

A qualitative exploration into the processes in which occupational therapists engage
when training a client to use external memory aids after a traumatic brain injury

Jonathan Armstrong

A thesis submitted to AUT University in partial fulfilment of the requirements of
the degree of Master of Health Science (MHSc)

June 2011

School of Rehabilitation and Occupation

Primary Supervisor: Kathryn McPherson

Table of Contents

Table of Contents	i
Table of Tables.....	vi
Table of Figures	vii
Attestation of Authorship	viii
Acknowledgements	ix
Abstract.....	x
Chapter 1: Introduction	1
Personal Reflections	1
The impact of traumatic brain injury.....	3
Incidence of TBI in New Zealand	4
Indications of the age of TBI survivors	4
The cost of TBI.....	5
The impact on employment.....	6
Memory deficits following traumatic brain injury	7
Memory rehabilitation	8
Occupation and memory rehabilitation.....	8
External memory aids	9
Focus of this study.....	10
Significance of the study.....	11
Structure of the thesis	11
Chapter 2: Literature Review	12
Traumatic brain injury and memory impairment	13
Memory rehabilitation approaches	14
External memory aids to compensate for memory impairments	15
Study participants	16
The variety of external aids.....	16
Which external aid best meets the clients' needs?	17
Potential barriers to the use of external memory aids.....	18

Involvement of significant others	20
EMA training programs	21
Assessment	21
Goal setting	22
Training stages	23
Re-assessment	23
Gaps in the current evidence	24
Summary	25
Chapter 3: Methodology and Methods	26
Rationale for choosing a qualitative methodology	26
Theoretical perspectives to grounded theory	27
Grounded theory methodology as it applies to the researcher	29
Grounded theory methodology as it applies to this study	31
Research methods	32
Participant selection	32
Sampling	33
Data collection	34
Data analysis	35
The use of literature	38
Ensuring rigour	38
Reflexivity	39
Transferability	40
Saturation	41
Review of interview technique	41
Member checking	41
Ethical considerations	42
Informed and voluntary consent	42
Respect for rights of privacy and confidentiality	42
Minimisation of risk	43
The right to withdraw from the study	43

Treaty of Waitangi.....	43
Summary	44
Chapter 4: Developing client insight.....	45
Developing client insight ó an overview of categories	46
Condition: Stage of rehabilitation	48
Condition: Severity of injury	49
Inter/action: Assessing.....	51
Inter/action: Educating.....	54
Inter/action: Experiencing failure.....	56
Inter/action: Supporting the client.....	58
Inter/action: Reflecting	59
Inter/action: Rapport building	60
Inter/action: Focusing on what they enjoy.....	62
Consequence: Seeing the point	64
Summary	65
Chapter 5 – Getting client buy-in	67
Condition: Client impairments.....	69
Condition: Service structures	71
Condition: Accessibility	74
Inter/action: Doing the groundwork.....	76
Inter/action: Keeping it simple.....	83
Inter/action: Making it meaningful.....	85
Consequence: Incorporating the EMA into daily activities.....	88
Summary	91
Chapter 6 – Getting others on-board.....	92
The conditions ó an overview	93
Condition: Properties of staff.....	94
Condition: Family set-up	98
Condition: Therapistø time	101
Inter/action: Recruiting	102

Consequence: Regular reinforcement.....	107
Consequence: Feedback relating to real life	109
Consequence: Sustained use	110
Summary	112
Chapter 7: Making it real	113
The conditions impacting on making it real ó an overview.....	114
Condition: Environment	115
Condition: Personal characteristics	117
The interactions in making it real ó an overview	119
Inter/action: Creating real life	119
Inter/action: Being in real life	122
The consequences of making it real ó an overview.....	124
Consequence: Sustained use	124
The interplay between making it real and the other processes	127
Summary	131
Chapter 8: Discussion.....	132
Developing client insight.....	132
Implications for clinical practice	140
Getting client buy-in.....	141
Implications for clinical practice	147
Getting others on-board	147
Implications for clinical practice	153
Making it real.....	153
Implications for clinical practice	158
Strengths and limitations of this study	159
Constant comparative method.....	159
Reflexivity.....	160
Transferability	161
Saturation	162
Areas for further study.....	163

