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Use of instant messaging to improve participation in rehabilitative prescribed exercises for sufferers of Acquired Brain Injury: a feasibility study

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2023-06

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Osato, Claudia Caterina. (2023). Use of instant messaging to improve participation in rehabilitative prescribed exercises for sufferers of Acquired Brain Injury: a feasibility study. [Master's dissertation, University of the Witwatersrand, Johannesburg]. WIReDSpace.

<https://hdl.handle.net/10539/39896>



Use of instant messaging to improve participation in rehabilitative prescribed exercises for
sufferers of Acquired Brain Injury: a feasibility study.

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15th March 2023

Final Submission date: 25th June 2023

Acknowledgements

I would like to thank the individuals who contributed to my ability to finish this report. I could not have completed this study without the kindness, love and encouragement of all of you.

To my Supervisor, Aline, to say that without you this would not have been possible is an understatement. Through every challenge you supported me and were unmatched in your ability to motivate me every time we spoke. Your knowledge and approach to your work is admirable and I will always be grateful for all you did.

To my parents, thank you for always encouraging me to learn and to further my education. You both moulded me into the woman I am today with a passion and love for learning and I would not have been able to believe in myself without your guidance.

Antonio, Stefano and Natalie without you three I can safely say I wouldn't be where I am today. Your consistent cheering on, your love, your encouragement and your gusto, pushed me to finish one of the most challenging things so far. I appreciate you all immensely.

To Lisa, a special mention would not be enough. You are a guiding light who pushed me through the darkest times in this process and provided me with the assistance, motivation and love that I needed at every point. I don't know what I would have done without you.

To my friends, especially Katia, Danielle and Mario, thank you for always asking about my project, for being interested when I spoke to you about my work, for being supportive when I cried from exhaustion and for pretending not to be bored when I complained.

A special thank you to Rikus, who assisted me with my results section and helped me think through how to visualise my data. I am so grateful for the knowledge and advice you shared.

Declaration

I declare that this research project is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university.



Claudia Caterina Osato

14th day of March 2023

Total Word Count: words (excl. Reference List, appendices etc)

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Abstract

This paper considers the feasibility of implementing an instant messaging program to improve participation in rehabilitative prescribed exercises for individuals with Acquired Brain Injury. Due to the common sequelae of brain injuries, such as prospective memory, motivation deficits and executive functioning, individuals with Acquired Brain Injuries (ABI) often do not complete homework. This study aimed 1) to create an instant messaging reminder Program to improve participation in rehabilitative prescribed exercise homework for individuals with Acquired Brain Injuries and 2) to assess the feasibility thereof. Four therapists participants were included in the study (two Occupational Therapists, one Physiotherapist and one Speech Therapist). Thematic analysis was utilised to assess responses to the semi-structured interviews to ascertain the therapists' perceptions of the feasibility of the proposed intervention. An ethnographic approach explored the researcher's experiences in relation to the process of the research. Results of the study included indications that due to both contextual and other challenges the Program could not be assessed for feasibility, as well as institutional challenges to implementation. The researcher found that the implementation of the proposed program was not possible due to various obstacles, which include, lack of ability to access public hospital patients, concerns of therapists regarding the sustainability of the intervention as well as changes and challenges in relation to the potential patients and participants. The researcher concluded that the implementation of the specific Program was not possible to implement in the context of both private and public rehabilitation services in Johannesburg and hence feasibility could not be ascertained.

Use of instant messaging to improve participation in rehabilitative prescribed exercises for sufferers of Acquired Brain Injury: a feasibility study.

Chapter 1: Introduction

ABIs are increasing in South Africa, however, access to appropriate neurorehabilitation and recovery are not sufficient (Joosub, 2019). This poses a large issue with reference to the ability of individuals to improve their lives through the use of therapeutic practice. Although brain injuries are caused by a singular event, the sequelae and long term consequences of these injuries pose problems for individuals for the rest of their lives, and as such, the individual requires significant rehabilitation and care for the duration of their life (Dams-O'Connor et al., 2018).

The following study sought to ascertain the feasibility of an instant messaging intervention to improve participation in rehabilitative prescribed exercises for individuals who have sustained ABIs. This included the creation of a Program which focused on telerehabilitation through cognitive rehabilitation, foregrounding Speech Therapy, Occupational Therapy and Physiotherapy. The aim of this research was to ascertain the feasibility of a compensatory instant messaging reminder system, focusing on telerehabilitation, which aimed to be implemented within the South African context of a lack of access to sufficient therapeutic resources, barriers to rehabilitation and the need for at-home intervention Programmes (Cobbing et al., 2014).

Telerehabilitation can be defined as the use of technology to increase access to rehabilitation services, thereby decreasing barriers caused by distance, time and financial factors (McCue et

al., 2010). Although telerehabilitation has been found to be successful in many countries around the world, research states that this form of rehabilitation faces many barriers to being a feasible means to offer therapeutic interventions in developing countries (Leochico et al., 2020).

This research report consists of six main chapters. The first of these is the Introduction, outlining the main purpose and structure of the study. The second is the Literature Review, where existing research within the field is considered and included in order to locate the study within the current knowledge economy. Following this is the Methods Chapter which details the manner in which the data was collected, participant sampling as well as the process of analysis utilised within the study. Chapter 4 covers the Results of the research as per the methods of analyses. This is then followed by Chapter 5, which includes the Discussion of the Results of the study as well as comparisons to the existing literature within the field. Finally, Chapter 6 details the Conclusions made by the researcher as well as Recommendations for Further Research and Limitations of the study at hand. The Appendices include all Participant Information Documents, Participant Consent Forms, Interview Schedules, Capacity to Consent Tool and the designed Program.

The following short Literature Review seeks to situate the study within the existing body of knowledge and to locate this study within the social and economic context against which it was conducted. The Literature Review will cover the main themes of Acquired Brain Injuries, Rehabilitation and Therapeutic Goals, Family and Caregiver Support and finally the Influence of Context and Socio-Economic Factors.

Chapter 2: Literature Review

2.1 Acquired Brain Injury

ABI is an umbrella term used to refer to both traumatic and non-traumatic injuries which cause damage to the brain and its functioning (Teasell et al., 2007). The term ABI is used to describe any injury or insult to the brain that is not congenital or perinatal in nature, and is most often the outcome of a single event or illness but cannot be attributed to a degenerative or progressive disease (Campbell, 2004).

Brain injuries can cause a varied array of symptoms that may impact basic functions, including autonomic (e.g. breathing and other vital signs), motor, sensory, and cognitive capacity which may jeopardise the life of patients (Elbaum & Benson, 2007). These functional deficits, and their different severity levels, are common consequences of acquired brain injuries and cause distress for both patients and families (Palmisano et al., 2020). Recently, the term neurobehaviour (Palmisano et al., 2020) has been used to group this sequelae and convey the idea that cognitive deficits, social behaviour, emotional responses and personality changes constitute a global response to brain dysfunction (Palmisano et al., 2020). Wood (2013) describes that the term neurobehaviour was created to define the organic nature of the associated deficits with ABIs and links to the idea that most often, these are natural consequences of the injuries themselves. One of the key features of an ABI is that the injury affects all aspects of everyday life and precipitates for the continuation of the individual's life (Wood, 2013). The types of ABIs and the associated deficits will be discussed below.

2.1.1 Types of Injuries

Acquired brain injuries are either traumatic or non-traumatic in nature. The two most common kinds of injuries to the brain include the application of mechanical force to the head as well as an interruption of the natural supply of oxygen to the brain (Elbaum & Benson, 2007). Mechanical force to the brain can be external or be caused by a haemorrhage as a result of a ruptured aneurism (Elbaum & Benson, 2007). The leading causes of traumatic brain injuries are falls, car accidents, assault, and sports or recreational activity that cause damage to the brain (Langlois et al., 2006). Non-traumatic brain injuries can be caused by brain lesions, tumours, vascular malformations as well as infections (Teasell et al., 2007). Neurological injuries do not always occur directly after damage to the brain but can also be a result of secondary injury, through brain swelling and a significant increase in intracranial pressure (Ghajar, 2000). It has been indicated that early identification of ABIs can contribute to lessening the risk of secondary injury and allow for a more significant chance of recovery (Ghajar, 2000).

The presentation of symptoms and associated deficits differ depending on the type, severity and time since of injury. Individuals who suffer from ABIs have to make greater and more substantial efforts to perform otherwise automated tasks and as such, overall behaviour is disrupted (Grealy & Rushton, 1999). One of the most important predictors of cognitive sequelae and the severity of those symptoms is the levels of consciousness immediately post-injury, which is measured using the Glasgow Coma Scale (Elbaum & Benson, 2007). This tool provides a score that measures the severity of brain injury and enables physicians as well as therapists to ascertain the level of damage to consciousness. Traumatic injuries are classified as either mild, moderate or severe depending on the level of consciousness and or the Glasgow Coma Scale after resuscitation (Ghajar, 2000). The following section of this Literature Review will highlight the most common sequelae of ABIs and will briefly explain the resulting deficits

and effects on the individual. These will be organised into the following categories, sensory and motor deficits as well as cognitive and personality and will foreground which sequelae are most significant with reference to this study.

2.1.2 Cognitive and Personality Deficits

Although a number of cognitive and personality deficits are present with individuals with ABIs, this review will focus on those that are most common but also most relevant to the study. These include, motivational deficits, prospective memory failures as well as deficits in executive functioning. The first of these to be discussed are motivational deficits, which are significant insofar as they influence the ability of an individual with an ABI to become involved in activities without further intervention by an outside source.

2.1.3.1 Motivational Deficits

One of the most commonly occurring sequelae of ABIs are motivational deficits. Motivation refers to the ability of an individual to start, regulate and maintain a goal directed behaviour to arrive at a specific outcome (Palmisano et al., 2020). Goal directed behaviours include a variety of processes to conclude either an immediate or later action, as well as an actual, physical or more abstract goal (Palmisano et al., 2020). Research has indicated that most individuals with ABIs have a diminished sense of motivation which disrupts almost all areas of life and is not specifically targeted (Al-Adawi et al., 1998). In instances where ABI individuals were previously highly motivated, these kinds of disruptions indicate a major change in behaviour and resulting personality. Motivational deficits have a significant impact on purposeful behaviour as well as ability to input effort into rehabilitation and therefore dependence on others increases drastically (Al-Adawi et al., 1998). In terms of everyday life, individuals with motivational deficits struggle to maintain relationships, forget to take medication and have

difficulty returning to a working environment (Palmisano et al., 2020). Motivational deficits manifest in difficulties engaging in both rehabilitative and every day activities and returning to normal levels of involvement in family and work life (Oddy et al., 2008). Challenges with motivation are however only one of the major issues with which an individual is confronted when they have a brain injury. The following section of this review will discuss another of the more pervasive sequelae of ABIs.

2.1.3.2 Prospective Memory Failures

A further cognitive sequelae experienced by these individuals are prospective memory failures, which disrupt capacity to initiate and carry out a future task. Memory impairments range from affecting short term, working, as well as long term memory, depending on the placement of the injury, as well as severity. Failures of prospective memory are one of the least studied sequelae of the brain, but are the most frequently occurring (Raskin et al., 2012). Chronic memory impairments are one of the most frequently reported deficits that are reported by survivors of ABIs (Lawson et al., 2020). These memory deficits interrupt independence in daily functioning and decrease quality of life. Research indicates that memory has been indicated as being slower to recover as opposed to other cognitive functions (Vakil, 2005). However, it is significant to note that memory is not a singular system but that it is composed of a variety of different cognitive sub-processes (Vakil, 2005).

A study conducted by Raskin et al. (2012) provides insightful information with regards to prospective memory and the ABI individual. The aforementioned study compared 25 healthy individuals with 25 ABI individuals on tasks related to prospective memory. Within this study, prospective memory was broken down into the following processes, ability to monitor time, ability to keep an action within one's awareness for a prolonged period of time, capability of

remembering the task itself and finally, the initiation of the action (Raskin et al., 2012). Results of the study concluded that in fact, all areas were affected for individuals with brain injuries. Moreover, when looking at delay, the study indicated that a delay of 15 minutes was sufficient to impair performance. This allowed for the conclusion made by the study that in the event that a compensatory mechanism were to be incorporated, the 15 minute window would be most appropriate for individuals with brain injuries (Raskin et al., 2012).

2.1.3.3 Deficits in Executive Functioning

In addition to the abovementioned deficits following ABIs, many more common sequelae exist. However, for the purposes of this study the last of those to be focused upon are cognitive dysfunctions in executive functioning. Executive functions (EFs) can be described as the mental capacities necessary for planning, formulation of goals, as well as carrying out such plans in an effective manner (Coelho et al., 1995). Cristofori, Cohen-Zimmerman and Grafman (2019) describe EFs as an umbrella term which refers to the higher order cognitive functions which are necessary to set out and achieve a specific goal. Due to the large range of functions which the EFs control, impairments in EF contribute to a reduction in an individual's ability to interact appropriately in social as well as a working environments (Cristofori et al., 2019). Deficits associated with brain injured individuals include self-awareness and goal setting, planning, self-direction, initiation of tasks, self-inhibition, self-evaluation as well as flexible problem solving (Coelho et al., 1995). The combination of these deficits causes both major disruptions to an understanding of self within one's daily life, but also, majorly disrupt both recovery as well as the individual's ability to participate in and fully dedicate themselves to the therapeutic process.

Most often, patients with memory deficits, motivational problems as well as executive functioning issues as caused by ABIs participate in a variety of therapies, such as physiotherapy, occupational therapy and speech therapy, which seek to alleviate such difficulties and provide compensatory strategies for functioning (Tsaousides & Gordon, 2009). These functional therapies adopt a variety of differing strategies to alleviate some of the deficits associated with ABIs. It is believed that a combination of these therapies, having intertwined objectives and increased participation, fosters positive results for individuals with ABIs (Palmisano et al., 2020). As such, patients who have access to these therapies are positioned within an environment which allows them access to the ability to change their daily lives. The following sections of this Literature Review will highlight the variety of approaches to cognitive and functional rehabilitation, with specific reference to the impact of therapy on the acquired brain injured individual.

2.2 Rehabilitation and Therapeutic Goals

Due to the nature of the deficits associated with ABIs, in conjunction with the positive results of therapeutic approaches, the following section of this review will focus upon the impact of rehabilitation on the ABI individual as well as the variety of options available in terms of therapy. Given the independent nature of cognitive, behavioural and physical deficits, evidence indicates that participating in a variety of therapies fosters positive results for individuals with brain injuries (Tsaousides & Gordon, 2009). Cognitive rehabilitation refers to a set of interventions which aim to improve the ability of individuals to perform cognitive tasks. Due to the cognitive dysfunction in EFs, as well as, and in conjunction with the those caused by ABIs in terms of memory, cognitive rehabilitation should be a major focus of therapy and is effective at any stage post-injury (Tsaousides & Gordon, 2009). It enables individuals with disabilities to achieve higher levels of well-being, reduces the impact of loss of functioning

with regards to activities of daily living and helps individuals achieve a level of independence (Wilson, 2013). As mentioned above, particularly with reference to ABIs, cognitive issues rarely exist in isolation and usually have an emotional, social and behavioural component. The main focus of cognitive rehabilitation is to restore functioning that has been lost or impaired due to neurological damage (Wilson, 2002). This will be elaborated upon below.

2.2.1 Cognitive Rehabilitation: Compensatory vs Remedial Strategies

Cognitive rehabilitation encompasses more than reducing cognitive deficits, but seeks to enable individuals to manage and compensate for their deficits (van Heugten et al., 2020). Therefore, it seeks to increase independence (Lewis et al., 2011). Given that brain injuries vary in presentation and deficits, treatment differs. As a whole, rehabilitation of cognitive deficits can be divided into two categories, namely remedial and compensatory (Fleming et al., 2005). As an overview, compensatory strategies are those that incorporate environmental modifications and intact cognitive mechanisms to overcome the limitations the individual is experiencing. Remedial therapies as well as the strategies which they seek to teach tend to place focus on repetition of exercises which rehabilitate skills. The following section of this Literature Review seeks to expand on the differences in approaches between compensatory and remedial therapies.

