify the specific behaviour you want to decrease through overcorrection
2. State how often the behaviour currently occurs, so you can monitor whether the program is working or not
3. Consider other behaviour management techniques – do you think that overcorrection is the most appropriate procedure for the target behaviour? In most cases a positive reinforcement procedure should be attempted first
4. Choose an overcorrection process that:
 - is related to the repair of the environment caused by the target behaviour
 - requires more effort than if the person had engaged in the desired behaviour in the first place
 - can be administered consistently by everyone involved
 - can be presented immediately following the behaviour
 - can be used frequently without causing aggression
 - is ethical, moral and legal
5. Identify an alternative and appropriate behaviour that allows the person to earn reinforcement
6. Carefully monitor the persons progress – is the frequency of the challenging behaviour decreasing?



Do you think any of the consequence-based procedures discussed (positive reinforcement, extinction, differential reinforcement and overcorrection) may be helpful in your situation?

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There are several other consequent-based behavioural procedures focusing on punishment (e.g. timeout procedures) and skill development (e.g. shaping and guidance procedures). However, the procedures discussed here are some of the most basic and powerful behaviour management strategies in managing challenging behaviours following brain injury. Furthermore, you may have found that by implementing antecedent strategies (such as creating a positive environment and routine) that challenging behaviours have already decreased. As stated previously, antecedent strategies are emphasised in behaviour management interventions for people with brain injury, as following brain injury people often experience difficulty with information processing and memory (making it more difficult to learn from consequence-based strategies).

If you have identified that challenging behaviours in your family member with brain injury are related to his or her inability to physically or cognitively complete a specific task, then skill development programs may be appropriate. The Primary Researcher will work with you during the 12-week Individualised Behaviour Intervention to discuss what programs may be most appropriate, and help you develop the skills required to implement these.

MODULE 7

What to do in a crisis...
& knowing where to get help



Aim

During this module we will discuss what to do in a crisis, and identify what services are available in South Australia that may be helpful in supporting you with the management of challenging behaviours following brain injury.

Outcomes

On completing this module you should be able to:

- know how to respond in a crisis, including:
 - the use of appropriate body language/ communication
 - strategies to keep yourself and the person with brain injury safe
 - who to contact in an emergency
- identify what services are available that may be helpful in supporting you to manage challenging behaviours following brain injury, and knowing when and how to access these.

Managing a crisis

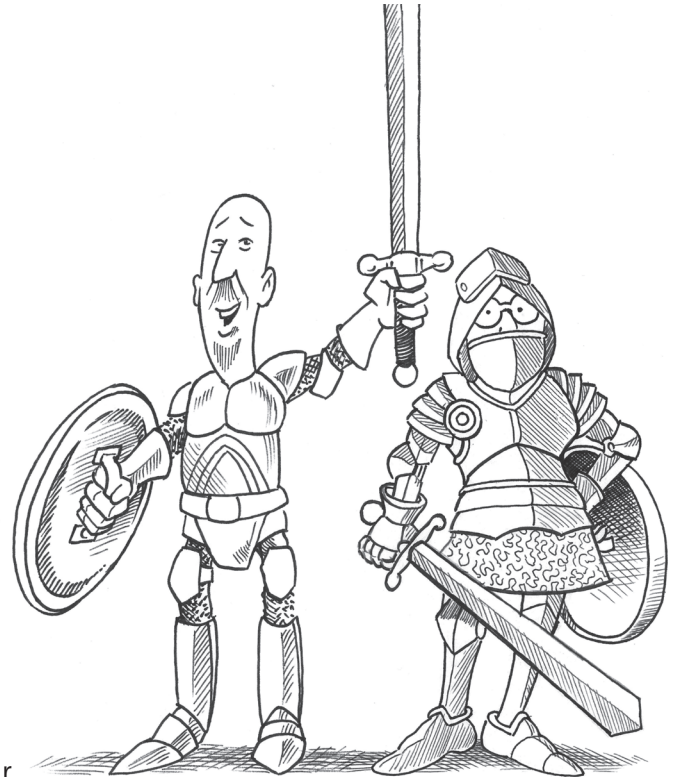
In Module 2 (page 31) we discuss what to do if anger behaviours are escalating.

We discuss the importance of:

- keeping calm and in control
- maintaining a safe distance from the person
- using non-confrontational body language
- thinking about the situation – e.g. is there anything reinforcing the behaviour? is anything frightening the person or are they being over or under stimulated?
- deciding on an intervention (how to respond to the behaviour)

It is important to acknowledge the concerns/emotions of the person whether you agree with them or not. This validates his or her experience, helping them feel 'understood'. For example, you might say "I can understand that (situation) is making you feel upset..."

If danger is present, clear the space if possible and remove others from the scene. Also make sure you can always see the person – it is important to never turn your back on a person behaving aggressively.



Restraint, medication (if prescribed and available) and self-defense should be used as a last resort.

If the situation seems uncontrollable, keep calm, leave as quickly as possible and go to a safe place.

If you are being confronted with high-risk behaviours, where the behaviour is presenting danger to you or the individual, please seek help immediately:

Domestic Violence Helpline (24 hours): 1800 800 098

Lifeline (24 hours): 13 11 14

Crisis Care (4pm-9am): 13 16 11

CRANA Confidential Support Line (for rural families) (24 hours): 1800 805 391

After an incident, it is important to debrief. Make time to speak with family/ friends or professionals regarding the incident – can you identify why the behaviour occurred? How did you respond? Can you think of how the situation might be avoided in the future?

After a crisis it is normal for a person to experience emotional and physical changes (both you and your family member with brain injury). If these changes persist, seek professional help.

Organisations/ services

Although there are limited services in South Australia that specifically support family caregivers with managing challenging behaviour following brain injury, there are a number of organisations that provide information and counseling, and run support groups for family caregivers. These are listed on the following pages.



Families4Families Inc.

Acquired Brain Injury Peer Support Network

Families4Families Incorporated

This support network offers peer support to people with brain injury and their family caregivers. Families4Families Inc. offers information sessions relevant to different stages of the ABI journey, including dealing with the shock, trauma and grief involved in brain injury. This support network runs information sessions specific to 'Anger and ABI' and provides peer support and networking. Online resources and materials are also available.

Ph: 0433 388 250

Email: office@families4families.org.au

Website: <http://families4families.org.au>

**34 Dunorlan road,
Edwardstown SA 5039**



Brain Injury SA

This network offers counselling and community support to people with ABI and their carers. They run seminars and forums, and offer programs including Springboard and Coffee Clubs. The Springboard Program supports people with ABI to reintegrate into the community through participating in physiotherapy, speech therapy and community learning and life skills, and meaningful community engagement. The Coffee Clubs provide individuals with ABI and their families the opportunity to network and find out more about other programs and events at Brain Injury SA..

Ph: (08) 8217 7600

Country Callers: 1300 733 049

**70 Light Square,
Adelaide SA 5000**



**Government
of South Australia**

Brain Injury Rehabilitation Community Home (BIRCH)

BIRCH offers home-based and outpatient therapies. This facility provides personalised and goal-orientated rehabilitation. They offer a range of multidisciplinary services and expertise relating to behaviour management following ABI. This service has specific criteria and is available for a limited period of time.

Ph: (08) 8222 1888 (northern clients)

Ph: (08) 8222 1414 (southern clients)

**Hampstead Rehabilitation Centre
207 Hampstead Road
Northfield SA 5085**



Flinders University Community Re-entry Program

This is a holistic rehabilitation program aimed at assisting adults with brain injury to enhance their social life and prevocational skills. The program includes a variety of social, recreational and educational workshops that incorporate movement, writing and communication, and skill development. The aim of the program is to empower members to fully participate in the community.

Ph: (08) 8201 3311

Email: crp@flinders.edu.au

**Flinders University
Sturt Campus
Bedford Park SA 5042**



**Government
of South Australia**

Department for
Communities
and Social Inclusion

Disability Services SA (DSA)

DSA offers case management to individuals with ABI, which may include home supports, personal care, and access to day programs. They also provide information and counseling, and run support groups for carers. This service requires individuals with ABI to have a sufficient permanent disability.

Ph: (08) 8272 1988

**Disability Services Central Office
Level 9, 103 Fisher Street
Adelaide SA 5000**



Diverge Consultation (Victoria)

Secondary consulting

Diverge is a non-for-profit organisation that provides a range of services to promote effective behaviour support. They offer psychological services, including behaviour assessment, intervention, counseling, training and research. You will need a referral to access these services. Information on referral requirements, and the referral form can be downloaded at <http://diverge.org.au/referrals/>

Ph: (03) 9329 4330

**60 Lothian Street
PO Box 777
North Melbourne Vic 3051**



Synapse (QLD)

This non-profit organisation is based in QLD. They publish a range of resources, fact sheets and books relating to challenging behaviours following ABI and community reintegration.

Ph: (07) 3137 7400

Ph: 1800 673 074 (outside Brisbane)

Website: <https://synapse.org.au>

**Level 1 262 Montague Road
West End QLD 4101**

Psychologists/ psychiatrists

(Neuro)psychologists and (neuro) psychiatrists can also offer specialised support in the management of challenging behaviours, and can help in developing individualised behaviour management plans.

There are a number of private and public (neuro)psychologists and (neuro)psychiatrists within South Australia. It may be worth asking your GP and other family caregivers in your support groups/ networks if they can recommend anyone in particular.



Take Home Messages

- Following brain injury, a person may experience changes in information processing, memory, cognition (thinking), personality/behaviour, and/or physical ability
- There are specific strategies that can be used to deal with these changes
- It is important to be able to identify potential triggers of anger and 'early warning signals' that a person is becoming angry. To better understand how to manage anger behaviour it is useful to understand the scale of anger (e.g. from calm to aggressive), and recognise that anger can be a secondary feeling (e.g. resulting from pain, fear or humiliation)
- Management strategies start with analysing the challenging behaviour, using the observation sheet. This may reveal patterns in the target behaviour, including similar times/settings when the behaviour occurs, and perhaps consistent antecedents or consequences that may play a part in reinforcing the behaviour
- There are behaviour management procedures that can be useful in managing challenging behaviours following brain injury
- Managing a crisis involves remaining calm and in control, keeping a safe distance from the person, using non-confrontational body language, analysing the situation, deciding on an intervention, and debriefing following the incident

THANK YOU!

Thank you again for participating in this program. We do hope you have found these sessions helpful and look forward to your feedback.

Individualised behaviour management plan

Now you have completed this four-week education program you will continue to meet with the Primary Researcher for approximately 1.5 hours each fortnight for six visits to develop and implement an individualised behaviour management plan. The Primary Researcher will make contact with you to confirm the details of these visits (what time and location will suit you best) and your involvement.



This workbook was supported by the project team with further content adapted from the following resources:

Dark, F.
Understanding Challenging Behaviour Following an Acquired Brain Injury
BRAIN INJURY Association of Queensland
Murphy Schmidt Solicitors

Responding to Challenging Behavior Following an Acquired Brain Injury
BRAIN INJURY Association of Queensland
Murphy Schmidt Solicitors

Jacobs, H. E. (1995)
Behaviour Analysis Guidelines and Brain Injury Rehabilitation
Aspen Publications, Inc.
Maryland

Martin, C. (2011)
Working with people with traumatic brain injury
Staff self-study Module 5: Understanding and managing behaviour changes following a TBI
http://www.tbistafftraining.info/SelfStudy/Module_5/5.o.htm
Brain Injury Rehabilitation Unit
Liverpool Hospital, Sydney

Ponsford, J., Sloan, S., & Snow, P. (2013)
Traumatic Brain Injury: Rehabilitation for Everyday Adaptive Living
Taylor & Francis Ltd
United Kingdom

Ylvisaker, M. & Feeney, T..J. (1998).
Collaborative Brain Injury Intervention: Positive Everyday Routines
Thomson Learning
Canada



Flinders
UNIVERSITY

CPIICOS No. 0014A

**Disability and Community Inclusion
School of Health Sciences**

P: (08) 8201 3745

E: Alinka.Fisher@flinders.edu.au

Disability and Community Inclusion Unit
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Adelaide SA 5001 Australia
flinders.edu.au/sohs



Central Adelaide Local Health Network
Royal Adelaide Hospital Human Research Ethics Committee
Level 4, Women's Health Centre
Royal Adelaide Hospital
North Terrace
Adelaide, South Australia, 5000
Telephone: +61 8 8222 4139
Email: Health.CALHNResearchEthics@sa.gov.au

Approval Date: 18 November 2015

HREC Reference number: HREC/15/RAH/486

CALHN Reference number: R20151116

Ms Alinka Fisher
Department of Disability and Community Inclusion
FLINDERS UNIVERSITY

Dear Ms Fisher

Project Title: Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: Feasibility Study.

Thank you for submitting the above project for ethical review. This project was considered by the Chairman of the Royal Adelaide Hospital Human Research Ethics Committee. I am pleased to advise that your protocol has been granted full ethics approval and meets the requirements of the *National Statement on Ethical Conduct in Human Research, incorporating all updates*. The documents reviewed and approved include:

- **NEAF Application: AU/1/D76228** determined to be LNR, **Sites covered by this approval:**
 - **South Australian Brain Injury Rehabilitation Services (SABIRS), Hampstead Rehabilitation Centre CPI: Ms Alinka C Fisher**
- **Research Protocol Version 2, dated 28 October 2015**
- **Participant Information Sheet Version 2**
- **Participant Intro Letter Version 2**
- **Screening Questionnaire Version 2**
- **Participant Consent Form Version 1**
- **Confidence Questionnaire Version 1**
- **Contact Permission Form Version 1**
- **Email to Organisations Version 1**
- **Exit questionnaire Version 1**

GENERAL TERMS AND CONDITIONS OF ETHICAL APPROVAL:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
 - (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
 - (b) changes to the protocol,
 - (c) premature termination of the study.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is valid for **5 years** from the date of this letter, after which an extension must be applied for. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each anniversary of the above approval date, within 10 working days, using the Annual Review Form available at: <http://www.rah.sa.gov.au/rec/index.php>
- The REC must be advised with a report or in writing within 30 days of completion.


Should you have any queries about the HREC's consideration of your project, please contact Ms Heather O'Dea on 08 8222 4139, or Health.CALHNResearchEthics@sa.gov.au.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a SA Health site until governance authorisation from the Chief Executive or delegate of that site has been obtained.