Conclusion	165
References	167
Appendix A ó Participant Information Sheet	176
Appendix B ó Consent Form	180
Appendix C ó Demographic Data Form.....	181
Appendix D ó Participant Demographics	182
Appendix E ó Interview Question Examples.....	183
Appendix F ó Interview Question Grid, August 2010	184
Appendix G ó Ethics Approval.....	185

Table of Tables

Table 1: Open coding	36
Table 2: Developing client insight	47
Table 3: The conditions - an overview	48
Table 4: The inter/actions ó an overview	50
Table 5: The consequences - an overview	64
Table 6: Getting client buy-in ó an overview	68
Table 7: The conditions ó an overview	69
Table 8: The inter/actions ó an overview	76
Table 9: The consequences ó an overview	88
Table 10: Paradigm components of getting others on-board.....	93
Table 11: The conditions ó an overview	94
Table 12: The inter/actions ó an overview	102
Table 13: The consequences ó an overview	106
Table 14: Making it real ó an overview.....	114
Table 15: The conditions ó an overview	114
Table 16: The interactions ó an overview	119
Table 17: The consequences ó an overview	124

Table of Figures

Figure 1: Ages of TBI clients.....	5
Figure 2: Work/education status at the time of injury.....	6
Figure 3: Four processes.....	46
Figure 4: A Summary of the inter/actions	60
Figure 5: The impact of conditions on inter/actions	63

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed:_____

Dated:_____

Acknowledgements

Firstly, I would like to express my appreciation to the participants of this study who kindly volunteered to be interviewed and share their reflections on their clinical practice. They have been generous with both their knowledge and time.

I would like to thank my employers ABI Rehabilitation New Zealand Ltd for their financial support and for allowing flexibility in my working hours. They have also contributed to some of the data reported in my introductory chapter for which I am grateful.

My thanks also go to my two supervisors, Kathryn McPherson and Shoba Nayar for assisting me in navigating my way through the research process. Kath's knowledge of research theory and brain injury rehabilitation, combined with Shoba's occupational therapy perspective and knowledge of grounded theory methodology has been the perfect combination for well rounded discussions during supervision sessions.

The grounded theory group at AUT University have also contributed to shaping my thoughts and provided me with valuable feedback during the discussions of my findings and data analysis. For the insights that this has given me I would like to thank you all.

Thanks also go to the numerous friends and colleagues who have been roped in to proof reading and given me feedback following various presentations of my findings as I have progressed through the research.

Particular thanks must go to my partner, Joseph, who has encouraged me through my high points and provided me with copious cups of tea and chocolate during my low points. He has been patient and understanding over the last two years as our social life has dwindled due to the commitments of my work and study. I feel incredibly lucky to have his love and support.

Abstract

Occupational therapists working in neurological rehabilitation frequently receive referrals to assist people with memory impairments following traumatic brain injury (TBI). Although there are a number of interventions available for the rehabilitation of memory, the evidence to date suggests that the use of external memory aids (EMAs) is one of the best approaches. Unfortunately, there is very little evidence to guide therapists in training clients with TBI to use an EMA and ensure sustainable use of the aid long-term.

Using grounded theory methodology occupational therapists working in the field of neurological rehabilitation were interviewed to explore the question: *How do occupational therapists train clients to use external memory aids after a TBI?* Eight interviews were conducted until data collection reached a saturation point. The data was analysed following the constant comparative method proposed by Strauss and Corbin (1998) and from this analysis four over-lapping processes emerged: Developing client insight, Getting client buy-in, Getting others on-board and Making it real

Developing client insight was the process that the occupational therapists went through in order to build their clients' awareness of their memory impairments and the impact these impairments had on their everyday activities. Getting client buy-in involved the occupational therapists finding ways to engage their clients in the training and making it meaningful to them. Getting others on-board was a process of recruiting people like family members, rehabilitation staff and employers into the training as a way to ensure reinforcement of training components when the client was not engaged in formal therapy sessions. Making it real emerged as the core process that encompassed and ran through the other three. It emphasised the need for the occupational therapists to use meaningful, functional activities in order to establish an aid that fit the client's real life.