Of the two types of therapeutic approaches, remedial therapies, or “bottom up” therapies are those that utilise techniques such as drilling and repetition in order to stimulate the damaged neural pathways and or to encourage the brain to create new networks of functioning (Fleming et al., 2005). Traditionally, “bottom up” approaches focus on small, separate components of skill and performance abilities (Brown & Chien, 2010). Brown and Chien (2010) state that these kinds of therapeutic approaches spotlight body structure and function, in specific relation

to impairments. In this way, remedial therapies focus on specific aspects of the injury and target responses to those deficits by directing therapy to fix those aspects of the individual's condition.

Due to the complex nature of ABIs, as well as the variety of deficits associated with this kind of injury, another approach to therapy is the use of compensatory mechanisms. Many theorists in earlier years debated whether compensation or restoration was more effective in cognitive rehabilitation (Wilson, 2002). Wilson (2002) states that during the Second World War several countries were conducting studies with soldiers with brain injuries and as a result, the functional adaptation approach was developed. This approach foregrounded the value of utilising intact skills to compensate for damaged functional areas (Wilson, 2002). Through the use of compensatory strategies, environmental adaptations are made and intact cognitive mechanisms are focused upon in order to overcome limitations for the ABI individual (Fleming et al., 2005). Of the two, compensatory strategies have been found to be effective in assisting in everyday tasks (Prince & Bruhns, 2017). Compensatory strategies are the focus of this study, as they provide practical means to increase independence and improve everyday life. Much of the value of compensatory strategies lies with the fact that remedial strategies require individuals to have healthy brain tissue in order to be able to relearn skills. For this reason, compensatory strategies have the ability to serve a wider range of individuals.

A study conducted by Fleming et al. (2005) involved three case studies with a pre and post intervention assessment process. In an 8-week period, individuals received one to two-hour sessions, which taught compensatory strategies. Upon later assessment, all three participants were found to have improved with regards to prospective memory and indicated that compensatory strategies are beneficial when they suit the individual (Fleming et al., 2005).

Fleming et al. (2005) describe that factors that need to be present before these kinds of strategies can be beneficial are that the patient buys-in to utilise the compensatory approach, as well as that the patient acknowledges the presence of a problem with their prospective memory and motivation. However, Fleming (2005) highlights that much research has been done on remedial mechanisms and repetitive or drilling approaches to therapy. Whilst these are effective within their setting and specific circumstances, studies indicate that the results of these approaches are exceptionally specific to context and their results do not translate to real life circumstances (Fleming et al., 2005). However, when considering that the ABI individual needs a therapeutic approach to improve activities of daily living, it is clear that compensatory strategies are relevant due to their significance in improving everyday functioning. For this reason, compensatory strategies are further explored below.

Research indicates that even when compensatory strategies are not necessarily taught, individuals tend to utilise these over other therapeutic strategies. A study conducted by Dirette et al. (1999) randomly assigned ABI participants into two groups (n=30). The remedial strategy group participated in therapy sessions of 45 minutes each where they were taught no compensatory mechanisms. The compensatory strategy group also participated in 45 minute sessions, however during these sessions they were taught three internal compensatory strategies (Dirette et al., 1999). When the results were collated, both groups were found to have improved significantly, however, 80% of both groups utilised compensatory strategies over remedial ones (Dirette et al., 1999). This indicated to the researchers that in fact the majority of the study participants automatically utilised compensatory strategies, and that for some of the participants, these were internal strategies. It can therefore be ascertained that compensatory strategies play a significant role in rehabilitation and are at times a natural response. Whether therapists choose to utilise compensatory or rehabilitative approaches to therapy, an essential

aspect of all therapeutic approaches is the process of goal setting. This is further discussed below.

2.2.2 Goal Setting in Therapy

For the purposes of this study, the kinds of therapies which will be focused upon are occupational therapy, physiotherapy and speech therapy. Research indicates that due to the heterogeneity of brain injuries and the variety of deficits that accompany these kinds of injuries, it is important to adopt a multiplicity of therapies post injury in order to best target the many different layers of issues present (Margulies & Hicks, 2009). Through this approach, one is able to adopt a variety of complementary therapies which thereby assist in confronting the same larger problem from a number of levels (Margulies & Hicks, 2009). In order to best approach these therapies, research has indicated that goal setting is of particular importance (Wade, 2009). The following section of this review will make reference to the idea of goal setting and the manner in which this can best influence therapy.

A key theme within the current research is that goal setting in therapy is an essential part of the therapeutic process (Baker et al., 2001). The identification of the problems associated with a particular injury are a significant component of rehabilitation and are especially important in goal setting. Identification of issues associated with an injury are determined by neuropsychological assessments (Wilson, 2002). However, neuropsychological assessments alone are not enough to inform all of the answers needed by therapists focusing on rehabilitation. It is for this reason that therapists need to ascertain the family dynamics, anxiety in relation to deficits, financial situation of the individual as well as other influencing factors (Wilson, 2002). Goal setting is an important aspect of care within this regard and assists in ascertaining the most appropriate manner to approach therapy. Wilson (2002) states that before

therapy can begin, goals need to be set in order for there to be agreement between families, patients and therapists and that this is a highly significant part of the therapeutic process.

Through goal setting, therapists are able to ascertain what the individual believes is achievable, their commitment to therapy as well as whether their cognisance of their injury is in line with reality. Wade (2009) described goal setting as a central feature of the rehabilitation process. In addition to the impact on the therapist's organisation, goal setting allows for motivation of the patient, ensures that team members within the rehabilitative process work together, safeguards that important actions and aspects are not overlooked and allows for the therapist to monitor change (Wade, 2009). Importantly, this indicates that goals are dependent on personality of the individual, ability to access therapy, as well as, and importantly, the kind of injury with which the person is presenting.

A review by Cullen et al. (2007) of literature between the years of 1980 and 2005 on interventions in ABI rehabilitation found that direct patient involvement in neurorehabilitation goal setting produced significant improvements in the patient reaching the required goal. The aforementioned point seeks to re-iterate the importance of the patient within both the goal setting process but also having choice and buy-in within the therapy. This Research Report specifically focuses on ABIs as well as the deficits and therapies associated with this condition. Due to the fact that there are many methods and approaches to therapy, the following section of this review focuses on Successful Rehabilitation within the bounds of this research.

2.2.3 Successful Rehabilitation

Rehabilitation is most effective the more the individual engages in the processes, homework and therapies assigned to them. De Luca and colleagues (2018) propose that rehabilitation can

be successful at any stage post-injury. The value of rehabilitation is that it can be done through different disciplines and in different modalities (De Luca et al., 2018). The complexities resulting from ABIs provides strong reasoning for the use of a combination of therapies (Margulies & Hicks, 2009). Furthermore, research indicates that the more physical therapies an individual engages with post-ABI, the more structural remodelling their brains are able to perform (De Luca et al., 2018). The value of cognitive rehabilitation has been studied and questioned by a variety of researchers. In a systemic review of the literature, it was found that in fact there is scientific evidence that cognitive rehabilitation is effective for individuals with ABIs (Rohling et al., 2009). A study conducted on stroke patients, compared results of a variety of therapy techniques through a process of twenty one trials of a variety of physiotherapy approaches (Pollock et al., 2007). Eight of these compared a neuropsychological approach to another treatment modality, eight compared motor learning to another treatment, and eight trials compared a mixed approach to another modality. Overall, a significant result was found for the effectiveness of the mixed approach over the other approaches presented within the study and patients who participated in the mixed therapy were found to have an increase in functional improvement and independence (Pollock et al., 2007).

Studies have attributed improvement in functional status and capacity to individual's participation in consistent rehabilitation (Ernst, 1990). Research has indicated that an increase in the number of therapy sessions per week leads to more long-term recovery (Ernst, 1990). A study conducted by Smith et al. (1981) indicated that the best results in relation to therapy were found with the most intense therapies being conducted. This is however not a possibility in most low resource environments. The study reviewed the influence of differing levels of rehabilitation on stroke patients and randomly assigned 133 stroke patients to three groups. One of the groups received intense therapy, four entire days a week, the second group were

recipients of what was deemed conventional therapy exposure, namely three and a half days a week, and the last group received no rehabilitation. Of the groups, when reviewed both post-intervention as well as 6 months later, the intense therapy group indicated the best and most long-lasting results of recovery (Smith et al., 1981). Ernst (1990) concluded that from a review of a variety of similar studies to the one mentioned above, it becomes evident that it does not matter what kind of therapeutic technique is used, the most important thing is that individuals with cognitive deficits benefit significantly from repeated exposure to therapy. A later study, conducted in America with subacute stroke patients over a 12 week period indicated that a structure therapeutic Programme indicated that increased therapy led to gains in endurance, balance as well as mobility (Duncan et al., 2003). This is one of the many reasons for which therapists, during the 21st century and with the rise of access to technology, have opted for an increased use of telerehabilitation, which will be expanded upon and explained in the sections below.

2.3 Telerehabilitation

In many ways, technology seems to be the manner in which many have sought to bridge a gap in the therapeutic process. Telerehabilitation is a term used to describe the use of technological devices to communicate rehabilitation and therapeutic strategies to patients (Chang & Boudier-Revéret, 2020). This form of therapy is especially helpful in still providing patients with rehabilitation, whilst they are not physically present with the therapist during such provision. It further assists in moving the rehabilitative process to the immediate surroundings of the ABI individual. New forms of technological rehabilitation have arisen in response to growing research and increased needs for therapies (Lawson et al., 2020). One such method involves the implementation of electronic devices, which are particularly useful when compensating for prospective memory deficits (Fleming et al., 2005). Successful use of technology can be found

when the external devices send external cues which are detailed so the individual is made aware of the nature of the task to be performed (Wilson, 2002).

An intervention using technological memory aids found that electronic organisers, such as cell phones, would be beneficial if they provided both context-specific reminders and could be easily retrieved (Kapur et al., 2004). However, at the time of the study these technological interventions were considered not to be entirely effective. This was due to a lack of active participation on the part of the therapists within the technological reminder system. Therefore, the study recommended that this gap could be accounted for in future interventions if therapists were to be more involved within the intervention process. In addition to the aforementioned issue, the memory aids required the individuals to have the foresight and understanding of when the device would be useful and had to manually enter the memory tasks. Fundamentally, technology provides a means by which to support rehabilitative therapy and aids therapy in becoming more accessible, allows for continual reminding and engagement with patients and provides another dimension to the therapeutic process.

Whilst more research can still be conducted within the area of telerehabilitation, particularly with reference to lower resource countries, the following study by McDonald et al. (2011) provides evidence for the positive influence of active tele-rehabilitation. When considering the impact and difference of technological reminders versus physical diary reminders, a study conducted by McDonald et al. (2011) investigated Google Calendar reminders as opposed to a physical diary entry. Twelve ABI individuals underwent a five-week baseline phase, followed by a five-week intervention phase where part of the participants received Google Calendar reminders, whilst the others did not (McDonald et al., 2011). The study included a family monitor for both groups. After the intervention stage, it was concluded that the Google

Calendar reminders were more effective but that the active reminders were also helpful triggers and decreased the need for family monitoring (McDonald et al., 2011). However, as can be derived from the above, a family and caregiver support is key, even in the face of telerehabilitation (McDonald et al., 2011). The following section of this review will consider the caregiver or family in relation to the ABI individual.

2.4 Family and Caregiver Support

Studies have indicated that individuals with ABIs are often dependent on lifetime support due to the associated deficits of their injuries (Jamwal et al., 2017). In circumstances where the individuals with ABIs are able, they may even pay for the additional support as caring for an individual with an ABI is often a full-time job (Jamwal et al., 2017). Due to the high levels of ABIs in South Africa, coupled with a lack of resources to hire caregivers, this responsibility most often becomes the responsibility of the families (Schlebusch & Walker, 2020). Studies have found an association between family support and a continuing success in rehabilitative therapies and attributed such support to being an essential factor that contributes to longer lasting recovery (Kuipers et al., 2014). Positive family support has been identified as a factor contributing to behavioural changes within the individual and shows positive changes within the individual's ability to cope (Fisher et al., 2020).

However, one must consider the lives of the families and caregivers themselves, who experience significant levels of distress resulting from the changes within their family member (Fisher et al., 2020). In addition, the prevalence of caregiver burnout is exceptionally high within the South African context, and many caregivers and family members are not properly equipped to deal with the level of care required for an individual with a brain injury (Webster et al., 2015). Caregiver burden can be defined as the multifaceted burden associated with caring

for an impaired loved one, such as and not limited to the physical, psychological, social as well as emotional problems associated with such care (Braithwaite, 1992). A study conducted by Webster et al. (2015) between 2008-2013 in Cape Town followed 175 family members supporting patients with traumatic brain injuries. The family members who formed part of the study found that all forms of education-based information provided the best kind of support post-injury but that written information had the most positive effect on assistance during the rehabilitation process. Important factors to be drawn from such a study indicates that understanding what a family member needs, the support that is beneficial and the necessary recovery aids that would contribute to success, are essential factors in the overall rehabilitative process.

South Africa's socio-economic context and the impact of it on recovery, access to therapy and support play an additional role in caregiver burnout. As stated by Webster et al. (2015) there is little evidence about families and survivors of brain injuries regarding the kind of support they have access to, but also the needs of these groups. This is however out of the scope of the current research but remains a significant factor that should be a topic of investigation. This is further supported by Boschen et al.(2007) who conducted a review of existing literature on family support and interventions for family members with ABI patients living within their home environments in Canada. Such a study found that not only are there few resources available for individuals outside of the major city centres to access support, but that too little research exists to provide an understanding of what kind of interventions, assistance and support is needed for family members of the ABI individual (Boschen et al., 2007). However, one point that emerged from existing research is that family members appreciate written, clear information both about ABIs and how to best assist in rehabilitation, but also that family interventions should be individualised (Boschen et al., 2007). In addition to the need of further

support of family members of individuals with ABIs, there are further contextual factors that contribute to rehabilitation and the environment in which such rehabilitation occurs. The following section of this review will consider the influence of context and socio-economic factors on the study topic.

2.5 Influence of Context and Socio-economic Factors

Within a South African context, government hospitals are understaffed and under resourced (Cobbing et al., 2014). In addition, individuals seeking to access public health care often struggle to be attended to and have low access to sufficient medical treatment. The aforementioned was aggravated by the global pandemic, which forced non-essential services to be suspended. This included the various therapies which were under immense pressure to maintain a standard of care able to cater for individuals with ABIs and other neurological diseases (Dantas et al., 2020). In conjunction with the safety laws and protocols that existed, individuals with ABIs were excessively vulnerable to infection by COVID-19 and associated consequences during their hospital or therapy visits. Therefore, during high stages of the outbreak of the pandemic, therapists attempted to compensate for their inability to physically meet with patients and opted for a variety of telerehabilitation methods (Dantas et al., 2020). For this reason, therapists began to place greater emphasis on the continuation of home-based exercise systems and interventions in order to be able to provide safe environments for ABI patients to participate in rehabilitation.

The promotion of home-based interventions may have an indirect impact on the psychological well-being of the patients, by reducing isolation, strengthening their contact with health care services and improving their engagement with health-oriented behaviours. This is out of the scope of the current research but is an area for potential study. Although rehabilitation

encompasses therapies which can be applied to a variety of diseases and disorders, this study focused on therapies geared towards ABIs. Individuals with ABIs most commonly engage in the abovementioned therapies and serve as only one of the many groups of people who could benefit from the proposed intervention.

It is of great significance to the study to introduce Bronfenbrenner's Ecological Systems Theory, which is a key consideration to the study at hand. Within this system's theory, the individual is considered to be influenced by their context, but with consideration of the various levels of this context and the subsequent impact that this has on the individual (Paquette & Ryan, 2015). Further explanation of this theory, as well as the manner in which it has relevance to this study are discussed below in detail.