This Committee is constituted in accordance with the NHMRC's *National Statement on the Ethical Conduct of Human Research* (2007).

The HREC wishes you every success in your research.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'A Thornton', enclosed in a rectangular box.

Digitally signed on behalf of the
Research Ethics Committee
Royal Adelaide Hospital
Time: 2015.11.25 19:44:20 CST

**A/Prof A Thornton
CHAIRMAN
RESEARCH ETHICS COMMITTEE**

Subject: APPROVED: RESPONSE: Ethics Modification Request (R20151116)
Date: Wednesday, June 29, 2016 at 3:12:32 PM Australian Central Standard Time
From: Health:CALHN Research Ethics
To: Alinka Fisher
Attachments: image001.gif, image002.png

Dear Alinka,

Re: RAH Protocol No: R20151116

Project Title: Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: Feasibility Study.

Thank you for the email below with attached documentation for the above study for review, including:

- Cover Letter
- Research Protocol with amendments (highlighted)
- Education phase feedback questionnaire/ interview questions
- FDBM overall feedback questionnaire/ interview questions
- Exit questionnaire/ interview questions -Three-month follow up
- Revised Participant Information Sheet

- **I am happy that existing participants are verbally re-consented to complete the additional questionnaires but new participants should be consented using the revised Information Sheet.**

I have reviewed the document(s) and there are no ethical or governance issues. The document(s) are **APPROVED**, effective **from the date of this email**.

Please accept this e-mail as **Acknowledgement of Receipt, Review and APPROVAL** of the document(s), **on behalf of RAH Human Research Ethics and CALHN Governance**, and retain a copy for your records.

For multi-centre studies a copy of this email must be forwarded to Principal Investigators at every site approved by the RAH HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.



A/Prof Andrew Thornton
Chairman, Research Ethics Committee
Royal Adelaide Hospital
ph (08) 8222 4139
mob: 0418 832 346

From: Alinka Fisher [mailto:alinka.fisher@flinders.edu.au]
Sent: Wednesday, 29 June 2016 2:56 PM
To: Health:CALHN Research Ethics
Subject: Re: RESPONSE: Ethics Modification Request (R20151116)

Subject: OH-00110 - SBREC Acceptance Notice (6 September 2016)
Date: Tuesday, September 6, 2016 at 3:10:16 PM Australian Central Standard Time
From: Human Research Ethics
To: Alinka Fisher, Michelle Bellon, Sheila Lennon, Sharon Lawn
Priority: High
Attachments: OH-00110 application (24 August 2016).pdf

Dear Alinka,

Your request for ethics approval from the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University based on the ethics approval already granted by the Royal Adelaide Hospital Human Research Ethics Committee has been received.

As outlined on the [Social and Behavioural Research Ethics Committee \(SBREC\)](#) website ethics approvals conducted by Flinders University staff and students (including those with adjunct status), for social and behavioural research, granted by another Australian NHMRC Human Research Ethics Committee (HREC) will be accepted by the SBREC without further review or scrutiny. This approach is in line with Chapter 5.3 of the *National Statement on Ethical Conduct in Human Research*, which encourages the minimising of ethical review duplication. On that basis, the research project listed below has been accepted by the SBREC.

Important Note

The application submitted (SBREC Project OH-00110) has been accepted by the SBREC on the condition that:

1. the research is not clinical in nature (as per the guidelines on the SBREC website); and
2. no participants will be recruited from any organisations under the banner of the [Southern Adelaide Local Health Network \(SALHN\)](#) which includes the Flinders Centre for Innovation in Cancer (FCIC).

ACCEPTANCE OF ETHICS APPROVAL

Granted by other NHMRC Registered HREC

SBREC Project Number:

OH-00110

Other HREC approval number:

HREC/15/RAH/486

Ethics approval granted by:

Royal Adelaide Hospital Human Research Ethics Committee

Project Title:

Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: Feasibility Study

Flinders University Researcher:

Ms Alinka Fisher

School / Dept

Disability and Community Inclusion

Email:

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Date approval
accepted:

6 September 2016

Conditions of Acceptance

As the ethics approval granted by the Royal Adelaide Hospital Human Research Ethics Committee has been accepted by the Social and Behavioural Research Ethics Committee (SBREC) it is a requirement that the following conditions be met:

1. Flinders University Letterhead

- a) If the Flinders University researcher is the principal researcher on the accepted application it is a requirement that all documentation and/or information to be distributed to potential participants is placed on the Flinders University letterhead. Please ensure that these changes are submitted to the original approving Human Research Ethics Committee (HREC) as a modification request and are approved by them prior to implementation. Please also submit a copy of the modification request (and any relevant attachments) along with the modification approval notice from the other HREC to the SBREC. This information will just be saved onto your electronic project file.
- b) If the Flinders University researcher is not the principal researcher on the project; then documentation to be provided to potential participants does not need to be placed on Flinders University letterhead.

2. Modifications / Amendments

With the exception of modifications that may be required in number 1 above, the research project will continue being monitored by the other HREC that granted ethics approval; and on that basis copies of modification requests and approvals do not need to be submitted to the SBREC.

3. Submission of Other HREC Reports

Copies of all reports (i.e., annual progress and final) submitted to the Human Research Ethics Committee that originally approved the application need to be submitted to the Social and Behavioural Research Ethics Committee (SBREC). The reports will be reviewed by the SBREC Chair and then placed on your project file (i.e., a report approval notice will not be emailed to you). When reports are emailed to the SBREC please ensure that the SBREC project number the report relates to is listed in the subject line of the email.

For Future Reference

If you need to contact the SBREC in relation to this email in the future please ensure that you quote the project number allocated by the SBREC (OH-00110).

Kind regards
Andrea

Mrs Andrea Fiegert and Ms Rae Tyler

Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday
Rae - Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au

Web: [Social and Behavioural Research Ethics Committee \(SBREC\)](http://Social and Behavioural Research Ethics Committee (SBREC))

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au
[Research Services Office](#) | Union Building Basement
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APPENDIX 9

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PhD Candidate

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Date

Dear Sir/Madam,

I am a PhD student in Disability and Community Inclusion, School of Health Sciences, at Flinders University.

I am undertaking research entitled "Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: A Feasibility Study."

This study seeks to determine the feasibility and acceptability of the FDBM program for family caregivers of adults with ABI. The FDBM program consists of an education component and an individualised behaviour intervention, which together aim to empower family caregivers to better manage problem behaviours following ABI in community settings.

If you are over 18 and the primary caregiver of a family member with ABI who:

- is 18-65 years of age,
- acquired their brain injury when 15 years of age or older,
- has been living in the community for at least 6 months (post-discharge), and
- has a recognised problem behavior which you are involved in managing,

I would be grateful if you would volunteer to assist by participating in this study.

Your participation would involve availability for an 8-month period from 1st March to 1st November, 2016, in which you would attend a 4-week education program (weekly 2-hour group sessions) and participate in a 12-week individualised behaviour intervention (consisting of fortnightly 1.5 hour sessions). You would also be asked to complete a series of short questionnaires which will be used to evaluate the program, including a 3-month follow-up after the program.

We are very interested in seeing if this program helps family caregivers better manage problem behaviours following ABI in community settings, and determining if the tools used to evaluate the program are appropriate.

Please refer to the Information Sheet for further details.

If you would like to participate, please return the consent form and contact permission form in the reply-paid addressed envelope provided, or contact me directly to register your interest.

Please be assured that any information provided will be treated in the strictest confidence and no participant will be individually identifiable in the resulting thesis or other publications. You are, of course, free to discontinue participation at any time or to decline to answer particular questions. Please be assured that this will not result in any discrimination, reduction in the level of support, or any other penalty. At the end of the study, you will be given the opportunity to read and comment on the data and conclusions made.

If you have any questions please contact me at Alinka.Fisher@flinders.edu.au or by telephone on (08) 8201 5956.

This research will be conducted according to the NHMRC National Statement of Ethical Conduct in Human Research, 2007.

If you wish to speak to someone not involved in the study about the conduct of the study you may contact the Executive Officer of the Royal Adelaide Hospital Human Research Ethics Committee at rah.ethics@health.sa.gov.au or by telephone on (08) 8222 4139.

Thank you for your time and help you may be able to offer to this study

Yours sincerely,



Alinka Fisher

PhD Candidate
Disability and Community Inclusion
School of Health Sciences,
Flinders University



About me: I have a Bachelor of Disability and Community Rehabilitation (First Class Honours), and specialise in positive behaviour support. I am a trained facilitator of the Triple P (Positive Parenting Program), facilitate workshops on 'Anger and ABI' for Families4Families Inc, and have worked for Relationships Australia SA conducting functional behaviour assessments. I have experience supporting adults with ABI with problem behaviours in community settings and spent two years in England supporting children on the autistic spectrum with complex behaviour needs.

INFORMATION SHEET

Title: Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: A Feasibility Study

Principal Investigator:

Alinka Fisher, PhD Candidate, Flinders University

Supervisors:

Dr Michelle Bellon, Prof Sheila Lennon & Ass Prof Sharon Lawn
School of Health Sciences, Flinders University

Description of the study:

Individuals often experience behavioural changes following an acquired brain injury (ABI). This can cause significant distress for families, and can be extremely challenging for family caregivers to manage. The FDBM program, which consists of 4-week education program and a 12-week individualised behaviour intervention, has been developed with the aim of empowering family caregivers to better manage problem behaviours following ABI in community settings.

Family caregivers are invited to participate in an 8-month study, which seeks to determine if the FDBM program helps family caregivers better manage problem behaviours, and determine if the tools used to evaluate the program are appropriate.

Purpose of the study:

This study aims to determine if the FDBM program is an acceptable and feasible intervention in supporting family caregivers to manage problem behaviours following ABI in community settings. In particular, it examines:

- if the FDBM program has an impact on a) the frequency of identified behaviours in individuals with ABI, b) levels of burden and c) levels of confidence in responding to problem behaviours by family caregivers; and
- if the tools used in evaluating the FDBM program are appropriate for capturing any changes in this study.

What will I be asked to do?

If you are over 18 and the primary caregiver of a family member with ABI who:

- is 18-65 years of age,
- acquired their brain injury when 15 years of age or older,
- has been living in the community for at least 6 months (post-discharge), and
- has a recognised problem behavior which you are involved in managing,

I would be grateful if you would volunteer to assist by participating in an 8-month study from 1st March to 1st November, 2016.

Please refer to the Screening Questionnaire to identify whether your specific behaviour(s) of concern are acceptable for the purpose of this study.

Your participation would involve:

- a) availability for an 8-month period from 1st March to 1st November, 2016
- b) completing questionnaires at 7 time points which relate to the person with ABI's abilities, community involvement, problem behaviours, and the impact these behaviours have on you as a family caregiver. Each series of questionnaires will take no longer than 45 minutes.
- c) attending a 4-week education program (weekly 2-hour group sessions at a negotiated time and location) which focuses on understanding and managing problem behaviours following ABI.
- d) participating in a 12-week individualised behaviour intervention. During this phase you would meet with the Principal Investigator at a location of your convenience for approximately 1.5 hours fortnightly and work together to develop and implement a behaviour management plan.
- e) completing a short questionnaire before and after the intervention which relates to your level of confidence in managing problem behaviours. This should take no longer than 5 minutes.
- f) completing three short questionnaires and interviews to gather your feedback regarding the program. These should take no longer than 15 minutes each.

We are very interested in seeing if this program helps family caregivers better manage problem behaviours following ABI in community settings, and determining if the tools used to evaluate the program are appropriate.

What benefit will I gain from being involved in this study?

By sharing your experiences, you are contributing to our understanding of how families can be best supported to manage behavioural changes following an ABI in the community. Your involvement directly assists the development and evaluation of the FDBM program. We are very keen to improve the supports and interventions available to families living with ABI.

Will I be identifiable by being involved in this study?

Please be assured that any information provided will be treated in the strictest confidence, and you will not be individually identifiable in the resulting report or any other publications.

Are there any risks or discomforts if I am involved?

We anticipate few risks from your involvement in this study, however if your involvement in the FDBM program or if any of the questions cause you to feel concerned, upset or needing further support, please contact:

Lifeline, Uniting Care Wesley Adelaide (24 hour counselling service) 13 11 14
This service will refer callers requiring more in-depth or ongoing support to a counsellor in the callers' local area.

If you have any concerns regarding anticipated or actual risks or discomforts, please do not hesitate to contact the Principle Investigator.

How do I agree to participate?

Participation is voluntary. If you agree to participate please read, complete and sign the consent and permission contact forms in the reply-paid addressed envelope provided. You can also contact the Principal Investigator directly at Alinka.Fisher@flinders.edu.au or by phone on 8201 5956 to register your interest and discuss the project before signing and returning the consent form for participation. We hope to recruit 10 participants to be involved in this study. The first 10 family caregivers who register their interest and meet inclusion criteria will be selected for participation.

You are free to withdraw from the study at any time without effect or consequences.

How will I receive feedback?

Outcomes from each stage of the project will be summarised and provided to you if you would like to see them.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Royal Adelaide Hospital Human Research Ethics Committee (Project number: R20151116). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8222 4139 or by email rah.ethics@health.sa.gov.au



APPENDIX 11

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CONSENT FORM FOR PARTICIPATION

I (family caregiver) being over the age of 18 years, hereby volunteer to participate in the research project titled *“Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: A Feasibility Study”*

1. I have read the information provided
2. Details of procedures and any risks have been explained to my satisfaction
3. I agree to data collected from the study to be used in preparing the dissertation, on condition that my name or identity is not revealed
4. I am aware that I should retain a copy of the information sheet and consent form for future reference
5. I understand that:
 - I may not directly benefit from taking part in this research
 - I am free to withdraw from this project at any time
 - while the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential
 - whether I participate or not, or withdraw after participating, will have no effect on any service/support that is being provided to me
6. I agree to data collected being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.

Family caregiver name:

Family caregiver signature: Date:.....

I certify that I have explained the study to the family caregiver and consider that he/she understands what is involved and freely consents to participation

Signed: Date:
(Principal Investigator)



APPENDIX 12

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CONTACT PERMISSION FORM

RE: *Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: A Feasibility Study*

I have read the information included in the 'information package' regarding this research project and I am interested in discussing my potential involvement with the Primary Investigator

I, give Alinka Fisher permission to contact me to discuss the above research project.