The processes uncovered by this study address a number of barriers to EMA training that have been highlighted in previous literature and give occupational therapists working in the field of brain injury rehabilitation guidance for clinical practice.

Chapter 1: Introduction

This chapter sets the scene for the thesis. I will describe the background to the study beginning with a personal reflection on my work as a clinician and the events that have led me to choose this topic as a research study. I will then explore the impact of traumatic brain injury (TBI) in New Zealand and the prevalence of memory issues following brain injury. I will describe the impact that memory impairments have on occupational performance and introduce the approaches that occupational therapists take to addressing some of these memory impairments. The reasons for a focus on external memory aids (EMAs) will be explained and the gaps in research literature briefly outlined. This will lead to a description of the focus of the enquiry and a statement of my study aims, and an explanation of how the findings of this study will contribute to the evidence base for the future clinical practice for occupational therapists. I will finish with an outline of the structure of the thesis itself.

Personal Reflections

As a third year occupational therapy student in the UK, I had a placement in a younger person's rehabilitation unit working predominantly with people under 65 years of age, with a variety of neurological conditions. It was at this time that I became fascinated with the clinical complexities of these clients, the challenge of understanding the neurological injuries and interventions employed that enabled people to participate more independently in daily life. This fuelled my passion for occupational therapy in neurological rehabilitation and since then I have sought out opportunities to work in a variety of neurological fields ranging from acute neurosurgical units to community stroke teams.

After my first two years of clinical work, I began to critically examine my practice in relation to emerging evidence and not solely learn clinical skills from the more senior therapists around me. I also began to supervise new graduate occupational therapists keen to learn practical skills in assessment and treatment. I began to delve deeper into the complex world of evidence-based practice and explore both *what* I was doing as a therapist and *why* I was doing it. At this time the evidence for occupational therapy interventions was relatively

sparse compared to other health professional practice and was also difficult to access as databases of literature were only beginning to become commonplace.

In more recent years I have been in a position of clinical supervisor and supported other therapists to build clinical knowledge and skills in providing occupational therapy to a variety of neurological populations. Throughout my clinical and supervisory experiences, and ongoing professional development, I have continued to gain knowledge of intervention techniques to address the myriad of occupational performance issues experienced by individuals with neurological injury. I have always had a desire for clinical practice to be based on sound reasoning and evidence from research and this is hopefully a value that I have imparted to those I have supervised and taught.

My professional journey has led me to specialise in the assessment and treatment of individuals following TBI, working predominantly in the post-acute stage of rehabilitation. My desire to continue my professional development has also lead to post-graduate study, unsurprisingly focused on neurological rehabilitation. Since working with a TBI population I have become increasingly involved in cognitive rehabilitation and explored evidence in relation to this. Memory rehabilitation has been a particular focus for the majority of my clients. Although this is an emerging area for research, many studies to date are focused on clients completing simple tasks such as recall of pictures or words within a research clinic environment, where they under go functional magnetic resonance imaging to establish brain areas activated during the tasks. For instance, there have been a number of such studies investigating the functional neuroanatomy for episodic memory retrieval (Buckner, Koutstaal, Schacter, Wagner & Rosen, 1998; Cabeza, Kapur, Craik & McIntosh, 1997; Lee et al, 2002). Although these studies yield interesting results regarding the areas of the brain involved in memory encoding and retrieval, they are often difficult to relate to clinical practice.

In the search for more clinically useful information I discussed the interventions taken to address clients' memory issues with other therapists working in the brain injury rehabilitation field. There appeared to be a general 'throw everything at it' approach, which included a combination of education, remediation activities, functional training and strategy training. A trial and error

or problem solving approach was being used which appeared to be mostly based on therapist experience and their intuition. This approach also seemed contrary to other brain injury rehabilitation evidence, such as errorless learning, to improve activity performance (Evans et al, 2000; Lloyd, Riley & Powell, 2009).