2.6 Rationale

The above literature review provided context for the academic papers that exist with regards to rehabilitation and the ABI patient. The studies described above attempted to comprehend the common ABI sequelae and have sought the most appropriate forms of rehabilitation to assist with the associated deficits of these patients (Fleming et al., 2005; Tsaousides & Gordon, 2009; Wilson, 2002; Wilson et al., 1997). Many studies have aimed to incorporate technology into the rehabilitative process and have utilised compensatory strategies to implement telerehabilitation as an effective therapeutic approach (Kapur et al., 2004; Tsaousides & Gordon, 2009; Wilson et al., 2005). All of the above studies have suggested that telerehabilitation is most effective where therapist participation is active within the telerehabilitation reminder, the ABI individual receives clear and specific cues and when the delay between the cue and completion of the homework is no longer than 15 minutes. These factors are of particular relevance to this paper, as the Researcher incorporated these aspects into the methodology.

Although this proposed intervention's purpose can apply to a variety of neurological diseases and conditions involving memory-deficits, the study focused on ABIs as these individuals most usually participate in a variety of therapies and present with prospective memory and motivational deficits. Therefore, this study created a proposed compensatory instant messaging reminder system that would encourage individuals with ABIs to engage daily in their rehabilitative prescribed homework. The current state of rehabilitation within South Africa suggests a need for further interventions and research to be done within the scope of telerehabilitation.

This study aimed to create and implement an intervention that would compensate for lack of motivation, prospective memory and command of executive functions that are most usually associated with ABIs (Raskin et al., 2012), and facilitate an increase in restorative training through home exercises. Within the South African context, with specific reference to the lack of access to therapy (Joosub, 2019), this study examined the possibility of implementing this kind of telerehabilitation Program. However, due to contextual challenges, a more pressing question was foregrounded, which is whether the intervention would be feasible within the South African context and with these specific kinds of patients.

A further aim of the study, formulated through the feedback and perspectives of the therapists involved as well as contextual challenges, sought to examine the feasibility of this kind of intervention with specific reference to the contextual factors involved in working with individuals in the South African health system, given that rehabilitation is expensive and in many cases inaccessible to numerous people (Joosub, 2019). This is the case in South Africa where therapy in the aftermath of an injury is a privilege (Cobbing et al., 2014; Morris et al., 2019). There is a disconnect between the vast need for therapy and rehabilitation after ABI and the availability of such to patients (Joosub, 2019). Within the private practice sphere, patients who have access to weekly therapy also receive homework from Occupational Therapists, Physiotherapists and Speech Therapists. All of the aforementioned exercises seek to improve functioning of individuals and aid with activities of daily living (Wilson, 2002).

However, considering the impairments of individuals with ABIs, often the homework is not completed by the patient. As a result, these individuals do not improve, and at times they may even regress, thereby decreasing quality of life and increasing the need for caregivers to compensate for such deficits (Joosub, 2019). There are many barriers to accessing therapies for

patients in the public sector (Cobbing et al., 2014; Morris et al., 2019). This research sought to address some of the abovementioned issues by assessing the feasibility of implementing an easily accessed, affordable and widespread means of rehabilitation.

Chapter 3: Methodology

3.1 Research Aims

The main aim of this study was to explore the feasibility of implementing an instant messaging intervention intended to improve and increase participation and engagement in rehabilitative prescribed exercise homework for sufferers of Acquired Brain Injuries (ABIs).

The study had three sub-aims, namely, to a) design an instant messaging reminder system Program, b) to explore the obstacles that a researcher faces during the process of implementing the aforementioned Program, and to c) investigate the opinions of therapists with regards to the potential implementation of the Program.

3.2 Research Design

The study utilised a qualitative research design overall as the Researcher sought to comprehend a topic that is not quantifiable but rather needs to be examined from the subjective perspective of the therapist participants (Klopper, 2008). The qualitative design sought to explore the feasibility of the intervention from the perspective of the therapists as well as the Researcher.

The design can be further subdivided into two main types. The first form of design utilised was to explore feasibility of the intervention from the perspective of the therapists through Thematic Analysis, specifically focusing on the meaning and experiences of those involved within the interview process. The small sample size allowed the study to focus on the perceptions and thoughts of the therapists in relation to their specific experiences and the manner in which these experiences influenced their views of the intervention (Worthington,

2013). This exploratory analysis was not aimed to cover the entire range of phenomena related to this topic but rather to present the selected information regarding the Program and related perceptions of the therapists (Malterud et al., 2016).

The second research design utilised by the study was an autoethnographic approach. Through this the Researcher was an active participant in the study, understanding the influence this had on the study (Farrell et al., 2015). The Researcher's experiences, barriers and obstacles faced as well as the outcome this had on the study were utilised as data to comment on the feasibility of the Program as well as on the process of implementation (Adams et al., 2017). This method is one that involves self-reflection as well as reflexivity during research (Adams et al., 2017), which are defined and more clearly outlined in a later section of the manuscript.. The Researcher's experiences are then compared to existing literature (Condon et al., 2021). Through rigorous note making, journal keeping of the Researcher and with specific reference to interviews which sought to ascertain the perceptions of the four participants of the study, the research paper utilised this approach in order to best address and fill the gaps within the knowledge economy (Adams et al., 2017; Condon et al., 2021). The Researcher of this study also conducted regular and honest debriefing sessions with her supervisor. This allowed for sharing of insights about her personal learnings with regards to both the research and the research process as a whole (Farrell et al., 2015). By being continually involved in self-narration, the Researcher made use of this approach to include both her voice and the voices of the therapists to provide further information regarding the Program but within a very specific context.

3.3 Sample and Sampling

The sample of therapists recruited was based on convenience, purposive sampling as well as snowballing. The purposive sampling aimed to recruit a very specific demographic of participant (Etikan, 2016). The inclusion criteria for the therapist sample were that the therapists were English speaking, either Occupational Therapists, Speech Therapists or Physiotherapists who specifically work with adults with Acquired Brain Injuries. Attempts at recruiting therapists were made at three private practices and three public hospitals¹.

The final participants of the study were therapists from four private practices. The sample included one Speech Therapist, two Occupational Therapists and one Physiotherapist from four different private practices. The therapists consented to be audio-recorded. The therapists with whom the interviews were conducted have been assigned pseudonyms for the purposes of this study and will be referred to as Participant 1, Participant 2, Participant 3 and Participant 4, respectively. This is done to protect the therapists right to anonymity and confidentiality. The table below summarises the demographic information of the participants.

Table 1 : Demographic Information of Therapist Participants

Participant Number	Profession	Gender	Private or Public Hospital
1	Speech Therapist	Female	Private
2	Occupational Therapist	Female	Private
3	Physiotherapist	Female	Private
4	Occupational Therapist	Female	Private

¹ Names of organizations included within both recruiting and final study are kept out of the reporting process to ensure confidentiality and anonymity.

3.4 Data Collection

3.4.1 Instruments

A brief interview was created and conducted in one session with each therapist. The interview included open-ended questions, which guided the conversation but allowed for additional comment and input from the side of the therapists. See the Interview Schedule for Therapists attached (Appendix 1). The interview schedule was designed to explore demographic and professional information of the therapists, the kind of therapy that they conduct with their ABI patients, the rehabilitation homework they administer and their perceptions around the importance of said homework. Questions added included perceptions of the therapists towards the intervention, specifically with reference to feasibility of the Program attached below (Appendix 2).

Before the study began, the interview schedule was piloted with two therapists who met the inclusion criteria for this study and who were asked to comment on the clarity of the questionnaire and comment whether any questions need to be added or changed. This allowed for the Researcher to enhance the quality of the questionnaire. Following the pilot stage, questions were added regarding potential obstacles to the implementation of the intervention, what may facilitate success of Program implementation, the impact of lack of face-to-face interaction with ABI individuals and the kinds of impact the Program would have on ABI patients (Appendix 2).

3.4.2 Procedure

Once ethical clearance was obtained, (ethics clearance number M210847) (Appendix 3) the Researcher approached three public and three private practices whose therapists fit the inclusion criteria. Inclusion criteria of the institutions include having Physiotherapists, Occupational Therapists and Speech Therapists who work with and provide rehabilitation services to adult ABI patients.

The first contact was made in October 2021, where invitations to participate were sent to three public hospitals and three private practices. These invitations requested permission to contact therapists within the abovementioned organisations and sought to ascertain the process of permission granting. No replies were received from the gatekeepers of two of the public hospitals and one private practice. The remaining public hospital replied with a confirmation of receipt of request and indicated the need of all permissions and signed copies with signatures of all HODs that would be involved in the study in order to then obtain feedback from the hospital's CEO. This process was not in line with the ethics requirements as the process outlined indicated that before HODs could be approached CEO approval was needed.

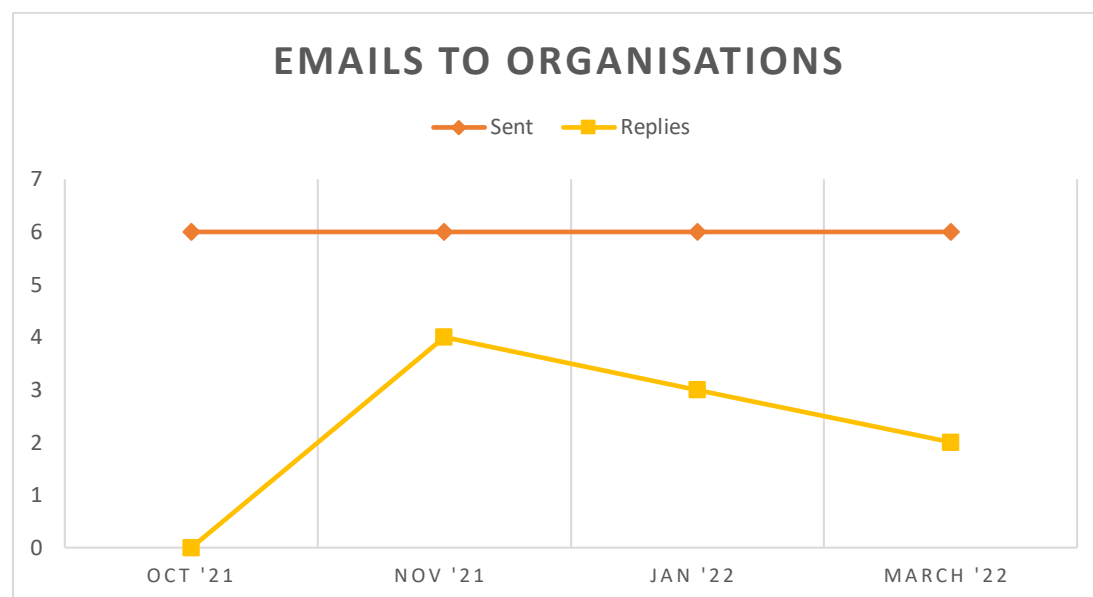
Follow up emails were sent in November 2021 where the second public hospital replied with a referral to the hospital's research committee. The hospital would need all protocols included in the study as well as NHRD confirmation before the study could be considered. However, NHRD confirmation could not be provided before the research was approved by the CEO.

In November, due to the low response rate, an alternative private practice was invited to participate for which an ethics amendment was submitted. In January 2022, further follow up emails were sent to the abovementioned individuals to ascertain if they were still interested in participating. In the January 2022 communication from a public hospital correspondent, the

Researcher was referred to another Clinical Executive who would possibly be able to assist with permissions related to the study. After January 2022, no further replies were received. In August 2022, another private practice was included due to the lack of response from the abovementioned institutions, for which another amendment form was submitted, and interviews were conducted in September 2022. Figure 1 depicts a graph of the number of organisations contacted per month by the Researcher between October 2021 and March 2022. In March 2022, the first interview was conducted with a therapist participant.

Figure 1

Emails sent to Organisations for Participation



The therapists who consented to be interviewed were provided with Participant Information Sheets (Appendix 4) and Consent Forms (Appendix 5) which they were asked to read and sign in order to participate in the study.

The therapists were briefed during the interview regarding the Program design. The procedure relevant to the results obtained below is as follows: The Researcher conducted four brief, open ended interviews with the therapists who had completed the information sheet and consent forms introduced above. Once the interviews had been concluded, the Researcher transcribed the interview themes which were then analysed.

For the ethnographic component of the study, the Researcher kept notes of the procedures and processes included within the research (Farrell et al., 2015). Journals and notes were kept to track the development of the research project and how the Researcher experienced the growth of this study. The Researcher had many meetings and debriefing sessions with her supervisor, which serve as a space for reflection and introspection about the processes encountered and to have a means by which to speak through her experiences. The researcher conducted the interviews but was not a interviewee at any point during the study.

3.4.2.1 Program

The Program designed by the Researcher is provided in full in Appendix 6. According to the Program, therapists would be contacted, explained the process of the research, interviewed and then asked to recommend patients. ABI individuals would be informed by their therapists that the Researcher would have contacted them to explain the intervention Program, what it would entail and what would be expected from them with regards to participation. No changes to usual therapy would be required for the Program.

Following agreement to participate, the relevant Information Sheets and Consent Forms detailing the scope of the study and what it hoped to achieve would be distributed (see

Appendix 7 and Appendix 8) can be provided to the participant (ABI individual). The University of California San Diego Brief Assessment of Capacity to Consent Tool (Appendix 9) adapted for use within this study would be administered to ABI individuals to ascertain ability to consent (Martel et al., 2018). Should the ABI individuals be determined as unable to provide consent they would be reassured that they are not required to participate in the study and that the lack of participation would have no bearing on their therapy.

The Program was designed as follows (Appendix 6): The ABI individuals would be contacted and asked questions in order to ascertain the nature of their exercise homework and how often they engage in such homework. After one week with no reminder messages being sent, the Researcher would call the participants to find out how many times they completed their exercise homework. In week 2, the Researcher would send reminders to the participants daily to engage in their rehabilitative therapy homework. Messages would be sent out at the same time every day. Participants would be asked to send a message of affirmation regarding whether they had managed to complete the exercises. After each week, the Researcher would call the participants to ask how many times that week they completed their exercise homework. The information the Researcher would obtain for each participant from these phone calls would be tabulated in an Excel spreadsheet. This participation index would allow the Researcher to understand the number of times each participant reported to have done their exercise homework.

The intervention would run for a period of 4 weeks to allow sufficient time for effective participation. At the end of the intervention period, the therapists would be asked to participate in a post-intervention interview. In addition, the ABI individuals would be read the post-

intervention interview (Appendix 10) and would be asked about how they found the intervention and whether they perceived it to be a helpful and feasible Program.

3.4.3 Data Analysis

3.4.3.1 Thematic Analysis

Data was collected through brief, semi-structured, open-ended interviews. Once data was collected and transcribed, Thematic Analysis was the chosen method of analysis utilised in the study. This analytical technique looks for themes and patterns in the data collected (Braun & Clarke, 2014). Coding is done in order to group themes. Thematic Analysis consists of six main stages namely, familiarising oneself with the data, generating of initial codes, searching for themes, reviewing potential themes, defining and naming themes and then producing one's report wherein which one includes quotes from the transcripts as evidence (Braun & Clarke, 2014). This method of analysis was chosen for the study as it appropriately allows for meaning to be drawn from reported information. Through the transcripts, this method of analysis allowed the Researcher to be able to draw meaning and comprehend the opinions of the participants with specific reference to the intervention (Braun & Clarke, 2014).

3.4.3.2 Ethnography

Within this mode of data analysis, the ethnographer moves between observer and participant, thereby being both an active contributor to results but also an observer who critically analyses the responses of the participants within the study. The process of data analysis within an ethnographic approach is on-going and consists of a Researcher keeping track, being amenable to change and developing the data from initial interpretations to the final concluding thoughts

of the study (LeCompte & Schensul, 2013). This involves reporting and continuous tracking of changes.

3.4.4 Credibility, Trustworthiness and Reflexivity

Within qualitative research, the concepts of credibility, trustworthiness and reflexivity play a significant role in ensuring the research is valuable and truthful. Credibility specifically refers to how precisely the Researcher collects the data and whether the analytical process of the research aptly addresses the purpose and focus of the research question at hand (Cope, 2014). The Researcher aimed to ensure credibility by providing and following precise, accurate and consistent descriptions of the processes included in the research. This was especially important during this study as due to the various obstacles and limitations faced, the Researcher needed to ensure that precise and continual information was being kept. This included continual checks with the research Supervisor of the study and ensuring that results and findings were verified throughout the process of the research.