Home Phone: Mobile:

Work phone: Email address:

My preferred method of contact is (circle): Home phone / Work phone / Mobile / Email

These are the best times to contact me:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Time/s							

Signature: Date:

APPENDIX 13

Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: A Feasibility Study

Screening Questionnaire for the presence of problem behaviours

If you can answer 'yes' to any of the behaviours below relating to your family member with ABI, you meet inclusion requirements regarding the presence of a recognised problem behaviour.

Behaviour	Yes (tick)
VERBAL AGGRESSION	
Makes clear threats of violence towards others?	
Swears/ uses foul language, making moderate threats directed at others or self? (eg., "F*** off you bastard!")	
Makes mild personal insults directed at others (e.g. "you are stupid!", "idiot"). If yes, does this happen at least once a day?	
Make loud noises, shout angrily, is clearly not directed at some other person (e.g., "bloody hell!")? If yes, does this occur at least once a day?	
PHYSICAL AGGRESSION	
Sets fire, throw objects dangerously (e.g. some other person is at risk of being hit by the object(s) thrown but is not actually hit)?	
Breaks objects/ smashes windows?	
Throws objects down (without some other person at risk of being hit by the object), kick furniture without breaking it, marks the wall? If yes, does this occur at least once a day?	
Slams doors, scatter clothing, make a mess in clear response to some antecedent? If yes, does this occur at least once a day?	
PHYSICAL ACT AGAINST SELF	
Mutilates self, causes deep cuts, bites that bleed, internal injury, fracture, loss of consciousness, loss of teeth. This includes suicide attempts.	
Inflicts small cuts or bruises, minor burns to self.	
Bangs head, hits fist into objects, throws self onto floor or into objects (hurts self without serious injury).	
Picks or scratches skin, hits self, pulls hair (with no or minor injury only). If yes, does this occur at least once a day?	
PHYSICAL AGGRESSION AGAINST OTHERS	
Causes mild - severe physical injury (broken bones, deep lacerations, internal injury – bruises, welts) to person(s) aggression directed at	
Strikes, kicks, pushes, pulls hair (without significant injury) to person(s) aggression directed at.	
Makes threatening gesture that is clearly directed towards some other person, swings at people, grabs at clothes. If yes, does this occur at least once a day?	
INAPPROPRIATE SEXUAL BEHAVIOUR	
Attempt to forcibly undress another person. Use of threat to obtain sex. Sexual penetration of another person who has not consented.	
Touching (or making attempts to touch) other people's breasts, buttocks, or genitals	
Masturbation in a public or shared setting when other people are in the area	
"Flashing", exhibiting genitals, undressing in public.	
Touching other people who do not want to be touched (but contact does not involve genitals). For example kissing hand or arm, putting arm around shoulder. Also includes touching clothing (e.g., lifting skirts). If yes, does this occur at least once a day?	
Comments of a sexual nature (e.g., "I've got a big dick", "I want to make babies with you", "You've got nice tits", "I could give you a good time", "when I am with a woman I like to...") If yes, does this occur at least once a day?	

PERSEVERATION/ REPETITIVE BEHAVIOUR	
Engages in prolonged continuation and repetition of a behaviour that has resulted in serious harm (e.g., continued, persistent eye rubbing; riding an exercise bike and only stopping upon exhaustion).	
Engages in prolonged continuation and repetition of a behaviour that has resulted in minor physical harm (e.g., continued, persistent touching, rubbing, or scratching leading to skin irritation; remaining in shower until skin is shriveled).	
Engages in prolonged continuation and repetition of a behaviour that has not resulted in physical harm (e.g., continued, persistent tapping, writing same letter over and over, unrolling entire toilet roll, asking the same question repeatedly: "do you watch the Bill?", "Will you marry me?"). If yes, does this occur at least once a day?	
WANDERING/ABSCONDING	
Escapes secure premises (e.g., through a doorway left open, by using security door codes, by climbing over fence). May physically resist attempts to stop such escape (e.g., wrestles with or pushes staff who attempt to stop or restrain them).	
Leaving the familiar, 'safe', environment when there is a good risk of becoming lost or seriously harmed (e.g, nursing home resident attempting to return to family home, walking onto freeways, needing to be located/recovered by police).	
Going into areas that are prohibited but where there no or low risk of harm (e.g., entering other resident's rooms, staff areas, kitchen). If so, does this occur at least once a day?	
INAPPROPRIATE SOCIAL BEHAVIOUR	
Presents a danger/risk to self or others Lights fires dangerously. (e.g., smoking in bed, starting bonfire near gas cylinder). Crosses road without evaluating traffic. Wheeling wheelchair in middle of road. Climbs ladders when perception and / or balance impaired. Excessive use of alcohol, cigarettes, or other substances where that is the key behaviour leading to risk or actual harm to self or others. Uses provision of sex to gain access to goods (such as money, cigarettes, drinks) or services.	
Petty crime or Unlawful behaviour Driving while unlicensed. Fraud (e.g., writing dishonoured cheques). Obtains goods by theft or deceit. Stealing.	
Noncompliant / oppositional Responds "no!" to prompts to do things. Refuses to discuss problem behaviours with staff. Will not follow toilet or shower routines. Refuses to take medication. Rejects or dismisses service providers who are helpful with home care. Intentional lying that is not due to poor memory. Will not (as opposed to Can not) follow rules.	
Nuisance / annoyance Interrupts other people's conversations. Actively does things to seek attention (e.g., spills food). Inconsiderate of other people (e.g., hogging TV channel or remote control). Nagging, impatient, "Butts in" to other people's affairs (e.g., advising staff/ management on how to improve residence, reporting on other clients' activities).	
Socially awkward Inappropriate laughter. Failure to monitor personal hygiene (e.g., does not shower regularly). Excessive apologising or thanking. Standing too close to strangers. Failure to pick up on nonverbal cues (that others are bored, the joke was not funny, the conversation is over).	
ADYNAMIA/ LACK OF INITIATION	
Person requires many prompts daily to undertake activities of daily living. If yes, does this occur throughout the day?	

This questionnaire consists of behavioural domains from the OBS (Kelly et al., 2006), using criteria developed by Sabaz et al. (2010).

APPENDIX 14

FDBM Program Behaviour Support Plan: Session 1

What is the target behaviour (behaviour of concern)?

Have you identified any triggers? Have you noticed any patterns around when the behaviour occurs? (E.g. particular times/ places/ people)

Have you identified any responses that might be reinforcing/ maintaining the behaviour?

Why do you think the behaviour occurs? (What is its purpose/ function)

What preventative strategies might be helpful? (E.g. environmental changes/ routine)

Will the person benefit from learning more acceptable alternative behaviours (E.g. communication skills)?

Do you think changing the response to the behaviour might be helpful? How so?

Do you think any of the behaviour management procedures we discussed might be helpful (E.g. positive reinforcement, extinction, overcorrection)? If so, which ones?

**FDBM Program
Behaviour Support Plan: Session 2**

What strategies worked well?

Did you have difficulties implementing any of the strategies? If yes, how so?

Were there any strategies you think didn't help, or strategies you would like to change?

Are there additional responsive strategies that might be helpful?

Might the person benefit from learning more acceptable alternative behaviours (E.g. communication skills)?

Do you think any of the behaviour management procedures we discussed might be helpful (E.g. positive reinforcement, extinction, overcorrection)? If so, which ones?

Were the reinforcers you used effective? If not, what alternative objects/ activities could you use instead?

So where to next? Let's make a plan for this week...

During this week we will:

**FDBM Program
Behaviour Support Plan: Session 3**

What strategies worked well?

Did you have difficulties implementing any of the strategies? If yes, how so?

Were there any strategies you think didn't help, or strategies you would like to change?

Are there additional responsive strategies that might be helpful?

Might the person benefit from learning more acceptable alternative behaviours (E.g. communication skills)?

Do you think any of the behaviour management procedures we discussed might be helpful (E.g. positive reinforcement, extinction, overcorrection)? If so, which ones?

Were the reinforcers you used effective? If not, what alternative objects/ activities could you use instead?

Record the instances of your target behaviours again this. This will help us identify whether your strategies are working (if the behaviour is decreasing) or not, and whether changes might be needed in our approach.

So where to next? Let's make a plan for this week...

During this week we will:

APPENDIX 15

**Family-Directed Behaviour Management (FDBM) program
Participant Demographic Information**

About you

Participant Name: _____

Age: _____ Gender: F / M

Relationship to family member with ABI (e.g. parent, child, spouse): _____

Length of caregiving role for family member with ABI: _____

Living Status (e.g. do you live with family member with ABI, do you live separately):

Marital status: _____

Employment (part-time/ full-time/ unemployed): _____

Information about your family member with ABI

Gender: F/ M Age: _____ Age at time of injury: _____

Injury circumstances (e.g. motor vehicle accident, stroke): _____

Medication: _____

Do they have any health issues? _____

Living status: _____ Marital status: _____

Employment: _____

Interventions & support received:

Any criminal history:

Care and Needs Scale

Tate (2003)

Name:

Administered by:

Date:

Instructions: Tick any of the care and support needs that apply (Section 1), then circle the number that corresponds to length of time that the person concerned can be left alone (Section 2)

Section 1: Type of care and support need		Section 2: Length of time that can be left alone
<p>Group A: CANS Levels 7, 6, 5 or 4: Requires nursing care, surveillance for severe behavioural/cognitive disabilities, and/or assistance with or supervision for very basic ADLs:</p> <p><input type="checkbox"/> tracheostomy management</p> <p><input type="checkbox"/> nasogastric/PEG feeding</p> <p><input type="checkbox"/> bed mobility (e.g., turning)</p> <p><input type="checkbox"/> wanders/gets lost</p> <p><input type="checkbox"/> exhibits behaviours that have the potential to cause harm to self or others</p> <p><input type="checkbox"/> has difficulty in communicating basic needs because of language impairments</p> <p><input type="checkbox"/> continence</p> <p><input type="checkbox"/> feeding</p> <p><input type="checkbox"/> transfers/mobility (including stairs and indoor surfaces)</p> <p><input type="checkbox"/> other: _____</p>	7 6 5 4	<p>Cannot be left alone</p> <p>- Needs nursing care, assistance and/or surveillance 24 hours per day</p> <p>Can be left alone for a few hours</p> <p>- Needs nursing care, assistance and/or surveillance 20-23 hours per day</p> <p>Can be left alone for part of the day, but not overnight</p> <p>- Needs nursing care, assistance, supervision and/or direction 12-19 hours per day</p> <p>Can be left alone for part of the day and overnight</p> <p>- Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills</p>
<p>Group B: CANS Level 4: Requires assistance, supervision, direction and/or cueing for basic ADLs:</p> <p><input type="checkbox"/> personal hygiene/toileting</p> <p><input type="checkbox"/> bathing/dressing</p> <p><input type="checkbox"/> simple food preparation</p> <p><input type="checkbox"/> other: _____</p>	4	<p>Can be left alone for part of the day and overnight</p> <p>- Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills</p>
<p>Group C: CANS Levels 4, 3, 2 or 1: Requires assistance, supervision, direction and/or cueing for instrumental ADLs and/or social participation:</p> <p><input type="checkbox"/> shopping</p> <p><input type="checkbox"/> housework/home maintenance</p> <p><input type="checkbox"/> medication use</p> <p><input type="checkbox"/> money management</p> <p><input type="checkbox"/> everyday devices (e.g., telephone, television)</p> <p><input type="checkbox"/> transport and outdoor surfaces</p> <p><input type="checkbox"/> parenting skills</p> <p><input type="checkbox"/> interpersonal relationships</p> <p><input type="checkbox"/> leisure and recreation/play</p> <p><input type="checkbox"/> employment/school</p> <p><input type="checkbox"/> other: _____</p>	4 3 2 1	<p>Can be left alone for part of the day and overnight</p> <p>- Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills</p> <p>Can be left alone for a few days a week</p> <p>- Needs contact for occupational activities, interpersonal relationships, living skills or emotional support a few days a week</p> <p>Can be left alone for almost all week</p> <p>- Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once a week</p> <p>Can live alone, but needs intermittent (i.e., less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support</p>
<p>Group D: CANS Levels 3, 2 or 1: Requires supports:</p> <p><input type="checkbox"/> informational supports (e.g., advice)</p> <p><input type="checkbox"/> emotional supports</p> <p><input type="checkbox"/> other: _____</p>	3 2 1	<p>Can be left alone for a few days a week</p> <p>- Needs contact for occupational activities, interpersonal relationships, living skills or emotional support a few days a week</p> <p>Can be left alone for almost all week</p> <p>- Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once a week</p> <p>Can live alone, but needs intermittent (i.e., less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support</p>
<p>Group E: CANS Level 0: Fully independent:</p> <p><input type="radio"/> Lives fully independently, with or without physical or other aids (e.g., hand rails, diary notebooks), and allowing for the usual kinds of informational and emotional supports the average person uses in everyday living</p>	0	<p>Can live in the community, totally independently</p> <p>- Does not need contact</p>

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Acknowledgement: From Tate, R. L. (2004). Assessing support needs for people with traumatic brain injury: The Care and Needs Scale (CANS). *Brain Injury*, 18(5), 445-460, reprinted by permission of the author.

Sydney Psychosocial Reintegration Scale-2
Form A: Change since injury (Relative version)
 Tate, Hodgkinson, Veerabangsa, and Maggiotto (1996, 1999)

Name: _____ **Administered by:** _____ **Date:** _____

BACKGROUND INTERVIEW

1. What is your relative's current occupation?
2. What are his/her work duties at present?
3. What was your relative's job at the time of the injury?
4. What were his/her work duties in that job?
5. How many jobs has he/she had since the injury (not including work trials or voluntary work)?
- 6 & 7. What are/were your relative's leisure interests, recreation, hobbies, and club membership, at present and at time of injury?

6. AT TIME OF INJURY	7. AT PRESENT
•	•
•	•
•	•
•	•

- 8 & 9. What is/was your relative's weekly programme of work, leisure/recreational activities at present and at time of injury?