I, and the other occupational therapists that I work with, felt a need to establish evidence based guidelines for ourselves when working with individuals with memory problems post brain injury and so a working group was formed to carry out a small action research project. We explored the literature relating to different approaches to memory rehabilitation and found that the use of EMAs to compensate for reduced memory function seemed to be the strongest recommendation from the handful of clinical memory studies and systematic reviews of cognitive rehabilitation available. Based on these recommendations we decided on a process of EMA training that we would complete with clients within our unit, with the aim of helping them to compensate for their memory impairments. This process was examined in a case study which was required as part of a post-graduate paper in 2009. The case study resulted in a number of clinical questions such as: how do we monitor the memory aid long-term and how do we know if it has been generalised from the rehabilitation environment to the home?

Despite having developed a more standardised process to work by, which assisted us as a clinical team to assess and establish an intervention strategy for clients with memory difficulties, I was still aware of unanswered questions that had emerged from the case study and gaps in the literature we had reviewed. These gaps included a lack of description of treatment or training methods for the memory aids that limited the clinical applicability of many studies. When it came to deciding on a subject for my Masters thesis, exploring this area seemed worthwhile, not only for my own curiosity but also with a desire to provide therapists working in the field of brain injury with more evidence on which to base their memory rehabilitation.

The impact of traumatic brain injury

In New Zealand traumatic brain injuries effect between 20,000 and 30,000 people a year (New Zealand Guidelines Group, 2006). A traumatic brain

injury (TBI) has been broadly defined by the New Zealand Guidelines Group as “an injury to the brain resulting from externally inflicted trauma” (2006, p.21). A TBI tends to be classified in terms of the severity of the initial injury and can either be “severe”, “moderate” or “mild”. Criteria for assessing the severity of the injury can be found in the evidence based best practice guideline *Traumatic Brain Injury: Diagnosis, acute management and rehabilitation* (New Zealand Guidelines Group, 2006) but in summary the classification of the injury is based upon the Glasgow Coma Score (Teasdale & Jennett, 1974) and duration of post-traumatic amnesia (PTA).