With reference to trustworthiness, two main concepts need to be considered, namely transferability and dependability. Transferability refers to the changes within the data over time as well as the manner in which the Researcher understands the changes and developments that are involved in the analytical process (Graneheim & Lundman, 2004). During the research described above, the Researcher needed to ensure that with edits and the processes involved within the study, the Researcher kept track of the changes within the study, the procedure as well as with reference to the main question of the paper. Dependability refers to consideration and acknowledgement of the context as well as a detailed description of the processes included

in the analytical portion of the study. The Researcher remained cognisant of the manner in which personal experiences, context as well as being influenced by the experiences in relation to the project itself had in relation to the manner in which the results were interpreted. During the research process, the Researcher kept track of thoughts and comments relating to both the transcripts and the process itself.

Reflexivity refers to the results being based on both the reporting of the therapists but also the interpretation of the Researcher, taking into consideration that the Researcher is an instrument in the study (Berger, 2015). Consideration of this leads to an understanding that the Researcher's knowledge, understandings and personal history plays a role with regards to the results that are produced. The Researcher considered that within the study, the Researcher's personal knowledge and influence played a role, and therefore the Researcher self-monitored and considered the impact of the Researcher's beliefs, biases and expectations. The Researcher is a white female, who has private health insurance and access to therapy should the need arise. She too, works within a private senior living community with elderly residents who have Dementia. These factors had the ability to impact reporting and was kept in mind by the Researcher throughout the process. This included an understanding of the subjectivity of the Researcher and a continual tracking of the aforementioned in order to comprehend the influence of these. This is especially significant with regards to the study and the impact of the changing circumstances, obstacles and ultimately the changes to the project at hand. The Researcher was not one of the four participants mentioned above that were interviewed with reference to the study. Through continual self-checks as well as consistent conversations with the research supervisor, the Researcher maintained an honest and rigorously documented thought process throughout the research study.

3.4.5 Ethical Considerations

The Researcher was committed to abide by ethical principles and standards throughout the study as stipulated by the Code of Ethics for Research on Human subjects and according to Ethics in Human Research Document from the University of the Witwatersrand. The Researcher was granted ethical clearance from the Human Research Ethics Committee (Medical) and conducted said research under the ethics number M210847. Permissions were requested from four private practices as when unconditional ethical clearance was obtained these were the only practices that had consented to participating in the study (Appendix 11). The draft of the letter is attached due to the confidentiality requirement. The signed letters are password protected.

When working with human participants it is essential to consider the various ethical issues that may arise during the course of the study. To protect the autonomy and dignity of the participants, therapists were notified that participation was voluntary and that no personal gain was associated with the study. The aims and activities of the research were fully described to the participants in writing (Appendix 7). Participants who wished to take part in the study signed a formal consent form (Appendix 8).

The therapists' anonymity within the study could not be assured during data collection, nevertheless, participants' anonymity was maintained in the reporting of the results by using pseudonyms. All the data associated with the study was kept on a password-protected computer in a password-protected file. Only the Researcher and the Research Supervisor had access to the data and both the questionnaires and related information were not shared with any other individuals.

During the interview process the participants were reminded that participation was voluntary and that there was no gain and no consequences associated with participating in the study. The participants could refrain from answering any questions and could withdraw from the study at any stage. The participants were informed that should they wish to receive the results of the study that they could be sent the final report.

A large portion of data collection was conducted during the COVID-19 pandemic, therefore the researcher was committed to following procedures to ensure the safety of the Researcher, the Research Supervisor and the participants. Most of the processes associated with the study were conducted online or telephonically, to avoid direct contact with the participants. Two of the four interviews were conducted via Zoom or phone calls, whilst two of the interviews were conducted face-to-face. The face-to-face interviews were conducted during a low level of the pandemic where mask laws had been dropped, however social distancing was still maintained. The Researcher adjusted protocols in adherence with the changes in the pandemic status.

Chapter 4: Results

4.1 Results

The following Results section is organised into two overarching subsections. The first describes the results in relation to the main aim of assessing the feasibility of the Program and in turn the interviews that were conducted. The second section describes the Researcher's ethnographic approach and obstacles encountered within the research stage of this study to detail the hurdles that the Researcher faced during the process of implementation of the Program. The qualitative, brief, open-ended interviews conducted with the four therapists were analysed using Thematic Analysis and the below themes emerged. The ethnographic portion of this results section sought to inform a reader regarding the many obstacles faced by the Researcher that limited implementation of the intervention in response to the sub-aim mentioned above.

The analysis of the interviews primarily focused upon six main themes which can be further divided into sub-themes. The main themes were drawn from the four interview transcripts. Themes include 1) common deficits of ABI patients experienced by therapists, 2) individualisation of the intervention, 3) perception of the importance of exercise homework, 4) influence of and on the caregiver and family, 5) delivery system of the Program, 6) technology and the participant, 7) barriers to implementation of the intervention. These are described below.

Within this study, intervention and Program are used synonymously to describe the Program created by the Researcher during the research study.

4.1.1 Common deficits of ABI patients experienced by therapists

The patients with whom the therapists work all present with ABIs and as such the participants agreed on the kinds of symptoms with which their patients commonly present. These symptoms may be grouped into two main categories: cognitive and personality and sensory and motor.

4.1.1.1 Cognitive and Personality

Therapists identify a series of symptoms that are commonly present in people with ABI. Their neuropsychological presentation involves deficits in cognition, with emphasis on higher level functions; and secondarily, behavioural and emotional problems, as illustrated by the quotes of Participants 2 and 3 below.

We see a lot of impulsivity, poor reasoning, um problem solving issues, um a lot of your executive functioning that becomes a problem (Participant 2)

The bigger issues... so definitely cognitive issues, executive functioning, um attention, impulsivity, poor safety awareness, memory, all of those and then behavioural issues like big time frontal lobe things (Participant 3)

These symptoms are presented as those that affect daily life and also moderate the patients' experiences of the therapy. This is illustrated in Participant 4's quote which articulates how a specific language deficit can interfere with the patient's capacity not only for communication, but the expression of feelings. Participant 4 goes a step further when she explains that this

cognitive limitation can often cause high levels of frustration and this negatively affects the patient's mental health, further aggravating the clinical presentation (e.g. depression).

Cognitively memory um a lot of aphasia, a lot of um, just cognitive decline, being able to hold a conversation is often difficult for them, naming is difficult and just being able to articulate feelings and emotions they find it quite difficult (Participant 4)

These deficits mentioned by Participant 4 indicate the difficulties experienced by ABI individuals and depict the manner in which these patients' deficits extend to their social lives.

...That brings along frustration which leads into the emotional side of things and they get very easily frustrated because they are not able to properly articulate how they are feeling or people are not able to understand what they are saying or what they want to do so there is a lot of frustration, a lot of sadness. One patient went through quite severe depression for quite a long time... (Participant 3)

The above comment is indicative that these deficits cause much more than the consequences of the symptoms themselves. Instead, because of the pervasive nature of these deficits, individuals with ABIs experience social and emotional issues in both daily life and therapy. This would ultimately also affect therapy but would play a role in the manner in which the patients experience the Program.

Cognitively, the symptoms that have been raised by the participants are those that were proposed to be targeted by the Program. Poor executive functioning, as well as issues with

memory and planning are key features, which encouraged the Researcher to create the proposed Program. In creating the Program, the Researcher sought to compensate for many of the abovementioned deficits in functioning and promote homework through compensation rather than re-training.

4.1.2 Individualisation of the Intervention

One of the most prominent themes that arose from the therapist interviews was the concept that each individual is different, both with regards to their injuries but also in relation to their therapy, homework, and home circumstances. The therapists communicated that all the aforementioned would have an impact on the intervention and its feasibility. In other words, the suitability of the reminder system is linked to the clinical presentation (ABI sequelae) (as described above) and alignment between therapeutic goals, personal characteristics and circumstances of the patient that can also affect the feasibility of the intervention. This indicates that a program that has a generic approach (such as text reminders) may not be a suitable strategy to increase engagement with the rehabilitation homework. In the following paragraphs, this topic is divided in sub-categories to address and illustrate separately the issue of therapeutic goal and individual variables in relation to the instant messaging support intervention Program.

4.1.2.1 Therapeutic Goal and the Use of Instant Messaging Support Intervention Program

Participants expressed the importance of establishing a therapeutic goal for their patients. All participants stressed that when deciding what therapeutic strategies to use, as well as how and when to give homework, this was dependent upon the goal of the therapy as well as, and in conjunction with, the ABI patient's understanding of the goals of the therapy. The participants used this logic to arrive at the idea that the instant messaging support that could have been

offered to their ABI patients could prove to be counterproductive if the skills that they were attempting to rehabilitate were opposed to the reminder system. For example, if the therapeutic goal is to improve memory, implementing a reminder system does not allow the participant to exercise this skill independently, therefore sabotages the rehabilitation progress.

With this in mind, homework is not always implemented as part of the rehabilitation process, as Participant 1 explains:

... Depends on the person and what their goals are and what they are asking for... homework is not a standard thing. (Participant 1)

Alternatively, reminders are suitable when the therapist decides that the goal of the individual who is participating in the intervention may benefit from messaging reminders. The quote below provides an example that where memory is not the main target of the intervention because, in this case, it cannot be rehabilitated, then reminder messages would be helpful as they would compensate for this loss by providing a way to remember to do the homework.

So because the core nature of the issue is actually her memory, if therapy is [not] going to achieve anything with her, we have to put that system in place. Yeah and in order to try and... and get that repetition of practice through the home Programme, that in the hope that that could improve her memory, but you aren't going to get that repetition without the reminders. (Participant 1)

On the other hand, Participant 1 was concerned for other patients where the goal is to develop the skill of memory, the instant messaging reminders would serve to be in misalignment with the goal of therapy and thereby defeat the purpose of the therapeutic goal.

it's almost like a vicious cycle.. but that is like one of the only cases I can think of where that kind of system of reminders is actually necessary and also does not detract from the goal of the therapy because I mean it is true that ultimately with a lot of your clients I mean you are trying to build their independence and also their own accountability for their own recovery and their own progress that they wanna make. (Participant 1)

The above response indicates Participant 1's understanding of the reminder as though it is reducing the client's accountability for the rehabilitation process and their own recovery and hampering their independence. Therefore, commitment to the homework in terms of self-motivated and self-monitored engagement are valued aspects of therapy for Participant 1, and a reminder system is viewed as negatively impacting the recovery process of the patient and the ultimate goal for independence.

Participant 1 highlights another aspect that detracts from the value of such Program, which is linked to long-term sustainability. A reminder Program that is understood as promoting dependency on it, will not allow the patient to acquire the skills that eventually will make him not need such reminders. Moreover, rehabilitations of this kind, that rely on messages sent by the therapist, are not capable of being maintained for long periods. Even when the objective of the Program is to reduce therapy sessions, if reminders of this kind are not automated, they will still demand therapist participation, which may not be pragmatic.

I mean it's not sustainable forever and it's not sustainable in the long term. I mean if you are always reminding them they are not going to be able to develop the internal strategies to remember for themselves. So you are almost working against a long term level of independent function... (Participant 1)

4.1.2.2 Individual Characteristics and Circumstances in Relation to Program Homework

The therapists involved in the interviews explained that there is more to consider in therapy than just the individual in the therapy session. Many comments and concerns were raised in connection with the individual patient's lifestyle specifically in relation to their therapy. The participants highlighted the importance of creating consistency and alignment between the ABI individual's lifestyle, therapy and prescribed homework.

Two of the participants stated that it is very important to ensure that the homework given to the patient is matched appropriately to them. The therapists reported finding that matching the homework to the person and their lifestyle makes completion of the prescribed homework easier and more likely. In addition to the above, making sure that the homework is relevant allows for meaning and purpose to be attached to said task. If the homework given is in line with the patient's life and goals, then it stands to reason that this would translate to the Program itself.

It becomes almost a meaning for them.. it's almost like you have to pitch really perfect with the homework so people want to engage. (Participant 2)

So again I think it's how you... how you structure the homework and how you embed it in their life and whatever else they do in their life. (Participant 1)

A possible deduction from the participants' statements is that no reminder is needed when the match between environment and homework is aligned. This promotes easier engagement and reduces the need for external reminders.

Other important personal factors that the therapists identified as significant in relation to both homework and the reminder system were those that concern the socio-cultural surroundings of the person.

I think the human factor in your study is huge because you are accounting for the personality type and their approach to work and things before the injury and then you're looking at it with memory problems, motivational problems, with socio-economic problems. I think there are so many factors...
(Participant 1)

Participant 1 points to the complex interaction between psychosocial variables and their influence on the design and success of rehabilitation strategies. The Participant suggests that a reminder system must take into account factors linked to costs, premorbid characteristics, and current symptoms. It can be extrapolated from this Participant that the take-up of a reminder system will be dependent on whether the person can afford a cell phone, the costs linked to receiving messages, has used cell phones in the past, has used them as a reminder or not, and whether the clinical presentation involves characteristics that precludes the patient from engaging successfully with it, for example due to motor or sensory issue, or due to other neurocognitive deficits.

4.1.3 Perception of the Importance of Exercise Homework

Exercise homework, for the purposes of this study, denotes exercises given to ABI individuals by their therapists to be completed by the patient without the therapists involvement. The Program was initially conceptualised under the premises that exercise homework is given by therapists to increase participation in the therapeutic exercises needed to facilitate improvement

and maintenance of functioning. Secondly, the homework may be a strategy used by therapists to track progress.

These premises were not shared by all of the therapists. This is indicated by the manner in which Participant 1 responded to a question of monitoring of homework.

I don't really monitor it as strictly because I don't use that as a gauge for therapeutic progress. (Participant 1)

The above is indicative that, for Participant 1, homework does not play a significant role in her work with clients, as it may not be an efficient tool to promote or track therapeutic progress, as she adds below.

Like I don't think her progress with me would change if she was doing it or not doing it (Participant 1).

However, Participants 2, 3, and 4 see the above from a slightly different perspective. These participants do track homework and see it as a way in which to inform if their patients are making any progress on their own.

When it comes to ADLs [activities of daily living] the unfortunate thing is that you can see when they don't do their homework, um so you use a lot of observation (Participant 2).

We really try to use it as a platform to find out what level of participation this patient is at.. (Participant 2)

Participant 2 explains that she utilises observation as a method to track participation in exercise homework. This may highlight that the best tracking system of therapeutic progress is clinical observation, conducted by each therapist.

Participant 3 indicates in the quote below that collateral information may play an important role in treatment planning. The participant raises the issue of information reliability as patients or/and caregivers can provide an unreliable account of the patient's problems.

Get collateral information from spouses, especially because of the ABI patients or carers they can often just tell you what you wanna hear (Participant 3).

Similarly, Participant 4 highlights the importance of clinical interviews that target the identification of functional difficulties and preserved areas as identified by the client and not only by the assessment tasks.

Go over and I ask what was easy about this and what was difficult (Participant 4)

The above approach indicates that yet again, homework tracking is dependent on the ABI individual, whose memory, planning and often executive functions are not fully intact. From this, one is able to infer that a reminder Program may need to incorporate an additional or reliable tracking system that takes into consideration the patient and caregiver's input.

4.1.4 Influence of and on Caregiver and Family

Therapists raised that there would be a benefit on the Program due to family and caregiver support. The caregivers and family members would also benefit from the support that the Program would provide for the families and caregivers. This can be divided into two sub-themes a) dependency of success on caregiver or family support and b) benefit for caregivers and families.

A key theme that emerged strongly throughout the interview process is the dependency of the success of the Program on the support of another individual. In most cases, the therapists referenced a caregiver or family member as the main means of support needed to ensure that the Program and homework to be successful.

When considering the feasibility of the intervention, Participant 1 raised that if there was no one to assist the ABI individual with their homework, the likelihood of participation in the homework was very low. Participant 1 included this as a reason as to why she often refrains from giving homework.

I suppose if I know there is no one to help them and they can't manage on their own, then that would be another reason [for not giving homework] (Participant 1).