8. AT TIME OF INJURY	9. AT PRESENT
•	•
•	•
•	•
•	•

10. What was your relative's marital status at time of injury?
11. What is it at present?
12. Who was in his/her circle of close friends at time of the injury?
13. Who is in his/her circle of close friends at present?
14. Who did your relative live with at time of injury?
15. Who does he/she live with at present?

OCCUPATIONAL ACTIVITY**1. Current work:** Have the hours of work (or study), or the type of work (or study) changed because of the injury?

Note: If your relative is a student, answer the questions in this section in terms of changes in his/her studies

- 4 Not at all: Same or better
 - 3 A little: Now works fewer hours per week
OR work duties (study) have changed to easier/lighter ones
 - 2 Moderately: Works casually
OR has some help from others in doing some work (study)
 - 1 A lot: Now unemployed
OR in rehabilitation
OR in a supported work programme
OR does volunteer work
OR receives remedial assistance in studies
 - 0 Extreme: Is almost unable to (or is unable to) work (study) at present
- NA Unable to assess: Did not work before the injury and still does not work

2. Work skills: Have the work (or study) skills changed because of the injury?

- 4 Not at all: Same or better
- 3 A little: Not quite as good; e.g., has to put in a lot of effort to get the same result, gets tired easily, loses concentration
- 2 Moderately: Definitely not as good; e.g., sometimes makes mistakes
- 1 A lot: Much worse; e.g., he or she is slower
- 0 Extreme: Very much worse; e.g., makes many mistakes, is very slow, work is of poor quality, needs constant supervision and/or reminders at present

3. Leisure: Has there been any change in the number or type of leisure activities or interests because of the injury?

- 4 Not at all: Same or more, and done as often or more
 - 3 A little: Has most of the same activities and interests,
OR has the same activities and interests but does them less often
 - 2 Moderately: Definitely less, but may have developed new activities and interests
 - 1 A lot: Only has some of the leisure activities and interests and has not developed new ones
 - 0 Extreme: Almost none (or no) leisure activities at present
- NA Unable to assess: Did not have leisure activities before the injury and still does not have leisure activities

4. Organizing activities: Has there been any change in the way your relative organizes work and leisure activities because of the injury?

- 4 Not at all: Same or better
- 3 A little: Needs prompts or supports from others
- 2 Moderately: More dependent on other people to organize activities; e.g., others suggest what to do and how to go about it
- 1 A lot: Needs other people to do the organizing; e.g., making arrangements, providing transport
- 0 Extreme: Almost completely (or completely) dependent on other people to suggest and organize activities at present

OCCUPATIONAL ACTIVITIES SCORE: _____

INTERPERSONAL RELATIONSHIPS**5. Spouse or partner:** Did your relative have a partner or spouse at the time of the injury? If NO, go to part b)

- a) If YES, has the relationship changed because of the injury?
- 4 Not at all: Same or better
 - 3 A little: Not quite the same due to the effects of the injury, but he/she still has the skills to form and maintain such relationships
 - 2 Moderately: Definitely not the same due to the effects of the injury but he/she probably has the skills to form and maintain such relationships
 - 1 A lot: A lot of changes, but he/she might have the skills to form a new relationship
 - 0 Extreme: Nature of the relationship has changed in a major way (e.g., partner takes on most responsibilities or is the primary caregiver
OR has broken down and he/she probably does not have the skills to form a new relationship
- b) How much change is there in his/her ability to form and maintain such a relationship compared to before the injury?
- 4 Not at all: Same or better
 - 3 A little: Not quite the same, but he/she still has the skills to form and maintain such relationships
 - 2 Moderately: Definitely not the same, but he/she probably has the skills to form and maintain such relationships
 - 1 A lot: A lot of changes, but he/she might have the skills to form a new relationship
 - 0 Extreme: Probably does not (or does not) have the skills to form a new relationship

6. Family: Have your relative's relationships with other family members changed because of the injury?

- 4 Not at all: Same or better
 - 3 A little: Not quite the same
 - 2 Moderately: Definitely not the same
 - 1 A lot: A lot of changes in relationships with some family members
 - 0 Extreme: Changed in a major way
OR a breakdown of relationships with some family members because of the effects of the injury
- NA Unable to assess: Did not have contact with family before the injury

7. Friends and other people: Have your relative's relationships with other people outside family (such as close friends, work mates, neighbours) changed because of the injury?

- 4 Not at all: Same or better
- 3 A little: Not quite the same, but still sees some friends weekly or more, makes new friends, and gets along with others (e.g., work mates, neighbours)
- 2 Moderately: Definitely not the same, but still sees some friends once a month or more and can make new friends
- 1 A lot: Only sees a few friends (or other people outside family), and does not make new friends easily
- 0 Extreme: Sees hardly any friends (or no friends at all), or other people outside family

8. Communication: Have your relative's communication skills (i.e., talk with other people and understand what others say) changed because of the injury?

- 4 Not at all: Same or better
- 3 A little: Some changes; e.g., rambles and gets off the point, talk is sometimes inappropriate, has some trouble finding the words to express himself or herself
- 2 Moderately: Definite changes; e.g., difficulty in thinking of things to say, joining in talk with groups of people, only talks about himself or herself
- 1 A lot: A lot of changes; e.g., having trouble understanding what people say
- 0 Extreme: Major changes, but can communicate basic needs
OR uses aids for communication
OR communication is almost impossible

INTERPERSONAL RELATIONSHIPS SCORE: _____

LIVING SKILLS**9. Social skills:** Have your relative's social skills and behaviour in public changed because of the injury?

- 4 Not at all: Same or better
- 3 A little: Some changes; e.g., is awkward with other people, does not worry about what other people think or want
- 2 Moderately: Definite changes; e.g., can act in a silly way, is not as tactful or sensitive to other people's needs
- 1 A lot: A lot of changes; e.g., is more dependent on other people, is socially withdrawn
- 0 Extreme: Major changes; e.g., has difficulty interacting appropriately with other people, behaviour is unpredictable, temper outbursts in public, requires supervision when with other people

10. Personal habits: Have your relative's personal habits (e.g., his/her care in cleanliness, dressing and tidiness) changed because of the injury?

- 4 Not at all: Same or better
- 3 A little: Does not take as much care as before
- 2 Moderately: Attends to own hygiene, dress and tidiness, but has definitely changed in this area; needs supervision
- 1 A lot: Needs prompts, reminders or advice from others, but responds to these
OR needs stand-by assistance
- 0 Extreme: Needs prompts, reminders or advice from others, but responds to these only after repeated requests
OR needs hands-on assistance
OR is totally dependent for assistance

11. Community travel: Have your relative's use of transport and travel around the community changed because of the injury?

Note: Do not include the driver of transport, or other passengers using such transport, in rating whether a person can travel "alone" or "by himself/herself"

- 4 Not at all: Same or better
- 3 A little: Unable to use some forms of transport (e.g., driving a car) but can still get around in the community by using other forms of transport without help
- 2 Moderately: Definite changes in use of transport, but after training can travel around the community on his/her own
- 1 A lot: Needs assistance to plan use of transport, but with such help can travel around the community on his/her own
- 0 Extreme: Very restricted in use of transport, but with supervision can make short, familiar journeys around the community on his/her own (e.g., going out to the local shop)
OR is unable to go out into the community alone

12. Accommodation: Has your relative's living situation changed because of the injury?

- 4 Not at all: Same or better
- 3 A little: Lives in the community, but with emotional or social supports provided by other people, such as family, friends or neighbours. Could not be left alone without supports for a 2-week period
- 2 Moderately: Definite changes and could not be left alone for a weekend unless someone was available to check that everything was OK
- 1 A lot: Lives in the community, but in supported accommodation, such as a group home, boarding house, transitional living unit
OR in family home but requires daily supervision or assistance
- 0 Extreme: Almost unable to live in the community, even with daily supervision or assistance
OR needs care, which may be at home requiring extensive, daily supervision or other care
OR is in an institution, such as a nursing home, residential service, rehabilitation unit

LIVING SKILLS SCORE: _____

TOTAL SPRS SCORE (OA + IR + LS): _____

Acknowledgement: Scale items from Tate, R. et al. (1999). Measuring psychosocial recovery after traumatic brain injury. Psychometric properties of a new scale. *Journal of Head Trauma Rehabilitation*, 14(6), 543-557, pp. 543-547 and Appendix, p. 557, reprinted with permission of Lippincott Williams & Wilkins and Wolters Kluwer. Format provided by Dr Tate.

Overt Behaviour Scale

Date of completing OBS

Rater's name

Client's name / identifier

Informant's name

Informant's role (e.g., spouse)

Challenging behaviours

Behaviours can be challenging or problematic if they are disruptive, make the client or other people uncomfortable, or go against the rules of community living. Such behaviours lead to distress or can disrupt things like social relationships and continuance of services. They can also result in significant financial cost to the service system.

What is this scale for?

This scale is designed to clarify the types of observable challenging behaviours that can occur following acquired brain injury (ABI). This can help to show how behaviours may have changed over time and can inform decisions related to clinical interventions. This scale can also be used to measure the frequency of challenging behaviours and the impact that they have on people living and/or working with the client (including family members and service providers).

What does this scale measure?

There are 9 categories of behaviour that can be scored on this scale; they are:

- **Verbal aggression**
- **Physical aggression against objects,**
- **Physical acts against self**
- **Physical aggression against other people**
- **Inappropriate sexual behaviour**
- **Perseveration / repetitive behaviour**
- **Wandering / absconding**
- **Inappropriate social behaviour**
- **Lack of initiation**

This scale enables you to score the severity, frequency, and impact of each behaviour.

How to use this scale

For each of the 9 categories of behaviour there is a heading (e.g., verbal aggression) and a relevant subscale. If your client exhibits no sign of that category of behaviour, mark the "no" box and go to the next behaviour.

If your client does show this type of behaviour you need to complete the subscale. Here you can indicate more clearly what sort of behaviour occurs. Under each heading there are a number of behaviour descriptions with realistic examples that correspond to increasing levels of severity (shouting is low severity, threats are more severe). Tick each of the types of behaviour observed and rate how frequently they occur and the impact that they have.

If a behaviour appears to fit 2 categories, use the single most appropriate one. See the Administration Guidelines for further information.

Timeframe

This scale represents behaviour that has occurred over the most recent 3 months.

More information

Developmental and psychometric information regarding the OBS has been published in Kelly, Todd, Simpson, Kremer, & Martin (2006). The Overt Behaviour Scale (OBS): A tool for measuring challenging behaviours following ABI in community settings. *Brain Injury*, 20(3), 307 – 319.

Administration guidelines are available at www.abibehaviour.org.au

How to rate behaviours

Tick each level that is a problem

For each category of behaviour there are a number of descriptions with examples that **illustrate** different levels of severity. Select the level(s) with a description or example that **best represents** the sorts of behaviour(s) that you have observed by placing a tick (✓) in this column.

Remember, these behaviours **are only examples**; if you have seen behaviours that are similar, but are not exactly the same, then tick this description.

Frequency

Rate how frequently the behaviour occurs using a number from 1 to 5 with the following definitions:

- 1 = less often than once per month
- 2 = once a month or more
- 3 = once a week or more
- 4 = once a day
- 5 = multiple times each day

Impact (distress or disruption)

“Impact” means the amount of **emotional distress** and/or **practical disruption** that a challenging behaviour causes. For example, **impact** refers to your experience of stress, worry, concern, or fear as a result of the behaviour. But **impact** can also refer to practical difficulties including needing additional staff, altered procedures, dealing with complaints from families or other residents, or having to acquire additional supports such as psychiatrists, police, or behaviour intervention. Disruption often translates into additional costs.

Rate how much this behaviour impacts upon yourself and/or other people by using a number from 1 to 5 and the following definitions:

- 1 = no impact
- 2 = minor impact
- 3 = moderate impact
- 4 = severe impact
- 5 = extremely severe impact

VERBAL AGGRESSION

Has the client shown any verbal aggression?

NO (go to next behaviour)

YES (rate the subscale below)

Severity

Levels

Tick each level that is a problem (✓)

Frequency

- 1 = < 1/month
- 2 = 1/month or more
- 3 = 1/week or more
- 4 = 1/day
- 5 = multiple daily

Impact

- 1 = no impact
- 2 = minor
- 3 = moderate
- 4 = severe
- 5 = extreme

Makes loud noises, shouts angrily, is clearly not directed at some other person (e.g., “bloody hell!”).

1

Makes mild personal insults clearly directed at some other person but does not include swearing/offensive sexual comments (e.g., “You are stupid!”, “idiot!”).

2

Swearing, use of foul language, moderate threats clearly directed at others or self (e.g., “F*** off you bastard!”).

3

Makes clear threats of violence directed towards others or self (e.g., “I’m going to kill you!” or “I’m going to finish myself!”) or requests help to control self (i.e., expresses anxieties that they will engage in aggressive act beyond own control unless someone make some immediate intervention). This includes suicidal threats.

4

PHYSICAL AGGRESSION

	Severity	Levels Tick each level that is a problem (✓)	Frequency 1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	Impact 1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
--	----------	----------------------------------------------------	------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------

Physical aggression against objects

Has the client shown any physical aggression against objects?

NO (go to next behaviour)

YES (rate the subscale below)

Slams doors, scatters clothing, makes a mess in clear response to some antecedent.	1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Throws objects down (without some other person at risk of being hit by the object), kicks furniture without breaking it, marks the wall.	2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breaks objects, smashes windows.	3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sets fire, throws objects dangerously (i.e., some other person is at risk of being hit by the object(s) thrown but is not actually hit) <i>If the object thrown does hit someone score this as Physical aggression against other people.</i>	4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Physical acts against self

Has the client shown any physical acts against self?

NO (go to next behaviour)

YES (rate the subscale below)

Picks or scratches skin, hits self, pulls hair (with no or minor injury only).	1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bangs head, hits fist into objects, throws self onto floor or into objects (hurts self without serious injury).	2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inflicts small cuts or bruises, minor burns to self.	3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mutilates self, causes deep cuts, bites that bleed, internal injury, fracture, loss of consciousness, loss of teeth. This includes suicide attempts.	4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Physical aggression against other people

Has the client shown any physical aggression against other people?