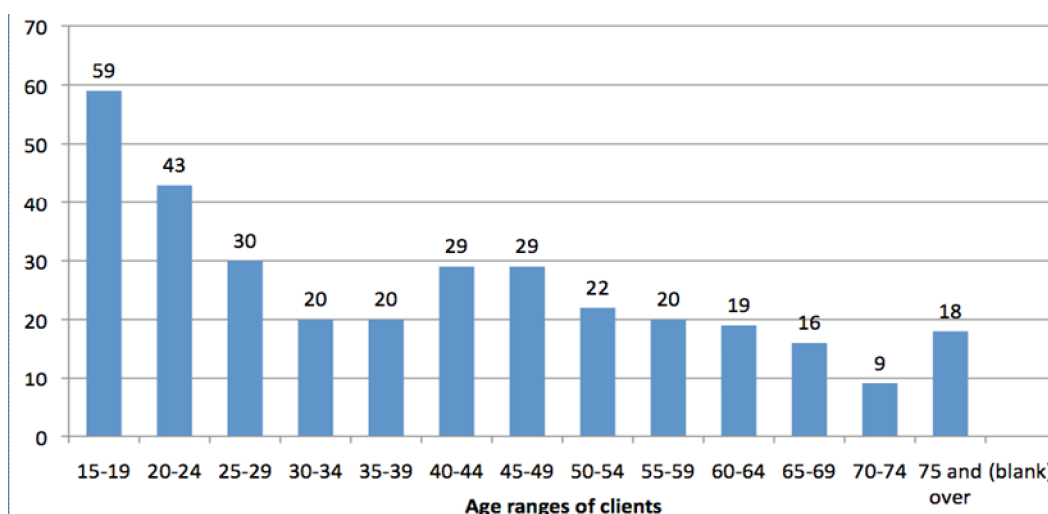
Incidence of TBI in New Zealand

Inconsistent and inaccurate diagnosis of TBI has led to an inability to determine the exact extent of TBI in New Zealand. Aggregated mechanisms of TBI in New Zealand, collected from a variety of sources, appear to be in agreement with international data from developed nations. Figures collected by the Accident Compensation Corporation (ACC) suggest that 61.9% of concussions occur in males, and that the incidence of TBI peaks in males between the ages of 15-30 and in those aged 60 and over (New Zealand Guidelines Group, 2006). New Zealanders experience TBI most often as a result of motor vehicle crashes, followed by falls, assaults, and sports injuries (The Brain Injury Association of New Zealand Inc., 2007).

Indications of the age of TBI survivors

One source of current data regarding moderate and severe TBI in New Zealand is prepared quarterly for ACC by ABI Rehabilitation Management Limited. This company is a rehabilitation service operating an intensive rehabilitation service contract for ACC in the northern half of the North Island (Northland, Auckland, and the Waikato regions). The most recent report from ABI Rehabilitation Management Limited (September 2010) indicates that, of the 334 clients within the service during the previous quarter, the median age of clients was 38.5 years. One in every three clients was under the age of 29 and nearly half of all clients were under the age of 35. The full range of ages can be seen in Figure 1 on the following page.

Figure 1: Ages of TBI clients (numbers of clients, n=334)



Reproduced with permission from ABIRM quarterly report, Sept 2010

The cost of TBI

In New Zealand, ACC pays over \$100 million per year for post-acute treatment and rehabilitation of clients with TBI, with over 90% of this devoted to care for severe cases (New Zealand Guidelines Group, 2006). The \$100 million figure does not include the additional amount of general operation funds that ACC supplies to District Health Board emergency departments, because the proportion of these funds devoted to treating people with TBI cannot be accurately calculated (New Zealand Guidelines Group, 2006). In addition to these reported costs is the loss of earnings experienced by many people with TBI. Even following a mild injury, lasting problems with cognition, communication, physical ability, and activity tolerance may impact upon work performance. Independent of gender and education levels, people with TBI work fewer hours, earn less, and have a shorter worklife expectancy than their uninjured counterparts (Gamboa, Holland, Tierney, & Gibson, 2006). This may lead, in some cases, to increasing dependence on social welfare programs, which can have far-reaching economic impact.

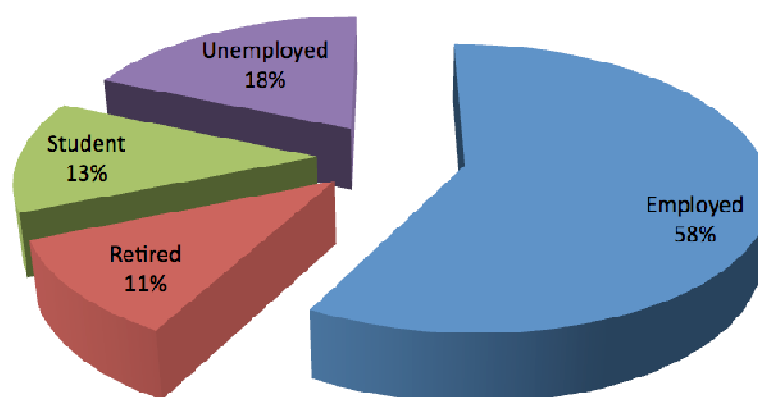
Perhaps less measurable, but by no means less real, are the costs of TBI such as emotional strain, stress on relationships, and personal discomfort. Reflecting the data outlined above, many of my clients tend to be males in their late teens and early 20s, many of whom have not yet established full independence in their lives or created stable, committed social relationships. It is

evident through observations during my clinical work that over time these clients tend to lose friendships and social support networks outside of their family. Their family relationships, particularly with their, relatively new, partner/spouse tend to become strained and they experience difficulty in establishing new social relationships. As a result, leisure and social activities become less frequent and the individuals become increasingly isolated. This 'social disconnect' was highlighted as one of the themes describing the experience of recovery after TBI in a recent metasynthesis of qualitative research by Levack, Kayes and Fadyl (2010).