This was supported by another participant who highlights that, in addition to the reminder, a caregiver would be needed to secure participation and completion of the activities.

Family or caregiver buy in would have made a big difference to the intervention, ... the consistency would come from them... initiated either by person, either caregiver, family or something else like an alarm clock.
(Participant 2).

It is noteworthy that despite the Program aiming to act as a reminder, Participant 2 indicates that the process of remembering would need to be supported by other means, including an alarm clock. This is further supported by Participant 3, who highlights the need of caregiver support for the Program to be feasible.

Bringing whoever is in the household on board... so that there is a reminder so that the family member is also part of the intervention (Participant 3)

This idea is supported by Participant 4, who adds that, despite the importance of caregiver participation, the Program would need to consider issues linked to caregiver load and capacity to incorporate this Program. Although the Program aims to reduce caregiver load, it may cause inconsistent use and the need for support from the caregiver's side.

It's difficult, lots of things going on, lots of family dynamics and sometimes I think just people are very overwhelmed and feel very burnt out and they don't know what to do.. even when assistance is provided. (Participant 4)

In contrast to the last point, Participant 1 indicates that a reminder system may offer more support to the caregiver than the patient by reducing the load that they carry when having to monitor the patient's treatment. This is supported by Participant 2.

The carer or the family member.... the benefit for them is probably greater than it is for the actual patient. (Participant 1)

Another person giving the same message... have given them some level of support...ease..from that side. (Participant 2)

All participants highlighted the need for caregiver support. With this in mind, Participant 2 indicates the potential of the Program to relieve the caregiver from some of the load. Hence, the intervention would need to explore the impact of the Program on caregiver load.

4.1.5. Delivery System of the Program

A common theme that arose was the mode of delivery, method of messaging, as well as the form and nature of the messages that would have been sent to the patients. Therapists touched on this theme in many ways as they raised a variety of questions and ideas in response to the nature and form in which the reminders would be distributed.

The Program is delivered by cell phone and monitored by the Researcher. The incorporation of a third party (the Researcher) in the treatment process was identified as a potential limitation. Participant 1 raised that the therapeutic relationship is of vital significance when looking at social contact with another person, and this may be negatively affected by the inclusion of the Researcher into that space.

You cannot take away the value and importance of being with another person and the therapeutic relationship... human condition of needing that other person and validation of someone else. (Participant 1)

The reminder system was perceived by Participant 1 as potentially undermining the importance of the face-to-face interaction with the client, which was raised as a significant component of therapy.

It might be a bit difficult at first, because a lot of your patients, I mean building a rapport with them is a big thing. And being there and sitting with them and building a relationship and showing them, and offering them that initial support and showing them how this is going to support them and then slowly withdrawing and you know pulling back. But yeah I think it might be difficult getting them to trust you.. [the Researcher](Participant 4)

Participant 4 highlights that these kinds of Programs where the Researcher sends the reminder and is not the therapist, may not succeed given the importance that rapport has on treatment uptake. The Participant highlights the possibility that, if good rapport is not facilitated between the person managing the reminder system and the patient, most likely the patient will not participate. The Participant focuses on the importance of considering who will be providing the reminders as an important aspect of the Program design.

4.1.6 Technology and the Participant

With specific reference to both the context in which the Program would have run as well as the kind of participant, specifically ABI individuals, the therapists raised a variety of issues that the intervention. The following paragraphs address both smartphone penetration rates as well as response to technology by the participant.

4.1.6.1 Smartphone Penetration Rates

A key consideration that came from the interviews was the idea that the interaction between technology and poverty would play a role in the Program and at times present a barrier to the success of it. Technology, or smart phones, was a vital proponent of the Program as well as the success of running the reminder Programme. Particularly from the perspective of the therapist and their homework, technology plays a vital role. Participant 1 offers homework through different apps and Participant 3 often ensures her patients have a video of the exercises, which serve as a visual reminder.

So what I normally do is I take a video of them doing the exercise and then I Whatsapp it or email it to them, whatever their chosen form of um communication is. Yeah it used to be, like there are lots of online things you can use for the exercise but I just found that they often have like these very poor body awareness issues... if they have a video of their own bodies doing it it sort of resonates. (Participant 3)

Participant 3 suggests, in the quote above, that in some instances WhatsApp may be a feasible platform. However, this also suggests that perhaps the intervention should consider the possibility of delivery by different platforms in order to adjust to the preferred mode of delivery instead of forcing a participant to acquire a new app.

In addition, the above quote demonstrates that Participant 3's messages are personalised, and therefore, generic messages may not have the intended effect on the participant and may be ignored.

However, within the South African context, smartphone accessibility becomes a fundamental barrier to the intervention and a possible confounding variable to measuring feasibility. Participant 2 raised her concerns regarding accessibility to data and the load shedding that is currently occurring in South Africa and the issues that both of these cause in relation to running a successful intervention through a smartphone and instant messaging.

“[Issues with reference to] data.. so from an external point of view obviously the load-shedding [pose problems]” (Participant 2)

Although the intervention would have offered data to the participants, this is not sustainable in the long term. Furthermore, Participant 4 raised that one would need to ensure that the ABI individuals have all that they need from a financial perspective in terms of acquiring airtime and data for the intervention to run fully.

Also financially, you know just in terms of making sure that there is data or minutes or SMS bundles on the phone (Participant 4)

4.1.6.2 Response to Technology

Since the Program was targeted at adults, Participant 1 raised the importance to consider the form in which older clients do and receive homework. Participant 1's comment below indicates

that there could be adults struggling to use the phone as the Program medium. This highlights the importance of considering different inclinations to the adoption of technology. This is a significant concept to understand the role that the Program's form would have for these patients.

older clients like things in hard copy (Participant 1)

This indicates the perception that instant messaging reminders may not be suitable for those participants who have low familiarity with cell phones or those who prefer to avoid engagements with technology.

A further consideration identified by Participant 3 and Participant 4 is the possible barriers that the ABI individual may find when engaging with the cell phone in terms of receiving, replying and independently comprehending the instant messaging reminders, as well as negative feelings linked to receiving the reminders (e.g. irritability).

*Their tolerance levels are like like zero and they get irritated from the sms's
and they'll be like again, why are you smsing me again (Participant 3)*

Specifically, Participant 4 raised that the severity of the injury may lead to a concern regarding whether the ABI patients would be able to utilise the phone or use all functionalities.

*because of the severity of their injury I don't think that would actually be
able to interact with the cell phone and know how to respond... you would
almost need to do this almost with a caregiver (Participant 4).*

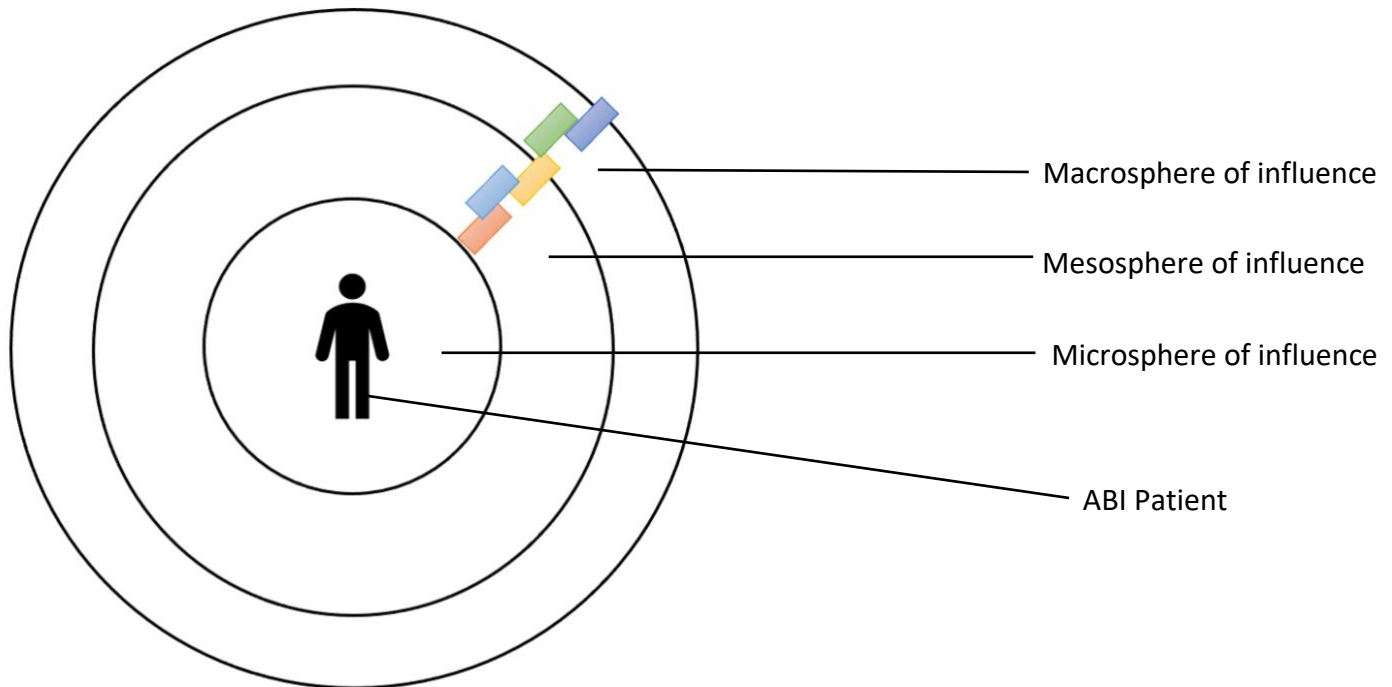
4.1.7 Barriers to Implementation of the Intervention

During the course of the study, the Researcher confronted a variety of barriers to implementing the intervention proposed. Obstacles were consistently and continually faced by the Researcher both in relation to obtaining replies and the recruitment of participants. This resulted in the inability of the Researcher to implement the Program as designed. The following will outline the barriers and obstacles to this intervention which were faced by the Researcher. These are informative factors which influenced the ability to implement an intervention with ABI patients in a South African context. This section will also be utilised to inform the discussion with reference to previous research and the manner in which this study compares thereto.

The Program designed by the Researcher had the ABI patient as the focus of analysis. As according to the theory of Bronfenbrenner, individuals are influenced by a variety of spheres within their contexts and environments (Paquette & Ryan, 2015). Figure 2 represents the ABI patient at the centre of the spheres of influence. The Researcher understood that accessing the ABI patient was influenced by macro, meso and micro contexts and that these contextual elements played a significant role in influencing the feasibility of the Program. Through the processes and procedures described above, the Researcher realised that in fact, there were many barriers within each of the spheres as described above. Figure 2 represents this concept.

Figure 2

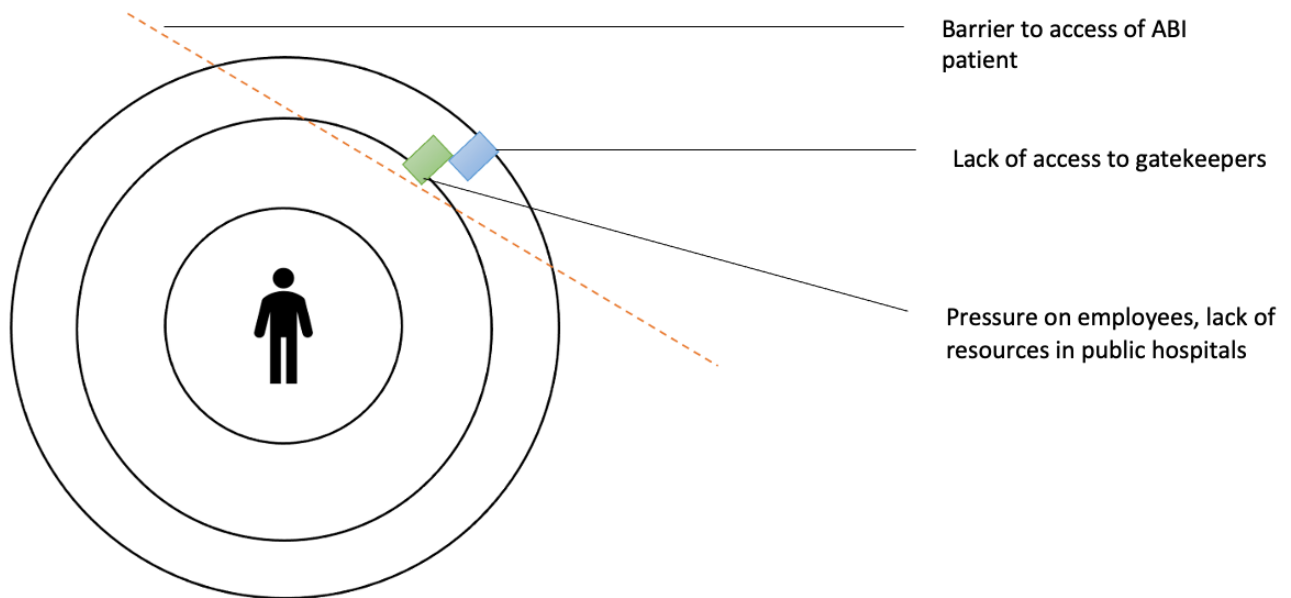
Depiction of Spheres of Influence on the ABI Patient with Barriers to Accessing the Patient



The coloured bricks in Figure 2 depict the manner in which barriers to the research, as imposed by external factors, ultimately restricted the Researcher from accessing the patients and from running the intervention with them. These bricks represent barriers to implementation, as have been explained throughout the study, are the obstacles that drove the shift of the analytical focus of the study and impeded the Researcher from inviting the ABI patients to participate in the Program. The barriers to implementation are described in the sections below. Each brick represents an inhibiting factor that arose between the Researcher and the ABI patient.

Figure 3

Depiction of Spheres of Influence on ABI Patients in Public Practice.

**Figure 4**

Depiction of Spheres of Influence on ABI Patients in Private Practice.