NO (go to next behaviour)

YES (rate the subscale below)

Makes threatening gesture that is clearly directed towards some other person, swings at people, grabs at clothes.	1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strikes, kicks, pushes, pulls hair (without significant injury) to person(s) aggression directed at.	2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attacks others, causing mild-moderate physical injury (bruises, sprain, welts) to person(s) aggression directed at.	3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Causes severe physical injury (broken bones, deep lacerations, internal injury) to person(s) aggression directed at.	4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

INAPPROPRIATE SEXUAL BEHAVIOUR

Has the client shown any inappropriate sexual behaviour?

NO (go to next behaviour)

YES (rate the subscale below)

Severity

Levels

Tick each level that is a problem (✓)

Frequency

1 = < 1/month
 2 = 1/month or more
 3 = 1/week or more
 4 = 1/day
 5 = multiple daily

Impact

1 = no impact
 2 = minor
 3 = moderate
 4 = severe
 5 = extreme

Sexual talk

Comments of a sexual nature (e.g., “I’ve got a big dick”, “I want to make babies with you”, “You’ve got nice tits”, “I could give you a good time”) where comments may be face-to-face or in the form of phone calls or letters. Explicit accounts of sexual activities (e.g., “When I am with a woman I like to ...”).

1

Touching (non genital)

Touching other people who do not want to be touched (but contact does not involve genitals). For example kissing hand or arm, putting arm around shoulder, patting someone’s knee, rubbing or caressing arm or leg or back. Also includes touching clothing (e.g., lifting skirts).

1

Exhibitionism

“Flashing”, exhibiting genitals, undressing in public. Failing to dress (e.g., walking about house without clothes on when coresidents could be or are present. Answering door when naked).

2

Masturbation

Masturbation in a public or shared setting when other people are in the area (e.g., masturbating in a car in a public carpark where passers by may see; masturbating in a common area in a supported residential setting).

2

Touching (genital)

Touching (or making attempts to touch) other people’s breasts, buttocks, or genitals (e.g., groping staff who walk by, fondling breasts of support workers, pulling other’s hands toward own groin).

3

Coercive sexual behaviour, Rape

Attempt to forcibly undress another person. Use of threat to obtain sex. Sexual penetration of another person who has not consented.

4

Victim details can be noted here

(The legal consequences of inappropriate sexual behaviour can differ depending on the sex and age of the victim.)

PERSEVERATION / REPETITIVE BEHAVIOUR

Has the client shown any perseverative behaviour?

NO (go to next behaviour)

YES (rate the subscale below)

Severity

Levels

Tick each level that is a problem (✓)

Frequency

1 = < 1/month
2 = 1/month or more
3 = 1/week or more
4 = 1/day
5 = multiple daily

Impact

1 = no impact
2 = minor
3 = moderate
4 = severe
5 = extreme

Engages in prolonged continuation and repetition of a behaviour that **has not resulted in physical harm** (e.g., continued, persistent tapping, writing same letter over and over, unrolling entire toilet roll, asking the same question repeatedly: "do you watch the Bill?", "Will you marry me?").

1

Engages in prolonged continuation and repetition of a behaviour that **has resulted in minor physical harm** (e.g., continued, persistent touching, rubbing, or scratching leading to skin irritation; remaining in shower until skin is shriveled).

2

Engages in prolonged continuation and repetition of a behaviour that **has resulted in serious harm** (e.g., continued, persistent eye rubbing; riding an exercise bike and only stopping upon exhaustion).

3

WANDERING / ABSCONDING

Has the client shown any wandering/absconding?

NO (go to next behaviour)

YES (rate the subscale below)

Severity

Levels

Tick each level that is a problem (✓)

Frequency

1 = < 1/month
2 = 1/month or more
3 = 1/week or more
4 = 1/day
5 = multiple daily

Impact

1 = no impact
2 = minor
3 = moderate
4 = severe
5 = extreme

Going into areas that are prohibited but where there no or low risk of harm (e.g., entering other resident's rooms, staff areas, kitchen).

1

Leaving the familiar, 'safe', environment when there is a good risk of becoming lost or seriously harmed (e.g, nursing home resident attempting to return to family home, walking onto freeways, needing to be located/recovered by police).

2

Escapes secure premises (e.g., through a doorway left open, by using security door codes, by climbing over fence). May physically resist attempts to stop such escape (e.g., wrestles with or pushes staff who attempt to stop or restrain them).

3

INAPPROPRIATE SOCIAL BEHAVIOUR

Has the client shown any inappropriate social behaviour?

NO (go to next behaviour)

YES (rate the subscale below)

Levels
Tick each level that is a problem (✓)

Frequency
1 = < 1/month
2 = 1/month or more
3 = 1/week or more
4 = 1/day
5 = multiple daily

Impact
1 = no impact
2 = minor
3 = moderate
4 = severe
5 = extreme

Severity

Socially awkward

Inappropriate laughter. Failure to monitor personal hygiene (e.g., does not shower regularly). Excessive apologising or thanking. Standing too close to strangers. Failure to pick up on nonverbal cues (that others are bored, the joke was not funny, the conversation is over).

1

Nuisance / annoyance

Interrupts other people's conversations. Actively does things to seek attention (e.g., spills food, rings buzzer, "Nurse, can you come here?"). Inconsiderate of other people (e.g., hogging TV channel or remote control). Nagging, impatient (e.g., always wanting something else to be done; can not tolerate waiting for supermarket queues). "Butts in" to other people's affairs (e.g., advising staff/management on how to improve residence, reporting on other clients' activities).

2

Noncompliant / oppositional

Responds "no!" to prompts to do things. Refuses to discuss problem behaviours with staff. Will not follow toilet or shower routines. Refuses to take medication. Rejects or dismisses service providers who are helpful with home care. Intentional lying that is not due to poor memory (e.g., denying drug use or stealing; fabricating stories to cover tracks). Will not (as opposed to Can not) follow rules. (e.g., leaving without telling someone where s/he is going).

3

Petty crime or Unlawful behaviour

Driving while unlicensed. Fraud (e.g., writing dishonoured cheques). Obtains goods by theft or deceit. Stealing (e.g., steals cigarettes from other residents, steals clothes or food from shops; materials from building sites).

4

Presents a danger/risk to self or others

Lights fires dangerously. (e.g., smoking in bed, starting bonfire near gas cylinder). Crosses road without evaluating traffic. Wheeling wheelchair in middle of road. Climbs ladders when perception and / or balance impaired. Excessive use of alcohol, cigarettes, or other substances where that is the key behaviour leading to risk or actual harm to self or others. Uses provision of sex to gain access to goods (such as money, cigarettes, drinks) or services.

4

LACK OF INITIATION

Explanation

This behaviour is different from the others because it is a **lack** of overt behaviour.

The person has difficulty getting tasks started or completed and is characterised as having a lack of motivation, initiative, or interest in day-to-day activities.

Examples

- The person may not wash, eat, or drink, shower or groom themselves without prompting from others. They may sit on the couch all day, not initiate social conversation or attend social activities without someone taking them.
- However, the person may engage in activities if someone else prompts them. Once asked to “wash the dishes”, the person may then commence and complete the task.
- Some people need more prompts: they might only wash dishes and then need another prompt for cutlery: “okay, you’ve finished the plates, what about the cutlery”?
- In severe cases, a person may not eat despite having a meal placed in front of them or fail to wash himself or herself even if standing under the shower. They would require constant prompts such as “put some soap on the washer, soap up your arms, now rinse etc”.

Has the client shown any lack of initiation?

NO

YES (complete scoring this item)

Levels

Tick if lack of initiation is a problem
(✓)

Severity

i.e., Amount of prompting required
1 = less than once/day
2 = approx. once/day
3 = more than twice/day
4 = many times/day
5 = all tasks, everyday

Impact

1 = no impact
2 = minor
3 = moderate
4 = severe
5 = extreme

SCORING

The OBS produces 3 key indices: Cluster, Total Levels, and Clinical Weighted Severity.

Cluster

Sum the number of **YES** boxes ticked. Range: 0 to 9

Total Levels

Sum the number of **Levels** boxes ticked. Range: 0 to 34

Clinical Weighted Severity (CWS)

Sum the **severity** numbers associated with each level ticked.

For **Lack of Initiation**, use the **Severity**/prompting score. Range: 0 to 84

Note.

The two other measures, **frequency** and **impact**, do not form the structure of the scale, but rather provide additional clinical data.

APPENDIX 19

Caregiver Appraisal Scale

NAME:

DATE:

The following statements describe feelings that caregivers of people with ABI sometimes have. We are interested in knowing how you are feeling regarding your situation as a caregiver at the present time. Please read each statement and select the one response number with which you most agree.

The blank line refers to the person with ABI in your family.

	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
1. My health has suffered because of the care I must give _____	1	2	3	4	5
2. My social life has suffered because I am caring for _____	1	2	3	4	5
3. I can fit in most of the things I need to do despite the time taken by caring for _____	1	2	3	4	5
4. I feel isolated and alone as a result of caring for _____	1	2	3	4	5
5. A strong reason for taking care of _____ is to be true to family traditions	1	2	3	4	5
6. Caring for _____ has interfered with my (family's) use of space in my home	1	2	3	4	5
7. I am very tired as a result of caring for _____	1	2	3	4	5
8. I should be doing more for _____	1	2	3	4	5
9. I am angry when I am around _____	1	2	3	4	5
10. I really enjoy being with _____	1	2	3	4	5
11. It's hard to plan things when _____'s needs are so unpredictable	1	2	3	4	5
12. Taking care of _____ is a way for me to live up to religious principles	1	2	3	4	5
13. It makes me happy to know that _____ is being cared for by his/her family	1	2	3	4	5
14. Taking responsibility for _____ gives my self-esteem a boost	1	2	3	4	5
15. I could do a better job in caring for _____	1	2	3	4	5
16. I am pretty good at figuring out what _____ needs	1	2	3	4	5

PLEASE TURN OVER →

	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
17. I am resentful of other relatives who could but who do not do things for _____	1	2	3	4	5
18. It's mostly _____'s needs that determine how my days are spent	1	2	3	4	5
19. _____ seems to expect me to take care of him/her as if I was the only one he/she depends on	1	2	3	4	5
20. _____'s pleasure over some little thing gives me pleasure	1	2	3	4	5
21. I have lost control of my life since _____'s injury	1	2	3	4	5
22. Caring for _____ doesn't allow me as much privacy as I would like	1	2	3	4	5
23. The things I do for _____ keep him or her from getting worse	1	2	3	4	5
24. Nothing I do seems to please _____	1	2	3	4	5
25. Taking care of _____ gives me a trapped feeling	1	2	3	4	5
26. The knowledge that I am doing my best gets me through the rough times with _____	1	2	3	4	5
27. Helping _____ has made me feel closer to him or her	1	2	3	4	5
28. I think of the help I give _____ as an opportunity to repay him or her	1	2	3	4	5
29. I don't have enough money to care for _____ in addition to the rest of my expenses	1	2	3	4	5
30. _____ shows real appreciation of what I do for him or her	1	2	3	4	5
31. I can take care of _____ with no help, or I could if I had to	1	2	3	4	5
32. A strong reason to care for _____ is to provide a good model for others to follow	1	2	3	4	5
33. Because of this time I spend with _____, I don't have enough time for myself	1	2	3	4	5
34. _____ is beyond being helped by most things I do for him or her	1	2	3	4	5
35. _____ asks for more help than he or she needs	1	2	3	4	5

APPENDIX 20

Family-Directed Behaviour Management (FDBM) following acquired brain injury (ABI) in community settings: A feasibility study

Caregiver confidence in managing problem behaviours following ABI

Overall how confident do you feel in managing the behaviours of concern exhibited by your family member with brain injury?

Very confident	Somewhat confident	Neutral	Not very confident	Not at all confident
----------------	--------------------	---------	--------------------	----------------------

Do you feel confident in identifying why your family member exhibits behaviours of concern?

Very confident	Somewhat confident	Neutral	Not very confident	Not at all confident
----------------	--------------------	---------	--------------------	----------------------

Do you feel confident in identifying the most appropriate strategies to use to manage the behaviour/s?

Very confident	Somewhat confident	Neutral	Not very confident	Not at all confident
----------------	--------------------	---------	--------------------	----------------------

APPENDIX 21

FDBM PROGRAM

FEEDBACK- Education Phase

(to be completed at the end of the four-week education phase)

1. How helpful did you find the education sessions overall?

Not at all helpful A little helpful Moderately helpful Very helpful Extremely helpful

2. Do you feel you have a greater understanding of why problem behaviours occur following brain injury?

Not at all Not really Somewhat Yes definitely

3. Did you find the management strategies presented useful?

Not at all Not really Somewhat Yes definitely

4. Did you find the ‘Family Education Workbook’ easy to use?

Not at all Not really Somewhat Yes definitely

5. During this period have you received other support regarding behaviour management following ABI?

If you answer is yes, please comment:

6. Have you experience any significant changes/ life event during this period?

If you answer is yes, please comment:

FDBM – FEEDBACK

(to be collected at the end of the six fortnightly individual sessions)

1. How helpful did you find the program overall?

Not at all helpful A little helpful Moderately helpful Very helpful Extremely helpful

2. Do you feel you have a greater understanding of why problem behaviours occur following brain injury?

Not at all Not really Somewhat Yes definitely

3. Did you find the management strategies presented useful?

Not at all Not really Somewhat Yes definitely

4. How helpful did you find the individual sessions with the Principal Investigator?

Not at all helpful A little helpful Moderately helpful Very helpful Extremely helpful

5. Do you feel the program/researcher supported you to make decisions about what management strategies to use?

Not at all Not really Somewhat Yes definitely

6. Do you feel you have the skills to make changes to the behaviour management plan if needed?

Not at all Not really Somewhat Yes definitely

7. Did you find the follow-up phone calls helpful?

Not at all helpful A little helpful Moderately helpful Very helpful Extremely helpful

8. Do you think you met with the Principal Investigator often enough?

Not at all Not really Somewhat Yes definitely

9. Do you feel the program overall went for an appropriate length of time?

Not at all Not really Somewhat Yes definitely

10. During this period have you received other support regarding behaviour management following ABI?

Yes/NO

If your answer is yes, please comment

11. Have you experienced any significant changes/ life events during this period?

Yes/NO

If your answer is yes, please comment

Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI)
in Community Settings: A feasibility study

Exit Questionnaire/ Interview
(to be completed at three month follow up)

1. How helpful did you find the program overall?

Not at all helpful A little helpful Moderately helpful Very helpful Extremely helpful

2. How many times have you referred to the 'Family Education Workbook' since you completed the Education Sessions?

Not at all 1-2 times 3-5 times more than 5 times

3. Do you feel you have the skills to make changes to the behaviour management plan if needed?

Not at all Not really Somewhat Yes definitely

4. Since completion of the program have you received other support regarding behaviour management following ABI?

Yes/No

If your answer is yes, please comment

5. Have you experienced any significant changes/ life events since completion of the program?

Yes/No

If your answer is yes, please comment

APPENDIX 22

FDBM PROGRAM

QUESTIONS RAISED DURING SEMI-STRUCTURE INTERVIEWS

Interview questions asked following the education phase:

1. What did you like about the sessions?
2. What have you found most helpful? Or what do you think was the most useful part?
3. What do you think could be changed? Or how do you think the sessions could be improved?
4. Do you have any other comments you would like to share?