The impact on employment

In terms of employment status, figures have again been taken from the ABI Rehabilitation Management Database Quarterly Report (Sept, 2010) as these statistics give a clear example of the employment status of a TBI client group. From the data available on 330 clients within the ABI service, at that time of the report, 58% of clients were employed at the time of injury; technical/trade workers and labourers were the most common professions. A further 11% of clients were retired and 13% were students. 18% of clients were unemployed at the time of the injury. Figure 2 gives a breakdown of these percentages.

Figure 2: Work/education status at the time of injury



Reproduced, with permission, from the ABIRM Quarterly Report (Sept 2010).

As this section demonstrates, the majority of TBI survivors are young, working people whose lives can be impacted enormously by a brain injury. Not only are the lives of the individuals with the injury affected but also those of their partners, family and friends. TBI often leads to young, employed and socially active individuals becoming unable to participate in their previous work and social activities due to the cognitive, physical and psychological impairments they experience post-injury. They therefore become increasingly reliant on the support of others including social care and welfare services. Increasing the ability of these individuals to return to greater levels of independence in home, work, social and leisure activities is often the focus of rehabilitation programs, which also has a secondary effect of reducing the need for carer support.

Memory deficits following traumatic brain injury

Memory deficits are one of the most marked and persistent issues faced by individuals following TBI and occur in 69% to 80% of those with moderate to severe TBI and 40% of those with mild TBI (Kapur, 1988; Stalnacke, Elgh & Sojka, 2007). Memory deficits can be seen across a range of memory areas following a TBI, including: working, prospective, semantic and episodic memory. Working memory organises the sensory information entering the brain into a form that can be passed on to other components of the cognitive system; prospective memory is remembering what to do and when to do it; semantic memory is long-term memory for general knowledge and facts (e.g. knowing the capital of France is Paris); and episodic memory is long-term memory of events linked to a time and place (e.g. remembering events from your holiday in Paris last summer).

Procedural memory is the long-term memory for mental and motor skills that are retrieved without conscious awareness, and this type of memory tends to remain intact for the majority of individuals (Grieve & Gnanaekaran, 2008). The ability for the individual to learn new skills by processing and retaining new information is limited, particularly in the initial stages of recovery from post-traumatic amnesia. This has an impact on rehabilitation services that must work with individuals on a procedural and functional level during this initial stage of

recovery and not attempt to overload a person with new information (Powell, 2007).

Following the emergence from post-traumatic amnesia, individuals' cognitive abilities can be assessed to establish ongoing issues and rehabilitation strategies can be put in place to address the deficits in cognition. Often these strategies will involve a combination of education, remediation training, functional activities and compensatory strategies (Powell & Malia, 2006).

For some individuals it is difficult to gain any insight into their memory impairments as the areas of the brain involved in self-awareness and self-regulation, i.e. the frontal lobes, are often the areas damaged in their injury. Other clients may struggle to develop awareness of their memory impairment due to the rehabilitation environment placing few demands on memory functions.

For the individual with TBI, frequent memory failures can be frustrating, embarrassing and even life threatening. These failures can limit the independence of these individuals, causing them to rely on a carer or support person for prompting. Memory deficits will affect an individual's chance to return to living independently in his/her own home, return to work and participate in social activities.

Memory rehabilitation

Memory rehabilitation has been investigated by a number of professions including speech and language therapists, psychologists and occupational therapists, and has tended to centre around two approaches: remediation and compensation. Remediation approaches include participation in activities such as memory games, exercises and drills to foster storage, retention and retrieval of information. Compensation approaches include the use of internal and external aids to work around the memory impairment. Evidence for these two approaches will be described in more detail in Chapter Two, which reviews the literature in these areas.