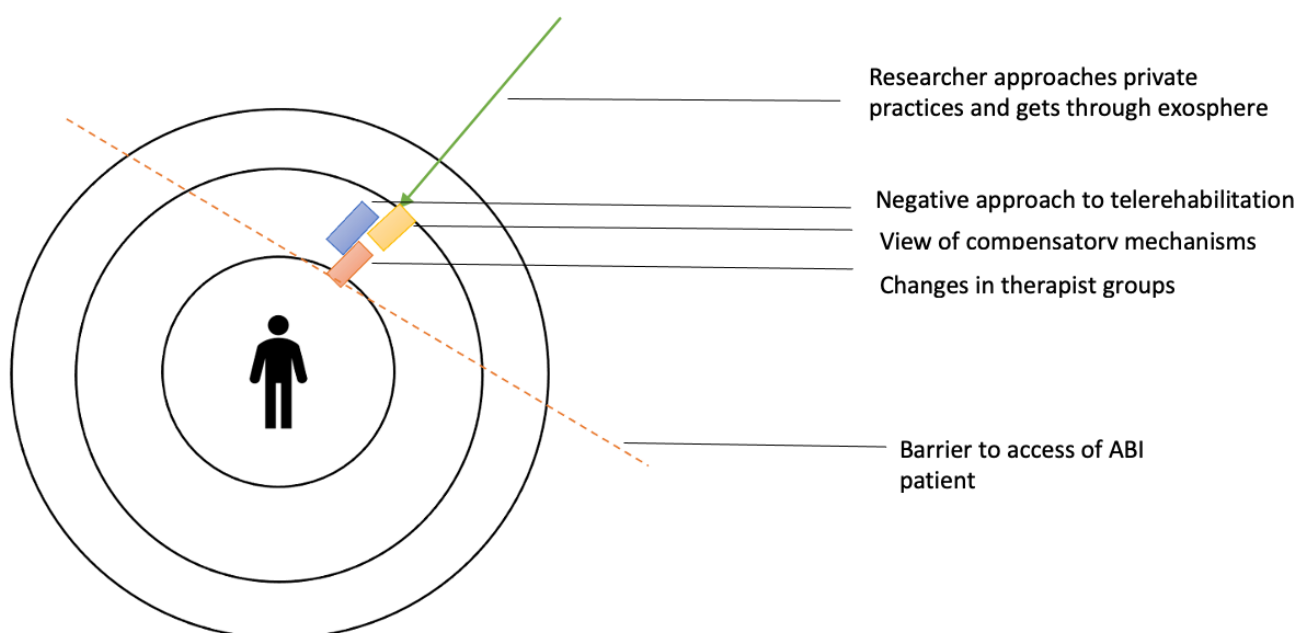


Figure 5

Depiction of Spheres of Influence on ABI Patients and Interaction with Researcher's Spheres of Influence

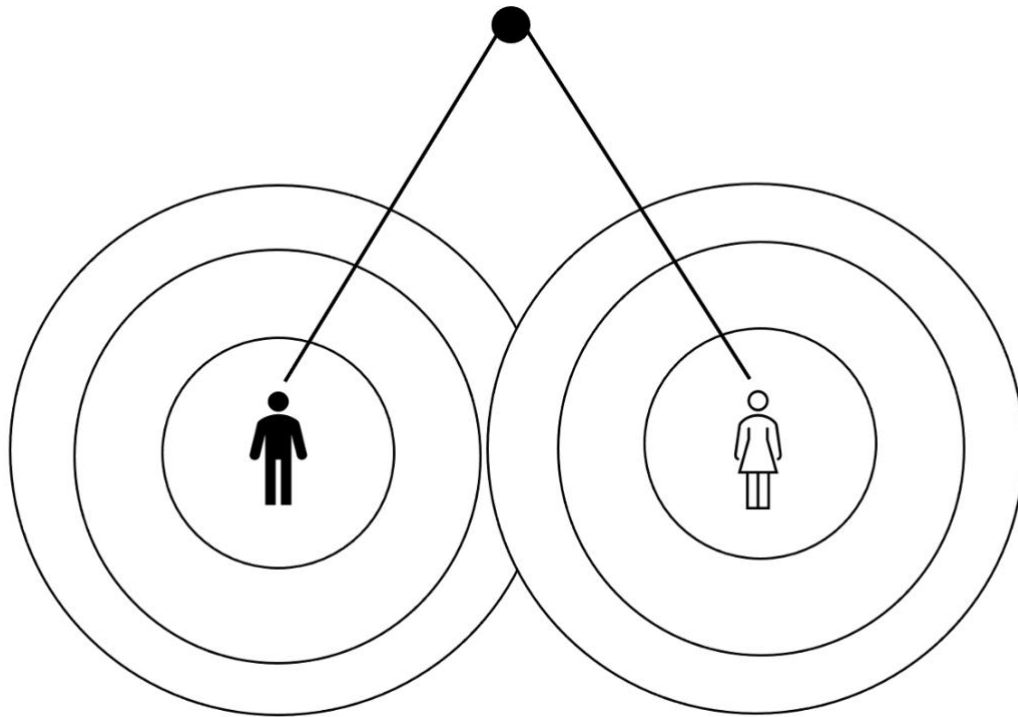


Figure 5 is a visual representation of the change in the unit of analysis within the project. On the left is the ABI patient, surrounded by the micro, meso and macro spheres which affect and influence the patient. On the right is the Researcher, surrounded by the micro, meso and macro spheres which affect and influence her. The line from the patient to the Researcher represents the ultimate change in the unit of analysis from patient to Researcher and indicates the pivot point which influenced the Researcher to alter the aims and analysis of the project. The macro sphere in the visual represents the broader context of South Africa, and includes the health care sector as part of the macro environment that affected both the Researcher but also the patient

The Researcher utilised the above visual to represent the distance between the Researcher and the patient, and the inability to bridge the gap between the two. based on the bricks within the

context and environment that was present. This called to question the feasibility of the Program proposed as it was evident to the Researcher that in this instance, and within this Program, context played a significant role in creating barriers to the research which are influenced to a large extent by South African systems, but also by closer factors such as the therapists themselves as well as the families of the patients (macro and mesospheres). This is represented in Figure 3 and 4 as a red line that depicts the distance between the Researcher and the patient.

4.1.5.1 Lack of Response and Reply

As depicted by the bricks in Figures 3 and 4, one of the most challenging aspects of the study was the lack of response received by the institutions and professionals contacted during the course of the study. This obstacle to the research began as early as October 2021 and formed part of the larger issue of an inability of the Researcher to recruit participants based on the lack of open communication. During the recruitment stage of the study, the Researcher made contact with six organisations, both private and public. Of the six original sites contacted, only two were part of the interview stage and an additional two sites were required to be included in the study in order for there to be a sufficient number of participants within the interview stage.

With specific reference to the public hospitals included in the recruitment stage of the study, the Researcher understood that there were a variety of organisation-based issues that contributed to the lack of responses received. In the public sector, there are many levels that one needs to pass through in order to conduct a research study with public patients. Challenges included emails bounced back, the email addresses were not available, there was not a clear procedure to follow to contact people to get relevant permissions. The Researcher further found challenges in making contact with the CEOs and MDs of the public hospitals as was expected

by the Ethics Committees. In addition, those who work in public practice are confronted with multiple variables that include a lack of sufficient resources, high patient loads, extreme capacity limitations as well as the pressure placed on employees of such organisations that a research project of this nature may be perceived as an added level of pressure and as such, a hindrance more than an assistance. It is possible that the lack of response is due to these issues.

In terms of the private practices, delays of a different nature existed. Initial contact with the two original private practices was made in October 2021, with follow up emails being sent in November 2021. Consent to conduct research was granted in December 2021, with formal unconditional approval being obtained in February 2022. Interviews with both participants from these organisations took place in March 2022. In June 2022, follow-up emails were sent to request the names and contact details of the ABI individuals that gave permission to be invited to the study, however, neither individual replied. In July 2022, the Researcher contacted both participants again. The therapist from the one private practice was unable to recommend ABI patients for the study due to patients' personal issues that made it impossible for the therapist to introduce them to the study. The therapist from the remaining practice was unable to recommend participants because she was undergoing a transition process in her practice and was not working with a consistent group of patients.

4.1.5.2 Issues Related to the COVID-19 Pandemic

The majority of the data collection for the study took place during the lockdowns associated with the COVID-19 pandemic. This limited the Researcher's access to both the therapists that were approached during the study but also to the patients themselves. The importance of establishing rapport with the therapists and the patient was raised by the participants as an important aspect in the rehabilitation process. COVID-19 reduced the capacity for this process

to take place. This increased the reliance on the materials that were presented to the therapists and not on the face-to-face interactions that would have been the preferred mechanism of communication. This hampered the establishment of trust between the Researcher and the therapists and was one of the major hurdles that hindered the implementation of the Program. It was not only a barrier to the therapist but was ultimately a barrier to between the Researcher and the ABI patients. As recorded by the therapists, rapport and trust are one of the key features of a patient following treatment structures. Therefore, one of the barriers for the Researcher was a lack of opportunity to build rapport due to COVID-19 restrictions.

4.1.5.3 Patient-Related Obstacles

Despite the head therapists of the private organisations replied within a reasonable period, they found it challenging to recommend participants for the study. Reasons for this included unexpected changes in private groups of patients which led to the therapists having to form relationships with new patients. Other barriers to recommending participants related to personal issues on the side of the ABI individuals and family related dilemmas. This made asking for permission to participate in a research study somewhat irrelevant and therefore caused further delays.

4.1.5.4 Therapist-Related Obstacles

In some instances during the research process, the Researcher understood that the therapist sample were in a manner, one of the barriers to the implementation of the Program, as it was difficult for them to allow the Researcher, an outsider, to enter their therapeutic space. Through these experiences, the Researcher realised that therapists could not see the Program as

beneficial to them, to the patient, and to their therapeutic goals and method of working, and therefore, there was no uptake.

Chapter 5: Discussion

The aim of the study was to assess the feasibility of an instant messaging telerehabilitation program that sought to remind individuals with ABIs of their homework linked to their treatment (e.g. Speech Therapy or Occupational Therapy). The following discussion will compare the results of this investigation with the existing literature and ultimately debate whether the application of the proposed program is feasible and appropriate the context in which the study was conducted. The structure of the discussion will include an analysis of themes, grouping these into three main categories, i.e factors in relation to the patient, factors relating to the families and caregivers and factors relating to the therapists. Finally, the theme of obstacles and barriers to the research will be discussed in order to explain the main threats to feasibility for the Program as created by the Researcher.

5.1 Factors Related to the Patient

The success of the Program is linked to the possibility to create a bespoke intervention. Each patient, each injury and each person's social, familial and economic lives differ drastically, therefore the intervention needed to approach each patient as an individual within their unique context. This notion of the therapeutic goal being in line with the individual and the intervention is echoed in previous research, which states that due to the heterogenous nature of brain injuries there is vital significance in individualising one's goals and approach to therapy (Margulies & Hicks, 2009). Goal setting allows the therapist to comprehend the manner in which the patient perceives their injury, ability to recover and the role they play within this recovery (Wade, 2009). The participants believed that the intervention should be aligned to the therapy goals. Hence, the program should not compensate for a skill that is being rehabilitated

in therapy or use it only when the therapist believes that it would promote other skills through the reminder system.

Although aspects of the above response are in line with research that exists within the field, there are some elements of this approach which differ fundamentally from prevailing research. The findings of this study in relation to the importance of alignment between goals and context mimic research conducted by Wilson (2002) which indicates that when goals are in line with contextual circumstances, therapists are able to yield the best results for their patients. This highlights two separate issues, namely recovery of memory functions versus compensation of memory functions. However, in earlier research by Wilson (1997) it was found that there are four main types of cognitive rehabilitation, namely, rehabilitation through drills and exercises, the use of cognitive psychology to identify and target deficits, a patient driven approach which incorporates a combination of learning theory, cognitive psychology and neuropsychology to identify and remediate functions and lastly, a holistic approach which indicates that cognitive rehabilitation cannot be removed from emotion, motivation and other non-cognitive functions of the patient. Essentially, this fourth approach considers all aspects of functioning and indicates that recovery is most positive where all aspects of functioning are addressed (Wilson, 1997). The findings of Wilson's (1997) study indicate that the first of these two approaches may not lead to good results in clinical rehabilitation and that Wilson's (1997) approaches three and four should be foregrounded within rehabilitation. A further study by Wilson (2013) updated and confirmed these results and indicated the value of holistic approaches to rehabilitation. It is possible to infer that the participants may often rely on practice-based exercises that are opposed to compensatory strategies, which reflect a specific line of work that seems these strategies as incompatible and not part of a holistic approach.

Furthermore, Wilson et al.'s (1997) study on NeuroPage, a California based paging system, indicated that when 15 brain injured individuals participated in a compensatory reminder program, a significant improvement between baseline and treatment phases was found for these individuals and all subjects benefited from the intervention described. The NeuroPage system was a reminder based system which required input from outside sources to generate tasks, and then allowed for automated reminders to be sent to participants (Wilson et al., 1997). A further study by Wilson et al. (2005) demonstrated that a paging system tested on two groups of 143 brain injured individuals, found a significant reduction in both memory and planning deficits when the paging system was utilised. Essentially, what this indicates is that the findings of this Researcher contrast the prevailing positive research within the field indicating the value of compensatory reminder systems.

Perceived success of the program is linked to the individual's lifestyle and the fit within their personal circumstances. A key theme that arose was the idea of overall consistency between therapy and lifestyle. Lewis et al. (2011) indicates that therapy seeks to foster independence, especially in consideration of the individual's previous lifestyle. Importantly, the therapists raised the concept that the intervention would need to ultimately consider the personality of the patient as well as their commitment to the goals set by the therapist. Other individual factors such as education, resources and access to therapy would all play a role in the response to this intervention because of the telerehabilitative nature and the personalisation element required by the reminder system. This theme is echoed by Wade (2009) who emphasises the importance of understanding an individual's context in relation to their goals, and their overall approach to therapy as a whole.

An additional barrier to the feasibility of the intervention is the response to technology by individuals with ABIs. Due to the cognitive deficits associated with ABIs and the resulting

behavioural disruption (Grealy & Rushton, 1999), therapists raised concern that some of their patients may not be able to appropriately respond and or comprehend the cell phone and instant messaging aspect of the intervention, which would pose a challenge to feasibility. Moreover, a lack of ability to follow-through, plan and co-ordinate activities would contribute to a lack of feasibility of the Program (Lawson et al., 2020). One of the therapists added that only one of their patients would be able to receive, respond and comprehend the messages without the support of the caregiver. This is in contrast to existing research in the field where a variety of studies indicate the effective use of technology with individuals with ABIs. One such study was conducted with 11 brain injured participants, split into two groups, one who received text reminders three times a day, whilst the other group received none (Culley & Evans, 2010). It was found that the group who received the reminders had a significantly greater goal recall than the group who did not (Culley & Evans, 2010).

The Researcher believes that the apprehension in relation to the telerehabilitation Program proposed by the study was in part due to the lack of knowledge and experience on the part of the therapists of having utilised this kind of approach. Research conducted by de Joode and colleagues (2012) included the completion of a web-survey to ascertain the attitude towards assistive technology of 147 professionals, 15 ABI patients and 14 caregivers. Results of this study indicate that although the majority of the professionals were willing to utilise technology within therapy, they had not yet done so (de Joode et al., 2012). This is in line with the information presented by the therapists included in this study. Therefore, this Researcher suggests that telerehabilitation and its benefits need to be more widely understood.

A further factor raised by the therapists was the instant messaging nature and form. Due to the sample chosen by the study, specifically adults, there was a perceived disconnect between the manner in which the patients usually receive homework and the intervention itself. However,

as was suggested in a study conducted by Kapur and colleagues (2004), it was proposed to send context specific reminders that were clearly instructed by an individual with whom the ABI patient had prior contact. In this way, the Program sought to bridge the gap between paper-based activities and the Program, by still ensuring the therapists handed physical homework out, but to merely have an external cue to assist as a reminder to look at said homework. The instant messaging system proposed mimicked a paging system that was found to be successful by Wilson (1997) and proposed an alternative means to provide rehabilitative support.

Although not directly expressed by the therapist participants, sensory and motor deficits identified by therapists within the study flag the possibility that many patients with ABI may not be suitable for unassisted homework due to these physical limitations.

5.2 Factors Relating to the Caregiver or Family

A theme that was consistently mentioned by the therapists was the reciprocal influence of the Program on the caregiver and family, as well as the influence of the caregiver and family on the Program. Every patient used as an example by the therapists had either a personal caregiver or a family member assisting in both general care but also therapy-related care. Studies indicate that individuals with acquired brain injuries most often require support for the duration of their lifetimes (Jamwal et al., 2017). Due to their need for support, the intervention was considered to be viable if and when the homework and therapy were explained to the support system in order to secure their buy in and additional support. Through this positive family support, there would be a constructive impact on the therapy but more importantly, on the intervention due to the significant influence that the families and caregivers have on the patients. This theme is echoed in Fisher et al. (2020) where positive family support was found to be beneficial in

terms of behavioural changes in ABI individuals, and further, the study found that families can be trained to develop and implement strategies to assist with behavioural support. Moreover, the approach to family support expressed by the therapists is echoed by research that indicated that positive family support is correlated to longer lasting recovery and rehabilitation (Kuipers et al., 2014).

The therapists expressed the view that the Program itself would provide more support for the family than for the patient. The Researcher understood through these responses that the therapists perceived the Program more as a supportive mechanism to take the burden away from the caregiver having to remind the patient to do their exercise homework, than as a support for the patients.

The alternative perspective expressed by some of the therapists indicated that the intervention could be beneficial for the caregivers insofar as it would be an additional supportive resource to reinforce the message they give regarding homework. The access to the written information, in the form of the messages and reminders was identified in a study by Webster and Balchin (2015) as being beneficial and helpful for the caregiver as the influx of information for them is often overwhelming. This proved to be successful as the carers had tangible resources to refer to when needed (Webster et al., 2015). Through this Program, caregivers would also have additional support and the ability to ask questions, check in with the Researcher and refer to exercises that they may have missed or misunderstood. In turn, this would result in easing some of the burden on the caregiver. However, this is a topic for further research as this study did not reach the stage at which carers were directly approached and hence this potential outcome could not be validated.