Interview questions asked at completion of all individualised sessions:

1. How have you found doing this type of behavior management program?
2. What did you like about it?
3. What did you find most helpful? Or what do you think was the most useful part of the program?
4. What kind of changes, if any, have you noticed in your family members challenging behaviours?
5. What strategies do you think you will continue to use now you have finished the sessions?
6. What were some of the difficulties or concerns you found with the FDBM program? Or what part of the program did you find most difficult?
7. What do you think should be changed? Or how do you think the program could be improved?
8. Do you have any other comments you would like to share?

Interview questions asked at three-months follow-up:

1. What kind of changes, if any, have you noticed in your family members challenging behaviours?
2. What strategies do you think you will continue to use now you have finished the program?
3. Do you have any other comments you would like to share?

APPENDIX 23

CANS results for Angus

Level 7: Cannot be left alone: needs nursing care, assistance, and/or surveillance 24 hours per day

CANS activity checklist

Group A: Requires nursing care, surveillance for severe behavioural/ cognitive disabilities, and/or assistance with the following very basic ADLs:

- Exhibits behaviours that have the potential to cause harm to self or others
- Continence
- Feeding
- Transfers/ mobility (including stairs and indoor surfaces)

Group B: Requires assistance, supervision, direction and/or cueing for the following basic ADLs:

- Personal hygiene/ toileting
- Bathing/ dressing
- Simple food preparation

Group C: Requires assistance, supervision, direction and/or cueing for the following instrumental ADLs and/or social participation:

- Shopping
- Housework/ home maintenance
- Medication use
- Money management
- Transport and outdoor surfaces
- Interpersonal relationships
- Leisure and recreation/ play

Group D: Requires support with:

- Informational supports (e.g. advice)
 - Emotional supports
-

APPENDIX 24

SPRS-2 Baseline scores - Angus

Occupational Activities				
Work	Work skills	Leisure	Organising activities	Total (mean) (Max=16)
BA1 = 0	BA1 = 0	BA1 = 1	BA1 = 0	1.5
BA2 = 0	BA2 = 0	BA2 = 0	BA2 = 2	
Interpersonal Relationships				
Spouse or partner/ ability to form relationships	Family	Friends and other people	Communication	
BA1 = 0 / 0	BA1 = 0	BA1 = 1	BA1 = 2	4
BA2 = 0 / 0	BA2 = 1	BA2 = 2	BA2 = 2	
Living Skills				
Social skills	Personal habits	Community travel	Accommodation	
BA1 = 0	BA1 = 0	BA1 = 0	BA1 = 0	0.5
BA2 = 1	BA2 = 0	BA2 = 0	BA2 = 0	

**For each item, 0 = Extreme change; 4 = no change or improvement*

Note: BA = Baseline Assessment

APPENDIX 25

OBS scores and PEM scores - Angus

	VA		PA object		PA self		PA people		SEX		PER/ REP		WAN/ ABS		SOC		INI	
	F	I	F	I	F	I	F	I	F	I	F	I	F	I	F	I	F	I
BA1	1	4	1	3	0	0	1	5	1	3	5	3	0	0	4	3	4	4
BA2	2	2	0	0	0	0	0	0	0	0	3	2	0	0	2	2	4	3
Mean	1.5	3	0.5	1.5	0	0	0.5	2.5	0.5	1.5	4	2.5	0	0	3	2.5	4	3.5
BA																		
OA1	2	2	1	2	0	0	1	3	2	2	3	3	0	0	3	2	5	3
OA2	0	0	0	0	0	0	0	0	0	0	4	2	0	0	3	2	4	3
OA3	0	0	0	0	0	0	0	0	0	0	5	2	0	0	0	0	5	3
OA4	0	0	0	0	0	0	0	0	0	0	4	2	0	0	1	1	5	3
OA5	0	0	0	0	0	0	0	0	0	0	4	2	0	0	0	0	5	3
PEM	80	80	80	80	80	80	80	80	80	80	20	80	0	0	60	100	0	100
%																		

F = Frequency; I = Impact

PEM = Percentage of data points below the median of baseline phase

Note: OBS = Overt Behaviour Scale; VA = verbal aggression; PA = physical aggression; SEX = inappropriate sexual behaviour; SOC = inappropriate social behaviour; WAN = wandering/ absconding; PER/REP = perseverative/ repetitive behaviours; INI = lack of initiation

Note: PEM ≥90% = suggests effective treatment; 70-90% = suggests moderate effect; 50%-70% = suggests mild effect; <50% = suggests ineffective treatment

APPENDIX 26

CAS Scores and PEM calculation – Kate

	BA1	BA2	Mean BA	OA1	OA2	OA3	OA4	OA5	PEM* %
Perceived Burden (max = 75)	42	42	42	48	48	45	45	48	100
Relationship Satisfaction (max = 55)	45	38	41.5	47	44	44	46	43	100
Caregiver Ideology (max = 25)	18	17	17.5	17	16	17	15	15	0
Caregiver Mastery (max = 20)	10	8	9	14	14	12	12	12	100

**PEM = Percentage of data points exceeding the median of baseline phase*

Note: PEM ≥90% - suggests effective treatment; 70-90% - suggests moderate effect; 50%-70% - suggests mild effect; <50% - suggests ineffective treatment

APPENDIX 27

Our Plan to PROMOTE POSITIVE BEHAVIOUR

Family-Directed Behaviour Management (FDBM)

Name: [ANGUS]

Angus has a great sense of humour, enjoys socialising, and being 'out and about'. However, due to his brain injury he has reduced ability to initiate involvement, can get 'stuck' on particular thoughts, and can sometime become under or over stimulated. **These factors can trigger behaviours of concern if not managed appropriately.** This plan will outline potential triggers of behaviours of concern and strategies to promote positive behaviour. **It is important to use preventative strategies identified to reduce the occurrence of behaviours of concern.** Important strategies for responding to be the behaviours are also identified.

Behaviours of concern:

- Repetitive behaviours
 - o 1) Repeated fixation on females (ex-girlfriend in particular). For example, will repeatedly state "I am going to marry Kirsten..."
 - o 2) Fixation on delusional ideas regarding Hitler. For example, will repeatedly state "Hitler lives next door"

Due to Angus' brain injury, he has reduced ability to initiate involvement in activities. He consequently relies on prompting from support staff. Instead of saying "Would you like to...?", rather start the process and wheel him outside.

e.g. If it is time to bring in the washing, start this process and wheel him to the washing line – when he is there he is more likely to willingly engage in task. However, if you ask him if he'd like to do this, this gives him the option of saying "no"

Possible triggers

- Authoritarian approach
- Exposure to romantic gestures between others (e.g. advertisements/ T.V)
- Exposure to army related experiences/ advertisements
- Individuals who look like ex-girlfriend (Thin, blond, European)
- Being under/over stimulated
- Hot temperatures

Warning signals – signs that he might be becoming agitated

- Tense through his shoulders
- Starts repetitive/ delusional phrases
- Shaky and agitated (increased verbal tone, & repetitive phrases)

Preventative Strategies:

Managing triggers

- Give Angus as much control over his own decisions as possible (e.g. choice of clothes, choice of toothbrush, choice of radio station)
- Avoid situations (where possible) that may have increased chance of triggers (e.g. if he's not involved in activities, initiate this process; if he has had a busy morning and seems "cooked", change things up a bit [e.g. garden activity/walk])
- **Keep Angus busy and involved**

ENSURE ANGUS' DAY IS BALANCED BETWEEN **ACTIVITIES HE ENJOYS DOING** vs ACTIVITIES TASKS THAT ARE NECESSARY BUT NOT ENJOYABLE (e.g. personal care routines)

Things that **Angus enjoys** doing are:

- Going to the café/ socialising
- People watching
- Gardening
- Listening to the radio
- Collectables – e.g. flags, garden gnomes, Meer cats, dragons

Angus has identified that time in his 'Comfy Chair' helps him calm down. He has also identified a "secret word" that you can use to prompt him to his chair – ask Angus about this. Remember to include Angus in developing these strategies.

Responsive strategies:

Responding to Repetitive/ Delusional behaviours

If Angus starts repeating phrases, first acknowledge what he has said, and then distract him to shift his thought process.

For example, if Angus says "*Hitler is in the next room, Hitler lives next door*" you might respond with:

"I don't think so, he passed away years ago. Hey, Angus, did you see the football game on the weekend?"

OR

Wheal him outside to do some gardening (as stated above, it may be best not to give him the option). Position him so he is able to engage in surroundings. For example, you might give him the hose – "*I think that tomato plant looks dry*"

If **distraction does not work**, and Angus appears to becoming increasingly agitated, it is best to prompt him to spend some time in his Comfy Chair. You might say one of the following:

Your secret agreed word (followed by a prompt) – “do you remember what this means..?”

OR

“You know how you said that the Comfy chair makes you feel calm.. let me know if you’d like to spend some time there..”

OR

“I’ve noticed that you seem a bit agitated, what might be a good thing to do...? (give him a chance to identify Comfy chair).. do you think it might be a good idea to spend some time in your Comfy Chair?”

IT IS BEST TO RESPOND TO REPETITIVE/DELUSIONAL BEHAVIOUR AS A SIGNAL THAT ANGUS IS BECOMING AGITATED, RATHER THAN GIVING TOO MUCH ATTENTION TO WHAT HE HAS ACTUALLY SAID.

REINFORCE the desired behaviours

If Angus identifies that he needs time in Comfy chair, *or* after prompting, spends time in his Comfy chair, remember to reward this behaviour. **VERBAL PRAISE** is often the best reinforcer (reward). You might say the following: *“That is so great that you identified that you need to spend time in your chair, well done”*

Later in the day after he has calmed down, you might even reflect on the experience. E.g. *“That was great that you spent time in your chair today when you were feeling agitated. I could see that really helped.. It’s excellent that you identified that this helps you calm down”*.

Crisis Strategies:

IF YOU ARE NOT IN THE RIGHT HEADSPACE TO RESPOND TO BEHAVIOURS (calm and in control), IT IS BEST TO TEMPORARILY REMOVE YOURSELF FROM THE SITUATION.

If Angus becomes increasingly agitated and is no longer in control of his behaviour. It is important to:

- Keep calm and in control
- Maintain a safe distance
- Remove items that he may throw/break out of reach
- Do not try and reason with Angus, or discuss the situation with him
- Let him know that it will be ok

- Remove yourself from situation, and let him know that you are close by (e.g. next room)

MONITOR YOUR STRATEGIES

Every couple of weeks, ask yourself and consider the following questions:

Are these strategies still working?

If not, you might need to change things up a bit. Remember to involve Angus – ask him what activities/ places/ objects help him feel calm. You might also think of a different “secret word”.

Is Angus’ daily routine balanced with enjoyable/meaningful activities, rather than only required but less desired activities (e.g. personal care routines)?

Does Angus have sufficient control/choice in daily decisions?

REFER TO YOUR FAMILY EDUCATION WORKBOOK

Revisit your workbook at any time to refresh your knowledge regarding why behaviour changes may occur following brain injury and what strategies might be helpful.

APPENDIX 28

Frequency recordings - Angus

Week	Anger					Perseveration					Delusional				
	Days					Days					Days				
	1	2	3	4	M	1	2	3	4	M	1	2	3	4	M
5	3	3	4	2	3	4	5	5	6	5	2	3	4	3	3
12	0	0	0	0	0	1	0	2	1	1	0	0	0	0	0
24	0	0	0	0	0	1	2	1	0	1	0	0	0	0	1.5
37	0	0	0	0	0	0	0	1	0	0.25	0	0	0	0	0

**M= mean*

APPENDIX 29

CANS results - Bob

Level 7: Cannot be left alone: needs nursing care, assistance, and/or surveillance 24 hours per day

CANS activity checklist

Group A: Requires nursing care, surveillance for sever behavioural/ cognitive disabilities, and/ or assistance with the following very basic ADLs:

- Bed mobility (e.g., turning)
 - Exhibits behaviours that have the potential to cause harm to self or others
 - Has difficulty in communicating basic needs because of language impairments
 - Continence
 - Transfers/ mobility (including stairs and indoor surfaces)
-

Group B: Requires assistance, supervision, direction and/or cueing for the following basic ADLs:

- Personal hygiene/ toileting
 - Bathing/ dressing
 - Simple food preparation
-

Group C: Requires assistance, supervision, direction and/or cueing for the following instrumental ADLs and/or social participation:

- Shopping
 - Housework/ home maintenance
 - Medication use
 - Money management
 - Transport and outdoor surfaces
 - Parenting skills
 - Interpersonal relationships
 - Leisure and recreation/ play
-

Group D: Requires support with:

- Informational supports (e.g. advice)
 - Emotional supports
-

APPENDIX 30

SPRS-2 Results – Bob

Occupational Activities				
Work	Work skills	Leisure	Organising activities	Total (mean) (Max=16)
BA1 = 0	BA1 = 0	BA1 = 1	BA1 = 0	1
BA2 = 0	BA2 = 0	BA2 = 1	BA2 = 0	
Interpersonal Relationships				
Spouse or partner/ ability to form relationships	Family	Friends and other people	Communication	
BA1 = 0/0	BA1 = 1	BA1 = 0	BA1 = 0	1.5
BA2 = 0/NA	BA2 = 1	BA2 = 0	BA2 = 1	
Living Skills				
Social skills	Personal habits	Community travel	Accommodation	
BA1 = 0	BA1 = 0	BA1 = 0	BA1 = 0	1
BA2 = 1	BA2 = 1	BA2 = 0	BA2 = 0	

**For each item, 0 = Extreme change; 4 = no change or improvement*

Note: BA = Baseline Assessment

APPENDIX 31

OBS Scores and PEM scores - Bob

	VA		PA object		PA self		PA people		SEX		PER/ REP		WAN/ ABS		SOC		INI	
	F	I	F	I	F	I	F	I	F	I	F	I	F	I	F	I	F	I
BA1	3	3	2	3	0	0	3	4	0	0	5	4	0	0	2	4	4	3
BA2	3	3	2	3	0	0	1	3	0	0	5	2	0	0	3	2	2	3
Mean	3	3	2	3	0	0	2	3.5	0	0	5	3	0	0	2.5	3	3	3
BA																		
OA1	3	3	1	2	0	0	2	3	0	0	4	2	0	0	3	2	5	4
OA2	3	2	0	0	0	0	3	3	0	0	2	2	0	0	3	2	5	3
OA3	3	3	0	0	0	0	2	3	0	0	5	2	0	0	0	0	5	2
OA4	4	3	0	0	0	0	2	3	0	0	4	2	0	0	0	0	4	3
OA5	3	3	3	2	0	0	4	3	0	0	4	2	0	0	5	3	4	3
PEM	0	20	80	100	0	0	0	100	0	0	80	100	0	0	40	80	0	20
	%																	

F = Frequency; I = Impact

PEM = Percentage of data points below the median of baseline phase

Note: OBS = Overt Behaviour Scale; VA = verbal aggression; PA = physical aggression; SEX = inappropriate sexual behaviour; SOC = inappropriate social behaviour; WAN = wandering/absconding; PER/REP = perseverative/ repetitive behaviours; INI = lack of initiation

Note: PEM ≥90% - suggests effective treatment; 70-90% - suggests moderate effect; 50%-70% - suggests mild effect; <50% - suggests ineffective treatment

APPENDIX 32

CAS Scores and PEM scores - Lauren

	BA1	BA2	Mean BA	OA1	OA2	OA3	OA4	OA5	PEM* %
Perceived Burden (max = 75)	38	45	41.5	35	38	40	44	54	40
Relationship Satisfaction (max = 55)	45	42	43.5	44	49	44	44	45	100
Caregiver Ideology (max = 25)	17	16	16.5	16	13	16	19	17	40
Caregiver Mastery (max = 20)	13	14	13.5	9	12	13	13	13	0

**PEM = Percentage of data points exceeding the median of baseline phase*

Note: PEM ≥90% - suggests effective treatment; 70-90% - suggests moderate effect; 50%-70% - suggests mild effect; <50% - suggests ineffective treatment

APPENDIX 34

Our Plan to PROMOTE POSITIVE BEHAVIOUR

Family-Directed Behaviour Management (FDBM)

Name: [BOB]

Bob has a great sense of humour, enjoys playing games, cooking and being outdoors. However, due to his brain injury he has reduced ability to initiate involvement and can become easily over-stimulated. He also has aphasia (communication difficulties), and has ongoing medical issues that can cause significant pain. **These factors can trigger behaviours of concern if not managed appropriately.** This plan will outline potential triggers of behaviours of concern and strategies to promote positive behaviour. **It is important to use the preventative strategies identified to reduce the occurrence of behaviours of concern.** Important strategies for responding to the behaviour are also identified.

Behaviours of concern:

- Agitated/ Repetitive Behaviours (e.g. repetitively state “7:30”, “I’ve had enough”, “Hello Hello”)
- Insults towards Staff (e.g. “Poofter”, “Bitch”, “pain in the bum”)
- Continuous Screaming
- Lashing out with arms towards staff

Possible triggers:

- Shower/ Toilet Routine
- Pain/ Medical Issues
- Movement (e.g. bed to lifter)
- Overstimulation (e.g. loud and busy environments)
- Being called [nickname]

Warning signals (signs that he might be becoming agitated):

- Lips moving (e.g.: smacking together – a) possibly thirsty & b) becoming agitated)
- Muttering
- Repetitive behaviors (e.g. “7:30”, “I’ve had enough”)

Preventative Strategies:

Managing triggers

- Involve Bob in decision making around his personal care routine (e.g.: afternoon showers may be more successful with reduced pain levels).
- Explain to Bob why you need to move him (give him time to process – i.e. 3-4 minutes)
- Avoid busy environments where possible (e.g. busy shopping malls)
- Talk in a calm and quiet manner while in Peterson house (i.e. avoid yelling through the house)
- Avoid calling him [nickname]
- Suggest calm music/DVD in the evening to reduce elevation

Due to Bob's brain injury, he has reduced ability to initiate involvement in activities; he consequently relies on prompting from support staff.

- You may need to actively prompt participation by making leading statements (e.g. state "it's lovely outside, let's go for a walk...") rather than asking closed questions (e.g. "would you like to go for a walk?").

Bob can become quickly overloaded with sensory information, it is therefore best to:

- use short and simple sentences
- use calm tone and avoid too much noise where possible

Bob has Aphasia and as a result, often has difficulty communicating what he actually means. For example:

- when he says "want to go to bed", but is already in bed, this may mean 'I want to go to sleep'
- when he says "I want to go home", but is already at home, this may mean 'I want to go to bed'

ENSURE THAT BOB'S DAY IS BALANCED BETWEEN **ACTIVITIES HE ENJOYS DOING** vs ACTIVITIES TASKS THAT ARE NECESSARY BUT NOT ENJOYABLE (e.g. personal care routines)

Things that **Bob enjoys** doing are:

- Going outside for walks or to the shops
- Playing Uno
- Assisting with preparing food
- Going for train rides
- Having family visit

Responsive strategies:

Responding to agitation/ repetitive behaviours:

First ask Bob if he needs anything. If he says no:

- Distraction. E.g. take him outside for a walk
- Let Bob know that you are in the next room and that you will give him 5 minutes to calm down
- Please leave door open and repeat after 5 minutes if needed
- **As a last resort**, offer a dose of PRN medication, if he says “no” give 5 minutes alone to calm down (repeating above) (**seek advice from medical practitioner**)

When Bob is agitated he needs space to calm down. Please do not offer him food to avoid risk of choking.

When communicating with **Bob do not lean into his personal space**, as this may make it worse.

If his behavior becomes unmanageable (i.e. the above strategies are not effective and he appears sweaty/ has a temperature/ is continuously screaming/ confused or jumbling words) please seek medical attention (as this may be a sign that he may be in pain).

Responding to agitation/ insults during personal care routine

Sometimes Bob can be sensitive to water whilst showering (this was also something he disliked prior to his injury), so use a sensitive approach. Try the following:

- Give Bob 5 minutes to calm down and let him know that you are just outside the door and will be back soon.

- If Bob states he does not want a shower, do not keep asking. He does not need a shower every day. However, if it is necessary (e.g: after a bowel motion) explain why he needs the shower; he may then be more likely to cooperate.
- Consider Bob's dignity; allow privacy where possible. Being dependent on others for personal tasks may also reinforce his reduced independence following brain injury. It is important to keep this in mind.
- Keep calm. Bob often becomes elevated during shower routine, so using calm body language and tone are very important to encourage him to stay calm.

Responding to Personal Insults

- Ignore **what** has been said
- A good response might be *"I can see that you are agitated is there something I can do for you?"* or use distraction? *Divert his attention to more desired activity/topic (e.g. put DVD on).* **Ensure activities are age appropriate.**

Do not take insults personally and respond to them as such. Do not give attention to *what* is being said and please do not respond jokingly to this behavior; when Bob says in German 'leck mich am arsch' ([English: "lick my bum"], which basically means "*p*ss off*"), and joking behaviour might make the behavior worse.

REINFORCE the desired behaviours

Desired behaviours:

- Not giving personal insults during personal care routine
- Being calm during manual lifting
- Communicating his needs verbally (i.e: that he would like to go to bed, to go home, not hungry, does not want to take medication or does not feel like having a shower)

VERBAL PRAISE is often the best reinforcer (reward). When these behaviours occur, you might say the following:

- *"You did really well during the shower today, well done"*
- *"Thanks for being so patient while we moved you, that was really helpful"*

If Bob communicates his needs appropriately reward this behavior by respecting his wishes, for example:

- If he says he is not hungry, say *"ok no problem. I'll ask you again later"* (don't continuously ask him if he has said 'no').

- If he says he does not want a shower, say *“That’s ok you don’t need to have a shower now”* (Bob does not need to have a shower every day if he does not want to. Possible strategy is to offer him a shower in the afternoon when pain levels are reduced).

Crisis Strategies:

IF YOU ARE NOT IN THE RIGHT HEADSPACE TO RESPOND TO BEHAVIOURS (calm and in control), IT IS BEST TO TEMPORARILY REMOVE YOURSELF FROM THE SITUATION.

If Bob becomes increasingly agitated and is no longer in control of his behaviours. It is important to:

- Keep calm and in control
- Maintain a safe distance
- Do not try and reason with, or discuss the situation with Bob
- Let him know that it will be ok
- Remove yourself from situation, and let him know that you are close by (e.g. next room)
- If Bob appears to be in pain (i.e: sweaty, temperature, screaming, verbally confused or jumbling words) call an ambulance

MONITOR YOUR STRATEGIES

Every couple of weeks, consider the following:

Are these strategies still working?

If not, you might change the strategies – are there changes to the environment that might further support positive behaviours? would it help to further reinforce (reward) the desired behaviours (or change the reinforcer/reward)?

Observing the problem behaviours (and what happens directly before and after the behaviours occurs) will help you identify why the behaviour is occurring, and what strategies might be helpful.

Is Bob’s daily routine balanced with enjoyable/meaningful activities, rather than only required but less desired activities (e.g. personal care routines)?

Does Bob have sufficient control/choice in daily decisions?

It is important to discuss these questions with your colleagues and supervisor, and make sure you have a consistent approach in managing behaviours.

APPENDIX 35

Frequency recordings - Bob

Week	Perseveration					Insults					Screaming				
	Days					Days					Days				
	1	2	3	4	M	1	2	3	4	M	1	2	3	4	M
10	16	12	14	18	15	15	10	11	16	13	11	6	5	10	8
21	32*	9	11	20	13	10	11	13	14	12	8	6	9	9	8
29	8	4	10	5	6.8	3	3	6	4	4	7	4	8	5	6
41	15	14	16	11	14	6	4	4	7	5.3	5	7	5	5	5.5

Note: M=Mean

**score omitted – it was confirmed that staff member recorded each time Bob repeated the phrase rather than instances of perseveration (during which he repeated single phrase multiple times)*

APPENDIX 36

FDBM Pilot Feedback Questionnaires

Feedback Questionnaire responses post education sessions

	Kate	Lauren
1. How helpful did you find the education sessions overall?^a	Extremely helpful	Extremely helpful
2. Do you feel you have a greater understanding of why BOC occur following brain injury?^b	Yes definitely	Yes definitely
3. Did you find the management strategies presented useful?^b	Yes definitely	Yes definitely
Did you find the FDBM Education Workbook easy to use?^b	Yes definitely	Yes definitely
During this period have you received other support regarding behaviour management following ABI?	No, but did have two appointments with neuropsychologist who is also monitoring behaviours	No
Have you experienced any significant changes/ life events during this period?	No	No

^a *Five-point Likert-type items: Not at all helpful; A little helpful; Moderately helpful; Very helpful; Extremely helpful*

^b *Four Likert-type items: Not at all; Not really; Somewhat; Yes definitely*

Feedback Questionnaire post individualised sessions

	Kate	Lauren
How helpful did you find the program overall?^a	Extremely helpful	Very helpful
Do you feel you have a greater understanding of why BOC occur following brain injury?^b	Yes Definitely	Yes definitely
Did you find the management strategies presented useful?^b	Yes definitely	Somewhat
How helpful did you find the individual sessions with the researcher?^a	Extremely helpful	Very helpful
Do you feel the program/ researcher supported you to make decisions about what management strategies to use?^b	Yes definitely	Yes definitely
Do you feel you have the skills to make changes to the behaviour management plan if needed?^b	Yes definitely	Yes definitely
Did you find the follow-up phone calls helpful?^a	Extremely helpful	Moderately helpful
Do you think you met with the researcher often enough?^b	Somewhat	Yes Definitely
Do you feel the program overall went for an appropriate length of time?^b	Yes definitely	Somewhat
During this period have you received other support regarding behaviour management following ABI?	Yes. 2-hr workshop regarding behaviour change through family support network, 1 appointment with neuropsychiatrist	No

Have you experienced any significant changes/ life events during this period?	No	No
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^a Five-point Likert-type items: Not at all helpful; A little helpful; Moderately helpful; Very helpful; Extremely helpful

^b Four Likert-type items: Not at all; Not really; Somewhat; Yes definitely

Exit questionnaire- three-month follow-up

	Kate	Lauren
How helpful did you find the program overall? ^a	Extremely helpful	Very helpful
How many times have you referred to the FDBM workbook since you completed the education sessions?	More than 5 times	1-2 times
Do you feel you have the skills to make changes to the behaviour management plan if needed? ^b	Yes Definitely	Yes Definitely
Since completion of the program have you received other support regarding behaviour management following ABI?	No	No
Have you experienced any significant changes/ life events since completion of the program?	No	[Bob] accepted to move to new accommodation facility

^a Five-point Likert-type items: Not at all helpful; A little helpful; Moderately helpful; Very helpful; Extremely helpful

^b Four Likert-type items: Not at all; Not really; Somewhat; Yes definitely

APPENDIX 37

Facilitator's reflections

Extracts from the researcher's PhD journal regarding the delivery of the FDBM program:

Education Phase

During the first education session, Kate was reflecting on the information provided and asked me if she had read 'a Flower Between the Cracks' by Helen Sage. She said that she cried all the way through the book, identifying closely with Helen's experience of being the mother of an adolescent who sustained a brain injury. Kate suggested to me that I read the book as a way of further understanding her situation. This was not the first autobiography I had read regarding family's experience following an ABI, but certainly one of the most powerful; perhaps contributing to these feelings was the association with the experiences shared by Kate. Reading this book definitely seemed to help in developing rapport with Kate. This may have been because I followed her recommendation, providing genuine interest in gaining increased insight and empathy regarding Kate's lived experience. *The researcher further reflects on the importance of such autobiographical accounts of families' experiences in providing a reminder to why she has chosen this field of work. Indeed, it is easy to become all consumed with the clinical aspects of research.*

Both Kate and Lauren appeared to be very motivated in their involvement and engaged throughout the process. Kate often reported revisiting the information on her long train rides to meet with me; with these trips in themselves reflecting a great commitment to her involvement. She appeared to reflect a lot on the information presented, and at times seemed a little overwhelmed with the amount of content provided. Indeed, although the participants reported high satisfaction in the content and pace of delivery of the education sessions, I felt some weeks were too “content heavy” – specifically the first education session, where I felt rushed in getting through all of the necessary content. I felt this increased pace did not allow enough time for participants to process the information provided. It may have therefore been more appropriate to give clear description of the core strategies for cognitive difficulties with more comprehensive examples, rather than including each of the possible cognitive difficulties and suggested strategies for each. The participants could then be directed to the information in the workbook relevant to their own situations, which could then be revisited during the individualised sessions if necessary. Furthermore, as the participants often wanted to provide specific examples from their experiences that illustrated the information presented. It would have been good to allow a little more time for these diversions.