Furthermore, the therapists expressed mixed reviews in relation to the impact of the intervention on the carer of the ABI individual. In correlation with existing research, the therapists raised that individuals who care for individuals who have sustained ABIs are often so overwhelmed that they have reached burnout (Braithwaite, 1992). In many circumstances the family member is confronting a new person, with a new personality, more deficits and a variety of needs not present before (Fisher et al., 2020). Therefore, to add another level of burden on them by having to assist with the intervention and the homework, could very possibly cause further distress for them and contribute to burnout, *inter alia*. A further contributing factor within the South African context is that not only are many individuals not able to pay for additional care, in which case the duty of care falls to the family members, but themselves may be under-resourced and under-educated to properly care for and assist individuals with said injuries (Webster et al., 2015).

5.3 Factors related to the Therapist

The therapists interviewed see therapy more as a way to recover some functionality and focus much less on compensatory strategies. This was evident as therapists focused on remedial strategies within their answers in the interviews. This is in contrast to the research that prevails within the field currently, where many programs and intervention strategies are focused on how best to support and compensate for deficits experienced by individuals with ABIs through therapeutic practice (Fleming et al., 2005). This is also striking insofar as one of the key pillars of cognitive rehabilitation, as according to van Heugten et al. (2020), is the ability of the rehabilitation to compensate for deficits. Ultimately, where functioning cannot be recovered, and especially in terms of normalising everyday life, compensation for deficits has proven both more successful and more practical (Prince & Bruhns, 2017). Research has indicated that even

where remedial strategies were taught over compensatory ones, participants related to a specific study still automatically utilised compensatory means to complete tasks (Dirette et al., 1999).

An intervention conducted by Kapur et al. (2004) indicated that reminder systems from external aids that were context-sensitive in other words, activated when a caregiver or family member was in the vicinity or where the individual engaged in therapy homework, therefore utilised within a specific space and time, easily retrieved by the patient and sent to ABI patients via cell phones were effective in improving everyday memory for ABI individuals, which was considered as positive results.

Within this study, this Researcher aimed to include the therapists within the Program from the start by choosing when the aid would be utilised in order to ensure participation when it was required. When the ABI individual has to choose when the reminders need to be set, the reminders are not utilised effectively. However, when a third party is involved, then positive results are found (Kapur et al., 2004). Kapur and colleagues (2004) identify the lack of therapist's involvement in the technological reminder system that was generated as an obstacle to memory improvement due to the fact that therapists did not indicate when the reminder would be beneficial for use (Kapur et al., 2004). The findings of this study also highlighted this as a barrier to implementation of the Program. However due to both the nature of the barriers to implementation as well as therapists' clear reservations regarding compensatory mechanisms in therapy, the Researcher was confronted with the same obstacle.

Further contextual factors influence the feasibility of the intervention. In particular, smartphone penetration rates were a major factor of concern for therapists who indicated that many of the patients within their practices, but also within the public sector, do not have access to phones. This is in line with research which indicates that the vicious cycle of poverty within the South African context continues to restrict access to technology and cellphones (Shambare, 2014). If one is to consider that the intervention relies on individual's having access to cellphones, electricity, data and sufficient funds then it becomes evident that this would be a major barrier to the feasibility of the proposed intervention.

5.4 Obstacles and Barriers to the Research

The Researcher was faced with a number of obstacles and barriers to implementing the Program that was created. ABI patients are surrounded by these systems and, from the perspective of this study, each system contains barriers that affect the feasibility of the Program. The Researcher utilised this approach to conceptualise that she too is and was surrounded by overarching systems and that the interactions of these systems, both with each other but also with the systems of the patients, ultimately influenced the research process as a whole. This is not a new concept within the field of research and is widely used in research efforts to comprehend the influence of wider systems, especially in countries with diverse populations and very specific contexts (Swanson et al., 2003). Onwuegbuzie et al. (2013) utilised Bronfenbrenner's system model in order to map research on levels of influence and through this approach, sought to inform the research process to comprehend the variety of factors influencing all levels of participants, as well as to award credit to individuals within their very specific contexts.

Although the Researcher refers to Bronfenbrenner's theory, this paper only draws on parts of the theory and is not a complete reference to it. The Researcher conceptualised the ABI patient surrounded by three main levels of influence, namely micro (this included the patient's personality, injury type and associated deficits), meso (family circumstances and relationships) and finally, the wider South African context, environment and health services. If one is to look at the patient, each and every patient is surrounded by family circumstances, changes in personality, associated deficits, loss of work, limitations related to therapy access, therapist relationships as well as financial circumstances. When one is to look at each and every one of these, they all ultimately influence the manner in which each patient would be able to access, work through and benefit from the Program. This is indicated by research that states that cognitive rehabilitation interventions should be tailored to patient specified goals, considering all patient related factors (Merriman et al., 2020).

For the patient in the public hospital, their third sphere of influence (i.e. the exosphere) was filled with the obstacles relating to the inability to access the gatekeepers at the public hospital level as well as organisational issues in relation to extreme limitations in public hospitals, pressure on employees and lack of resources. This played a role as a barrier because in these cases, the Researcher could not surpass the third level of influence (i.e. the exosphere). This is further depicted with reference to the red line separating the Researcher from the patient. This was too found in research where it is evident that therapists act as gatekeepers in order to ensure the safety of their patients, but at the same time, are counterproductive in this manner as they are prohibiting patients from connecting with other levels of support (Brunner et al., 2021).

With reference to the ABI patient in private practice, the Researcher was able to get closer to accessing the patient but was similarly affected by hurdles within the spheres of influence.

With the private practice patients, initial contact at an organisational level was made and responses, although slow at times, were received. However, within the secondary level (i.e the mesosphere) the Researcher experienced barriers in relation to family or personal financial issues, caregiver burden, perceptions of the therapists as well as consistently changes to the groups and patients that the therapists engaged with.

In public hospitals, this can be explained by a variety of factors. Cobbing et al. (2014) highlighted that in a South African context the government hospital staff are overwhelmed with patients, under-resourced and under-staffed. This affected the Researcher as during the recruitment stages, very few responses were received by the Researcher when attempting to contact HODs, CEOs and management staff of these hospitals. It stands to reason that in an environment so heavily understaffed, a research proposal attempting to assist could at some level, create additional work and administration for individuals who are already overwhelmed by their professional circumstances. In addition, no financial compensation would have been included for participation in the research and this allowed the Researcher to consider that perhaps the threat of extra work for no immediate gain may have been a confounding variable to the study.

In addition, the study's recruitment stage was affected by the COVID-19 pandemic, which caused further obstacles for therapy. The public health system was focused on life preservation during a time of complete overload (Dantas et al., 2020) as a result of the pandemic. Most "non-essential" services took a backseat during the pandemic, therapists within these contexts were forced to attempt to preserve therapy under extreme circumstances. The Researcher believes that the pandemic, in conjunction with low access to therapy and overwhelmed staff,

played a large role in the barriers and obstacles to accessing public hospital patients (Joosub, 2019).

As described above, the Researcher was faced with many obstacles to implementing the Program. This was particularly due to factors that prohibited her from inviting the ABI patients themselves to take part in the Program. The Researcher began to comprehend this process through the visuals pictured above but also through a conceptualisation and understanding of Bronfenbrenner's Ecological System's Theory.

The Ecological System's Theory, originally conceptualised by Urie Bronfenbrenner, describes child development through a context of influence of levels and relationships of systems within the child's environment (Paquette & Ryan, 2015). Although the Theory originated within child development, this model has been used to understand the impact that different systems have on an specific person (Onwuegbuzie et al., 2013). Bronfenbrenner proposed that four major subsystems influenced human behaviour and development, namely the microsystems (immediate settings), mesosystems (interaction between major settings) and macrosystems (overarching institutions) as well as exosystems (Killam & White, 2017). In essence, the interaction of these systems has a significant impact on behaviour and need to be considered when attempting to understand the manner in which to approach and interact with others.

Another noteworthy aspect which struck the Researcher is that with the rise in telerehabilitation, and with the risk and dangers associated with exposure to COVID-19, the Researcher understood that the therapists would have more easily adopted the idea of a program which sought to complement face-to-face sessions. Ultimately, the majority of themes identified in the data point to low feasibility of this intervention, which is in contrast with the

fast development of tele-health post COVID-19. This is echoed in research as ABI individuals report positive associations with telerehabilitation interventions, whose efficacy has been reported (Tam et al., 2003).

Ultimately, the Researcher's approach to the study became one where an alteration in the interaction between the Researcher and the ABI patient developed in a different manner to what was initially envisioned. The study grew throughout the process of the research and the pivot point depicted above was one that altered the study to encompass both the Researcher's experiences and the patient's influencing factors as equally important within this report.

Essentially, the data indicates that the Program could not be adequately assessed for feasibility due to the lack of ability for implementation as a result of a variety of reasons. These include 1) reservations on the part of the therapists in relation to the compensatory and non-remedial nature of the program that was created, 2) institutional challenges (public hospital barriers and private practice obstacles), and 3) concerns of the therapists regarding both the burden that would be placed on the caregivers as well as the perceived negative response that the patients would have to the specifics of the intervention. The Researcher found that within this South African context, the Program could not be tested for effectiveness.

Chapter 6: Conclusion

6.1 Summary of Findings

The ultimate purpose of the study was to explore the factors that would influence the perceptions of feasibility of the proposed program created by the Researcher, both from the perspective of the therapists and the Researcher herself. The qualitative analysis of the participants' responses indicated that they had a very specific understanding of therapy as being remedial and this influenced their perceptions. Furthermore, this discussion will indicate that contrary to research that prevails within the field, this study found that a compensatory program of reminders was not able to be tested for feasibility within the very specific context in which the research was conducted.

The Researcher found that therapists interviewed viewed therapy as a means to recover functions following ABIs. Where this is the focus of therapy, the proposed program can be perceived to be incongruent with the expected outcome. The patients whom the therapists had envisioned for participation in the proposed program were patients whose EFs, planning and memory were either mostly preserved or the therapists were hoping to recover these skills to baseline functioning. Part of what made the proposed program not able to be assessed for feasibility is the inability of the therapists to imagine incorporating this kind of Program into their own therapeutic work. From this perspective, participants of the study perceived the Program as having more value for a reduction of the load placed on families and did not see the Program's importance in compensating for deficits in functioning. Participants of the study raised many concerns regarding the workings of the Program and proposed that their perception of the Program was that it would ultimately be not feasible.

This is in contrast to research undertaken in other countries, where compensatory studies and telerehabilitation were both found to be successful and beneficial with regards to compensating for functional loss. Essentially, in cases where the deficits in EFs are long-term and cannot be improved, as well as with kinds of therapies that require constant practice, this kind of Program can be used to compensate for small specific interventions where the threat of not remembering to do the exercises or take on the responsibility of doing them independently, may threaten the functioning of the patients.

6.2 Limitations

As has been detailed above, the study was met with a variety of limitations, both with reference to the kinds of individuals targeted by the study, the impact on therapy as caused by the COVID-19 pandemic as well as the socio-economic circumstances within the South African context and the result of this on access to participants. Limitations of the study are detailed below.

The inclusion of both public and private practices would have enabled the study to have a greater relevance to the majority of South Africans. The inclusion of only private practices lowers the ecological validity of the study in relation to the wider demographic of the country. This serves as one of the major limitations of the study.

Further limitations include the kind of individual targeted as individuals with ABIs typically struggle with memory, motivation and ability to participate in therapy itself. In addition, as was raised by many of the therapists involved in the study, some of their patients with ABIs are

unable to use phones, read messages and comprehend the need for appropriate responses. This posed a limitation to the ability of the study to fully ascertain feasibility in relation to the Program itself. This also limited the therapists being able to recommend participants for the study.

One cannot ignore the impact that the high rate of poverty within South Africa had on both the intervention and on the perceptions in relation to feasibility. Data costs, resources, access to smartphones as well as access to therapy automatically excludes certain members of the population from participation. This is a limitation of the study.

COVID-19 caused limitations to the study but also to the ability of the Researcher to contact and form relationships with the therapists. Due to the fact that the study took place over a variety of COVID-19 lockdown stages, the volatility as well as continued changes of allowances and stages posed a large challenge to the status of the study. COVID-19 also had an impact and caused changes in the patients with whom the therapists were working and posed issues in relation to access of patients and face-to-face contact. In addition, rapport between the therapists and the Researcher was threatened due to the lack of one-on-one conversations and a possible disparity in the therapists' understanding of the Program.

6.3 Recommendations for Further Research

Recommendations for further research range, depending on which aspect of the study one is looking to target. One of the possible recommendations is to consider having two participant groups, one control group (no reminders sent) and one group who receive reminders. This would allow a future Researcher to ascertain the feasibility of the intervention itself with the

ability to compare a group who receives reminders to one who does not. The inclusion of the ABI participants would also allow a future Researcher to comprehend whether these individuals would be able to utilise the program.

Furthermore, a key recommendation for further research would be to gain access to participants from the public sector. This would open future studies to being more relevant to the true demographics of South Africa and would ensure that future research within this field would be more ecologically valid. This would open the study to a demographic group, patients in public hospitals, who would normally not have access to these kinds of Programs, and therefore, could test whether this kind of Program is applicable to the broader demographic.

From the ethnographic experiences of the Researcher, she suggests that further research considers incorporating time to create rapport between the therapists and the Researcher conducting the study. Through this, the therapist and Researcher can ensure that the homework and Program suggested would be aligned and could therefore form a trust relationship between the therapists and the Researcher. In the same way, the therapist could then introduce the Researcher to the prospective patients and thereby encourage a trust relationship between the Researcher and the patients.

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APPENDIX 1

Interview Schedule for Therapists Pre-Intervention

1. Name and Surname
2. Occupation
3. Organisation to which you are affiliated (if any)
4. How often do you see your ABI patients?
5. What kinds of problems do you encounter with your patients?
 - a. Complete this question by asking about cognitive, behavioural, emotional, financial, and social changes/challenges associated with ABI
6. When working with these patients do you give home exercises to be completed?
 - a. If yes, what kinds of exercise homework do you give? What kind of materials are needed to complete the homework you prescribe?
 - b. If no, what are the reasons for not sending homework to your patients.
7. How do you evaluate patients' progress and whether they engage or not with the prescribed homework?.
8. In your opinion, what makes it easier for patients to do homework? What makes it difficult for them?
 - a. Complete this question by asking about specific cognitive, behavioural, emotional, financial, and social challenges.

Please note that any ABI patients that you recommend need to have conversational English proficiency.

APPENDIX 2

Interview Schedule for Therapists (Amended Version – Final)

1. Name and Surname
2. Occupation
3. Organisation to which you are affiliated (if any)
4. How often do you see your ABI patients?
5. What kinds of problems do you encounter with your patients?
 - a. Complete this question by asking about cognitive, behavioural, emotional, financial, and social changes/challenges associated with ABI
6. When working with these patients do you give home exercises to be completed?
 - a. If yes, what kinds of exercise homework do you give? What kind of materials are needed to complete the homework you prescribe?
 - b. If no, what are the reasons for not sending homework to your patients.
7. How do you evaluate patients' progress and whether they engage or not with the prescribed homework?.
8. In your opinion, what makes it easier for patients to do homework? What makes it difficult for them?
 - a. Complete this question by asking about specific cognitive, behavioural, emotional, financial, and social challenges.
9. After an explanation of the proposed intervention, how do you believe an intervention like this would facilitate increased participation in exercise homework?
10. What are the potential obstacles to such an intervention?
11. What would help facilitate the success of an intervention like this?
12. How would the lack of face-to-face interaction play a role in experience of therapy with regards to both you and the patient?
13. What would the impact of this kind of intervention be on the patient with regards to:
 - a. Functional capacity?
 - b. Family load?
 - c. Financial load?
 - d. Follow up?
 - e. Improvement of therapy?