Both participants had some difficulty defining the target behaviours in observable terms; in fact, this seemed to be one of the hardest activities for participants. The example in the workbook was very helpful; however, both Kate and Lauren needed further prompting to step back from the behaviour and describe them objectively, rather than including broad umbrella terms (such as “angry”) personal opinion and presumed functions (i.e. ‘he was angry because...’) of behaviour within their definitions. I felt an additional activity could be included to further reinforce

this skill. These same difficulties were faced in recording the ABC data, with their observations being quite subjective. I felt that video examples would be a great addition to this section, allowing the families to practice the observation and for me to be able to provide feedback, rather than waiting for participants to report on their observations during the following session.

The participants appeared to be engaged and interested in the more comprehensive behavioural procedures presented in the fourth education session; however, again this seemed a little overwhelming. I felt they were taking away the key information, and felt the examples were very effective in illustrating these procedures, however felt these could have been further simplified. It may have been better to cover concepts of positive reinforcement and differential reinforcement (DR) strategies, providing more activities and examples regarding these procedures; this would further reinforce their knowledge in the most commonly used procedures, and then they could read up on concepts such as overcorrection could be included as extra reading for those interested.

On one occasion Lauren cancelled a session because was called in for a 'behavioural emergency'. I had some concern that Lauren being called in to support Bob was setting up a negative pattern of behaviour for Bob, who may learn that he could get Lauren to come in when he had significant screaming episodes, but also for staff, in relying on Lauren 'coming to the rescue' rather than learning strategies to manage the situation at hand. In this one situation, I suggested that Lauren could provide some strategies over the phone and could let staff resolve the situation, especially as this was not identified as a medical emergency. This also occurred at time when Lauren reported to be struggling with mental health issues, and I felt it

was important to put her own needs first in this situation. At the time, Lauren seemed disconcerted with this advice, however, this prompted some good conversations in their following session regarding why she did not feel staff could manage such situations, and the importance of her looking after her own wellbeing.

Individualised sessions

In her journal entries, the researcher's notes reflect the experience of training families to implement strategies, rather than personally conducting the functional behaviour assessment and implementing and monitoring strategies herself: This was a new experience for me, with definite moments of 'itchy feet', wanting to intervene or at least 'be a fly on the wall'. However, it was great to reflect on what information was included within the education phase, and which strategies were then implemented by participants in the individualised sessions. The strategies focussed on positive setting events and antecedent strategies, with verbal praise used as a positive reinforcement for desired behaviours. I did not question appropriateness of the strategies that participants proposed; indeed, these strategies appeared to reflect proposed functions of behaviours and appeared effective in reducing behaviours. However, in considering the reports of Lauren, I felt that perhaps more comprehensive procedures would have had further benefits (i.e. teaching Bob alternative communication methods). However, due to the barriers presented by Lauren having limited control over strategies being implemented by support staff, and the added challenges of Lauren's the inability to ensure the reliability of observation data, such strategies were not feasible. However, given the proposed function of Bob's BOC, which appeared to most directly relate to

environmental factors and staff interactions and responses to the behaviour, the strategies utilised were appropriate in addressing these. It was possible to identify what Bob was trying to say given his current level of communication; however, there was concern of decline in his communication skills. If the primary function of behaviour had been a directly related to Bob's communication difficulties, these strategies would have been the primary focus of the individualised session.

During the individualised sessions Lauren expressed frustration that the staff did not appear to be implementing recommendations made by the neuropsychologist, but also suggestions that had been recommended from functional behaviour assessment conducted a few years earlier through the accommodation agency; she questioned whether staff even referred to this document. Lauren felt the behaviour of staff was exacerbating Bob's BOC. She felt much of this to do with communication style, which she felt was further exacerbated by the fact that English was a second language for a number of the support staff. I prompted her to clearly outline what staff behaviours were negatively effecting Bob's behaviours, and what simple guidelines may be helpful for staff in improving the staff member's communication style. I also reinforced the difficulties faced by staff in working in this field with limited English language, with the hope of fostering further empathy in Lauren. I felt by trying to promote further rapport between Lauren and the staff, that staff may be more 'open' to making the suggested changes. Although Bob and Lauren have little control over who provides care (which is indeed another issue warranting discussion elsewhere), it seems that the communication behaviours she identifies as being the greatest issue (i.e. using nickname, responding to his insults in joking manner, speaking in loud voice and singing songs appropriate only for a young child), could be addressed with some clear basic guidelines. Support workers

could also be given more specific guidelines in interpreting his requests (which are sometimes not articulated in a clear manner).

Lauren expressed to me that the staff had no practical resources to refer to, and felt they may be limited in their comprehension of such educational resources due to limited English literacy. This prompted me to develop a simplified version of the FDBM workbook, providing staff with simple PBS guidelines with illustrations. This booklet was provided to both Kate and Lauren at completion of the program as an educational resource for paid support workers.

During the individualised sessions the participants showed me their current behaviour support plans. These consisted of very generic information, with no clear guidelines or specific examples of how to respond to BOC. Indeed, in responding to the behaviour, one of the plans recommended “reinforce desired behaviour”. How is the family caregiver meant to know what this means?: how do they reinforce behaviour? What is a reinforcer? What might be an *appropriate* reinforcer? This has prompted further questions about what might be a more helpful template for a BSP from the perspective of non-specialised caregivers. This is suggested for further research.

I also found it interesting that both participants, with their high levels of reported confidence and engagement, appeared quite anxious about the program coming to an end. She reflects on the importance of ongoing support, making the comparison with paid support staff, who have ongoing supervision and support in the caregiving roles. *This issue is discussed further in recommendations in the further development of the FDBM program.*

Laurens levels of stress appeared to fluctuate with each session, she also reported having her anti-depressants changed in the third individualised sessions. She also reported an increasing tension between her and the managers of her father's housing agency. She felt they were not sufficiently catering to her father's needs or taking on board her suggestions, and as a result had initiated a full investigation of the disability organisation through the health commission and was looking into possible alternative housing arrangements for Bob.

At follow-up, I felt Lauren had 'given up' on trying to make positive changes to Bob's current situation, but was rather looking forward to his transition to his new accommodation. She seemed positive about her communication with the staff through this agency, and was hopeful they would be more responsive to her suggestions around Bob's behaviour support plan.

APPENDIX 38

Wednesday, August 24, 2016 at 3:09:42 PM Australian Central Standard Time

Subject: APPROVED: RESPONSE: R20151116 - Ethics Modification Request
Date: Wednesday, June 8, 2016 at 2:25:21 PM Australian Central Standard Time
From: Health:CALHN Research Ethics
To: Alinka Fisher
Attachments: image001.gif, image002.png

Dear Alinka,

Re: RAH Protocol No: R20151116 HREC/15/RAH/486

Title: Family-Directed Behaviour Management (FDBM) following Acquired Brain Injury (ABI) in Community Settings: A Feasibility Study

Thank you for the email below with attached documentation for the above study for review, including:

- Cover letter template for organizations
- Research Protocol with amendments (highlighted)
- Recruitment Email
- Participant Letter of Introduction
- Workbook Feedback Form

Thank you for the Organization letter. That is very good. I have reviewed the document(s) and there are no ethical or governance issues. The document(s) are **APPROVED**, effective **from the date of this email**.

Please accept this e-mail as **Acknowledgement of Receipt, Review and APPROVAL** of the document(s), **on behalf of RAH Human Research Ethics and CALHN Governance**, and retain a copy for your records.

For multi-centre studies a copy of this email must be forwarded to Principal Investigators at every site approved by the RAH HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.



A/Prof Andrew Thornton
Chairman, Research Ethics Committee
Royal Adelaide Hospital
ph (08) 8222 4139
mob: 0418 832 346

From: Alinka Fisher [mailto:alinka.fisher@flinders.edu.au]
Sent: Wednesday, 8 June 2016 10:08 AM
To: Health:CALHN Research Ethics
Subject: Re: RESPONSE: R20151116 - Ethics Modification Request

Dear Andrew,



APPENDIX 39

Alinka Fisher
PhD Candidate

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[DATE]

Dear Sir/Madam,

I am a PhD student in Disability and Community Inclusion, School of Health Sciences, at Flinders University.

I am undertaking research looking at family involvement in behaviour management following brain injury.

This part of my research aims to find out if the Education Workbook titled “Understanding and Managing Challenging Behaviour following Brain Injury” is helpful for family members.

This workbook includes information on common behaviour changes following brain injury and basic behaviour management strategies. It has been developed as part of a two-stage intervention for families following acquired brain injury called the Family-Directed Behaviour Management (FDBM) program. This program is currently being trialed at Flinders University.

I am specifically looking at whether the book is written in a way that is easy to read and helpful for family members. The workbook is 82 pages long, but consists of many pictures and is not dense with written information.

If you are over 18 and have a family member with brain injury who exhibits behaviours of concern, I would be grateful if you would volunteer to participate in this study.

Your participation would involve reading the 82 page Education Workbook (over a two week period) and completing a one-page feedback form.

Please be assured that any information you provide will be treated as confidential. You are also under no obligation to participate, and this will not result in any discrimination, reduced support, or any other penalty.

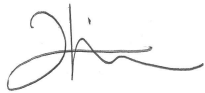
If you have any questions please contact me at Alinka.Fisher@flinders.edu.au or by telephone on (08) 8201 5956.

This research will be conducted according to the NHMRC National Statement of Ethical Conduct in Human Research, 2007.

If you wish to speak to someone not involved in the study about the conduct of the study you may contact the Executive Officer of the Royal Adelaide Hospital Human Research Ethics Committee at rah.ethics@health.sa.gov.au or by telephone on (08) 8222 4139.

Thank you for your time and help you may be able to offer to this study

Yours sincerely,



Alinka Fisher

PhD Candidate
Disability and Community Inclusion
School of Health Sciences,
Flinders University



About me: I have a Bachelor of Disability and Community Rehabilitation (First Class Honours), and specialise in positive behaviour support. I am a trained facilitator of the Triple P (Positive Parenting Program), facilitate workshops on 'Anger and ABI' for Families4Families Inc, and have worked for Relationships Australia SA conducting functional behaviour assessments. I have experience supporting adults with ABI with problem behaviours in community settings and spent two years in England supporting children on the autistic spectrum with complex behaviour needs.



APPENDIX 40

Alinka Fisher
PhD Candidate

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Understanding & managing challenging behaviours following brain injury: Workbook feedback

Dear _____,

Thank you for taking the time to provide feedback on the Family Education Workbook. This workbook has been developed as part of a two-stage intervention for families following acquired brain injury called the Family-Directed Behaviour Management (FDBM) program, which is currently being trialed at Flinders University.

With your feedback, we hope to ensure the workbook is written and presented in a way that is easy to read and helpful for family members.

Please return this completed form within 2 weeks of receiving it (due date is Friday 3rd February 2017). A reply paid addressed envelope is provided for this purpose.

You are very welcome to keep the workbook at the end if you like.

Yours sincerely,

Alinka Fisher,
PhD Candidate
Flinders University

Information about you:

1. What is your postcode? _____
 2. Are you:
Male ___ Female ___
 3. How old are you? _____
 4. What study have you done since school?
 - a. None _____
 - b. TAFE/ Trade qualification _____
 - c. Undergraduate qualification _____
 - d. Postgraduate qualification _____
 - e. Other (please indicate) _____
 5. What is the main language/s spoken in your home? _____
-

Family Education Workbook - Feedback

The workbook was easy to read

Strongly disagree Disagree Agree Strongly Agree

The information in the workbook was clearly explained

Strongly disagree Disagree Agree Strongly Agree

The topics were presented in enough detail

Strongly disagree Disagree Agree Strongly Agree



The layout and pictures were helpful

Strongly disagree Disagree Agree Strongly Agree

The workbook helped my understanding of challenging behaviours after brain injury

Strongly disagree Disagree Agree Strongly Agree

The workbook helped me identify strategies that might be useful in managing challenging behaviours after brain injury in my family member

Strongly disagree Disagree Agree Strongly Agree

What did you like most about this workbook?

What aspects of the workbook could be improved?

Please share other comments here:

Thank you for your feedback!

APPENDIX 41

FDBM Education Workbook survey responses

FDBM Workbook Likert-Type responses

	Strongly disagree	Disagree	Agree	Strongly agree
The workbook was easy to read			66.7% (n=4)	33.3% (n=2)
The information was clearly explained			50% (n=3)	50% (n=3)
The topics were presented in enough detail			66.7% (n=4)	33.3% (n=2)
The layout and pictures were helpful			66.7% (n=4)	33.3% (n=2)
The workbook helped my understanding of challenging behaviours after brain injury			50% (n=3)	50% (n=3)
The workbook helped me identify behavioural strategies that might be helpful		16.7% (n=1)*	33.3% (n=2)	50% (n=3)

**a footnote was included on this survey stating 'a lot of this doesn't apply to my relative'*