APPENDIX 3

Ethical Clearance Certificate



R49 Ms CC Osato

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE NO. M210847

NAME:
(Principal Investigator)

Ms CC Osato

DEPARTMENT:

School of Human and Community Development
Department of Psychology
University

PROJECT TITLE:

*Use of instant messaging to improve participation in
rehabilitative prescribed exercises for sufferers of
acquired brain injury: a feasibility study*

DATE CONSIDERED:

2021/08/27

DECISION:

Approved unconditionally

CONDITIONS:

This approval applies only to the study sites listed
in Annex 1 attached
Further sites may be added on presentation of
evidence of management approval to the HREC (Med)

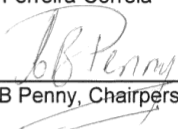
NOTE:

If contact information regarding student study participants is required,
please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>

SUPERVISOR:

Dr A Ferreira-Correia

APPROVED BY:


Dr CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL:

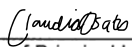
2021/11/16

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report.** When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **August** and therefore reports and re-certification will be due in the month of **August** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).


Signature of Principal Investigator

2022/01/24
Date

APPENDIX 4

Participant Information Sheet for Therapists



Dear Sir / Madam,

My name is Claudia Osato and I am a Masters student in Research Psychology at the University of the Witwatersrand, Johannesburg. As part of my degree, I have to undertake a research project, and I am investigating whether an instant messaging reminder can improve participation in rehabilitative homework for people with acquired brain injuries. This study also aims to explore the feasibility of such an intervention. The project is supervised by Dr Aline Ferreira-Correia.

As part of this project, I would like to invite you to take part in answering two questionnaires aimed to explore your thoughts about the feasibility of this intervention. The first one will take place before the intervention and the second afterwards.

There will be no personal costs to you if you participate in this project. You will not receive any direct benefits from participation and there are no disadvantages or penalties if you do not choose to participate or if you withdraw from the study. You may withdraw at any time or choose not answer specific questions if you do not want to. Your participation will be completely confidential and your responses will be anonymized in all reports as I will be using a pseudonym (false name) to represent your participation in my final research report. Your participation will remain confidential and all the information you provide will be securely stored and not disclosed to anyone else aside from my supervisor.

If you have any questions during or afterwards about this research, feel free to contact me or my supervisor on the details listed below. This study will be written up as a research report which will be available online through the university library website. If you wish to receive a summary of this report, I will be happy to send it to you. The data collected in this project, with your permission, will be kept for further research. It will be stored on a password protected drive, with pseudonyms. If you have any concerns or complaints regarding the ethical procedures of this study, please contact the Human Research Ethics Committee Medical on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Yours sincerely,
Claudia Osato

Researcher :
Claudia Osato, 1087169@students.wits.ac.za, 0835320707

Supervisor:
Dr Aline Ferreira-Correia, Aline.FerreiraCorreia@wits.ac.za

APPENDIX 5

Participant Consent Form Therapists



PARTICIPANT CONSENT SHEET

Project Title: Use of instant messaging to improve participation in rehabilitative prescribed exercises for sufferers of Acquired Brain Injury: a feasibility study.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto; Yes No
2. I was given time to read it, or had it read to me, in the language I best understand; Yes No
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory; Yes No
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be; Yes No
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time; Yes No
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained Yes No
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts Yes No
8. I give the researcher permission to audio record the interview . Yes No

Contact details:

Claudia Osato, telephone no. 083 532 0707, or by e-mail at claudiaosato77@gmail.com

Aline Ferreira-Correia, PhD
Senior Lecturer/Clinical Psychologist/Neuropsychologist
Psychology Department
University of the Witwatersrand
Supervisor, by e-mail at Aline.FerreiraCorreia@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

..... (signature)
..... (name of participant)
..... (date)

..... (signature of researcher)
..... (name of researcher)
..... (date)

APPENDIX 6

Digital reminders for ABI Patients receiving Occupational Therapy, Physiotherapy and Speech Therapy

The main objective of this Program is to increase participation in exercise homework for sufferers of acquired brain injuries. The Program aims to act as a reminder system that would deliver a daily message to each patient, specifically designed to re-iterate the therapeutic message of needing to complete exercise homework daily.

The Program includes the following:

1. Interview with ABI participant pre-intervention
2. Weekly phone calls with ABI participants (to be personalized based on patient)
3. Daily messages to ABI participants (to be personalized based on patient)
4. Interview with ABI participant post-intervention
5. Participation Tracking Documents
6. Mapping of Program and Stages

1. Interview ABI participants pre-intervention

Interviewer: Hello, my name is [insert name of researcher/clinician here]. I am contacting you with regards to the Program that I am running. I have been informed by your therapist that you have signed the consent form and have read through the information sheet about this study. Is this a good time to ask you some questions?

1. How old are you?
2. What is your gender?
3. Tell me about your injury. What happened and when did it happen?
4. How many years are you post injury?
5. What therapy/therapies are you currently involved in?
6. Tell me about these exercises, what do you need to do and how often? Where do you do these exercises?
7. What helps you to get your exercises done?
 - a. Complete this question by asking about cognitive, behavioural, emotional, financial, contextual, and social facilitators
8. What gets in the way of getting your exercises done?
 - a. Complete this question by asking about cognitive, behavioural, emotional, financial, contextual, and social facilitators
9. What is the best time of the day for you to do the homework from your OT/ Physio/speech?
10. What are your expectations of the reminders and how do you think they will help you?
11. Do you prefer to receive your reminders via Whatsapp or SMS?

2. *Phone Call Drafts*

Phone Call Questions after Week 1

Interviewer: Good morning/afternoon [insert name of patient here]. I am calling to find out how you've been getting along with your exercise homework. Is this a good time to talk?

1. Did you get rehabilitative homework to do this week?
2. Were you able to complete homework this week, if so, how many times? If not, what made it difficult? What helped?

Phone Call Questions after Week 2, 3 and 4

Interviewer: Good morning/afternoon [insert name of patient here]. I hope your week has been a good one. It is nice to speak with you again. I am calling to find out how you've been getting along with your exercise homework. Is this a good time to chat?

1. Did you get rehabilitative homework to do this week?
2. Did you receive the messages this week?
3. Did you get them at a good time?
4. Would you prefer to receive them at a different time?
5. Did you engage with your exercise homework?
6. What was your experience of receiving the daily message?
7. Would you change the reminder in any way? How?

3. Draft of daily messages to be sent to ABI participants

After one week of no message reminders, these reminder messages are sent every Monday to Saturday for the duration of 3 weeks. On every Sunday, the participant will receive a phone call.

Day 1: Good morning/afternoon [insert name of patient here]. I hope this is a good time to message. Just a quick reminder about the importance of exercise homework! Today is a good day to do your homework.

Day 2: Good morning/afternoon [insert name of patient here]. Exercises are important for mobility, functioning and for your brain. Try make some time to do your exercise homework today.

Day 3: Good morning/afternoon [insert name of patient here]. It's another day, which means another good day to do your exercise homework! Have a good day and remember to make some time to do those exercises.

Day 4: Good morning/afternoon [insert name of patient here]. Today is a good day to have a good day. Why don't you do some exercise homework to start your day off on a positive note?

4. Post-intervention questions for ABI participants

1. Tell me about your experience of the reminder intervention?
2. What were the most helpful parts of the reminder system?
3. What were the most unhelpful parts of the reminders?
4. Is there something that you would change about the reminder system?
5. Would you recommend the intervention to people wanting to improve their participation with therapy-related homework?

5. *Participation Tracking Document*

Participant	Week 1	Week 2	Week 3	Week 4
1	No intervention Baseline assessment	Intervention 1- Assessment of engagement	Intervention 2- Assessment of engagement	Intervention 3- Assessment of engagement
n				

6. Program Mapping

STEP 1:

Develop Program designed to assist patient with ABIs

- Develop Program based on the risks related to and deficits with the specific patients
- Identify OT/PT/ST practitioners conducting rehabilitation with ABI patients

STEP 2:

Identify organizations and therapists

- Identify organizations whose practitioners and patients fit criteria for inclusion
- Establish formal written contact with the organizations/practices identified as suitable.

STEP 3:

Conduct Interviews with therapists and explain Program

- Make contact with therapists and explain intervention
- Researcher provides written copy and explains Participant Information Sheet and Participant Consent Form
- Explain inclusion criteria for patients
- Conduct pre-intervention interview with therapists

STEP 4:

Therapists to make contact with appropriate ABI patients

- Therapists to identify patients for the study
- Therapist to have initial conversation with their patients to explain contact will be made by researcher and to ask permission for researcher to contact the patient with the aim of inviting them to participate
- Provide researcher with names and numbers of patients who have given initial consent and meet inclusion criteria

STEP 5:

Researcher to make contact
with ABI patients

- Personalise questions and message prompts
- Researcher calls patient and invites them
- Researcher explains Program, what is included as well as purpose
- Researcher does UBACC to ascertain capacity to consent
- Sets up time for pre-intervention interview

STEP 6:

Researcher conducts pre-
intervention interview with
ABI patient

- Researcher provides written copy and explains Participant Information Sheet and Participant Consent Form
- Researcher conducts pre-intervention interview with consenting participants

STEP 7:

Researcher starts Program
with ABI patient

- Week 1 – researcher sends no reminder messages to the participants
- Phone call after week 1 to ascertain number of times participant engaged in homework without being reminded
- Week 2,3,4 – daily reminder messages sent to participant
- Phone call after week 2 – 4 to ascertain number of times participant engaged in homework with reminders being sent
- Collate and track participation

STEP 8:

Researcher conducts post-
intervention interviews

- Researcher to conduct post intervention interview with therapists
- Researcher to conduct post intervention interviews with ABI participants

APPENDIX 7

Participant Information Sheet Acquired Brain Injured Individuals



Dear Sir / Madam,

I would like to invite you to participate in a study.

What is the study about?

This study will explore whether an instant messaging reminder system can help people with acquired brain injuries do their therapy exercise homework more often.

Who are the researchers?

My name is Claudia Osato and I am a Masters student at the University of the Witwatersrand. My supervisor is Dr Aline Ferreira-Correia, who is a clinical psychologist and neuropsychologist. This research forms part of my Masters degree.

What does participation involve?

As part of the study you will need to answer a few short questions about your therapies, which will be audio recorded. You will need to agree to receive daily messages from me reminding you to do your therapy homework. These messages will begin in the second week of the intervention and run until the end of the fourth week. I will call you at the end of each week and ask you a few questions about your exercise homework. At the end of the intervention, I will ask you the last few questions to see how you found the reminder system.

Are there costs or benefits if I participate?

There are no costs or benefits for your participation. The researchers will provide you with cellular data so that you do not experience costs because of your participation. You are allowed to withdraw at any stage of the study without incurring any penalties.

What about confidentiality and anonymity?

The only people who will know about your participation in the study are your therapist, myself and my supervisor. Your name will not appear in the reporting of the study as I will use a fake name to represent your information.

How can I learn about the results of the study?

If you are interested in the findings of the study, I will be happy to send you a summary.

If you have any questions or concerns please use the following:

Contact details:

Claudia Osato, telephone no. 083 532 0707, or by e-mail at claudiaosato77@gmail.com

Aline Ferreira-Correia, PhD
Senior Lecturer/Clinical Psychologist/Neuropsychologist
Psychology Department
University of the Witwatersrand
Supervisor, by e-mail at Aline.FerreiraCorreia@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

APPENDIX 8

Participant Consent Form ABI Individuals



PARTICIPANT CONSENT SHEET

Project Title: Use of instant messaging to improve participation in rehabilitative prescribed exercises for sufferers of Acquired Brain Injury: a feasibility study.

I, ..., agree to participate in this research project.

I understand what the research project entails and what is expected of me as a participant. The research has been explained to me and I understand what my participation will involve. I agree to the following:

Please circle Yes/No:

- I agree that my participation will only be shared with the researchers and my therapist.

Yes

No
- I agree to receive daily messages reminding me to do my exercises. Yes No
- I agree to allow the researcher to audio record my interview Yes No
- I agree to receive a weekly call from the researcher Yes No
- I agree that any information I share will be confidential. Yes No
- I agree that the researcher can use quotes that I have said as long as the researcher **does not** use my name. Yes

No
- I agree that the information that I supply can be stored to be used anonymously at a later stage for further research. Yes No

Contact details:

Claudia Osato, Principal Investigator, telephone no. 083 532 0707, or by e-mail at claudiaosato77@gmail.com

Aline Ferreira-Correia, PhD
 Senior Lecturer/Clinical Psychologist/Neuropsychologist
 Psychology Department
 University of the Witwatersrand
 Supervisor, by e-mail at Aline.FerreiraCorreia@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

..... (signature)
 (name of participant)
 (date)

..... (signature of researcher)
 (name of researcher)
 (date)

APPENDIX 9

University of California San Diego Brief Assessment of Capacity to Consent (UBACC)

- 1. What is the purpose of the study that was described to you?**
 - If unable to respond: Is it to find out about therapy? Is it to learn about therapy homework and memory?
- 2. What makes you want to consider participating in this study?**
 - If unable to respond: Is it to help us understand if reminders can help you remember to do your homework? Will you receive more therapy?
- 3. Do you believe this is primarily research or primarily treatment?**
- 4. Do you have to be in this study if you do not want to participate?**
- 5. If you withdraw from this study, will you still be able to receive regular treatment?**
- 6. If you participate in this study, what are some of the things that you will be asked to do?**
 - If unable to respond: Will you need to come in for extra treatment? What kind of things will we ask you to do or tell us about?
- 7. Please describe some of the risks or discomforts that people may experience if they participate in this study.**
 - If unable to respond: Is it possible that... your treatment may be affected by your participation, you may be asked something that upsets you?
- 8. Please describe some of the potential benefits of this study.**
 - If unable to respond: Will it help us learn? Will you receive money for participating? Will you receive free therapy?
- 9. Is it possible that being in this study will not have any benefit to you?**
 - If unable to respond: Do you understand that this study may not help you today, but will help us understand how to treat people in the future?
- 10. Will you be charged money for being in this study?**

Please note: Bolded sections are the questions as per the assessment, non-bolded text is the prompts if the person is unable to initially respond.

*Study version of the University of California San Diego Brief Assessment of Capacity to Consent as adapted to meet the requirements of this paper.

APPENDIX 10

Post-intervention interview with therapists

Interviewer: Good morning/afternoon. I hope you are well and keeping safe. Thank you for taking part in this study.

The aim of this interview is to hear about your experience of the reminder system and your opinion regarding the implementation of this intervention.

1. In your opinion, what were the strengths of this system?
2. What do you think were the weaknesses?
3. What do you think would improve the value of these kinds of intervention?
4. How do you think the patients experienced the intervention?
5. Did you have the opportunity to engage with any of the participants during the intervention?
If so, did you observe any changes regarding their engagement with the activities you prescribed as homework?

APPENDIX 11

Permission Requests for Hospitals



Johannesburg, July 2021

To Whom It May Concern
(enter Hospital Name here)

RE: Permission to conduct research

Good day. My name is Claudia Osato and I am a Masters student in Research Psychology at the University of the Witwatersrand, Johannesburg. As part of my degree, I have to undertake a research project, and I am investigating whether an instant messaging reminder can improve participation in rehabilitative homework for people with acquired brain injuries. This study also aims to explore the feasibility of such an intervention. The project is being supervised by Dr Aline Ferreira Correia.

I am seeking permission to approach the occupational therapists within your occupational therapy department at (insert Hospital Name here) who work with individuals with acquired brain injuries, as well as the patients themselves, in order to request their participation in the study. The intervention will run for a 4 week period during the month of August or September.

On the part of the therapists participation will involve:

- Participating in a 30 minute pre-intervention interview
- The recommendation of ABI patients for the study
- Participating in a 30 minute post-intervention interview

On the part of the individuals with acquired brain injuries participation will involve:

- Participating in a pre-intervention interview
- Receiving weekly calls from the researcher
- Receiving daily reminders from the researcher
- Participating in a post-intervention interview

If you have any further questions or concerns, please feel free to contact me.

Sincerely,

Claudia Osato

Principal Investigator, telephone no. 083 532 0707, or by e-mail at claudiaosato77@gmail.com

Aline Ferreira Correia

Supervisor, by e-mail at Aline.FerreiraCorreia@wits.ac.za