Occupation and memory rehabilitation

Occupation is described as being 'purposeful or meaningful activities in which humans engage as part of their normal daily lives' and 'all aspects of

living that contribute to health and fulfilment for an individualö (McColl et al, 2003, p. 11). After brain injury individuals will often experience memory deficits that will have a profound effect on their ability to participate in a variety of occupations. Everyday memory includes being able to remember peoples names and faces, routes to familiar places, the stages of cooking a meal, keeping track of a conversation, following the storyline of a book or television program and recalling instructions from an employer. Memory is important for a sense of self as people have memories of their past experiences that they can share with others. öSome aspects of memory are involved in almost everything we do, and the way we use it depends on our own lifestyle and experienceö (Grieve & Gnanasekaran 2008, p. 148).

In clinical practice, occupational therapists assess the impact of memory deficits on an individualö occupational performance within a range of environments and activities. This assessment may take the form of informal interviews with clients and their carers, questionnaires, functional observations, standardised assessments or a combination of these. Occupational therapists are trained to analyse a clientö performance within an activity and consider the impact of the environment. Intervention for memory deficits by occupational therapists include the use of errorless learning to prevent mistakes occurring, repetition and rehearsal with verbal or visual cues, education and information to the client and their family, or introducing compensatory strategies (Grieve & Gnanasekaran, 2008).

In brain injury rehabilitation occupational therapists often address memory problems using a compensatory approach as this tends to be more relevant to everyday functioning; more easily generalised into functional settings and can assist clients with generally reduced cognitive capacity. Compensation approaches include the use of external aids to work around the memory impairment. External aids include the use of environmental adaptations, notebooks, diaries or various electronic devices.

External memory aids

Studies have looked into a variety of EMAs ranging from low-tech diaries or notebooks (Donaghy & Williams, 1998; Fleming, Shum, Strong & Lightbody 2005; Schmitter-Edgecombe, Fahy, Whelan & Long, 1995) to more

high-tech pocket computers and electronic aids (Van Hulle & Hux, 2006; Wright et al., 2001). A recent systematic review for the use of external aids as a memory compensation technique concluded that studies are universally supportive of the general practice of using external aids to compensate for memory impairments following TBI (Sohlberg et al, 2007). Although the research to date highlights the potential of EMAs to improve the functional independence of people with memory impairments, Sohlberg et al (2007) identified a lack of sufficient evaluation of treatment implementation parameters to support clinical practice. There appears to be a need for research that addresses questions related to device selection, specific training protocols and factors that lead to long-term use of aids. More detail of the literature pertaining to EMAs and their use will be discussed in the following chapter.

Focus of this study

The impact of memory deficits on the TBI population seemed evident in literature, statistical reports and my own clinical practice; yet my investigations into memory rehabilitation left me with a number of questions. I therefore decided to use the opportunity of my Masters study to investigate the use of EMAs in occupational therapy intervention with brain injured clients.

My study seeks to establish the processes that occupational therapists use when they are training their clients to use an EMA following a TBI. For the purpose of this study an EMA will be defined as a device that provides the user with a way to compensate for memory impairment by either limiting the demands on a persons impaired ability or transforming a task or environment to match the persons abilities. These may be high-tech devices such as pocket computers or smartphones, or low-tech supports such as diaries, wall planners or white-boards.

The aims of this study are:

- Explore occupational therapists' experiences of external memory aid training
- Identify a process to external memory aid training
- Inform future clinical practice and research by generating a process for external memory aid training

- Provide support for clinicians/service managers in justifying this type of cognitive rehabilitation to funders

Significance of the study

As indicated in the study aims, my goal in undertaking this study was to inform my own clinical practice and that of other occupational therapists who will have some guidance on training their clients to use an EMA. It is also hoped that the findings of the study will support clinicians through rigorous and methodologically sound qualitative data, which will add to the overall evidence base for compensatory memory rehabilitation.

Structure of the thesis

This thesis is comprised of eight chapters. In this first chapter I have introduced the background to the study including my own personal reflections, a description of the TBI population, the impact of memory impairment on occupation and the current questions related to memory rehabilitation literature which have lead to my desire to complete a study such as this. In Chapter Two I extend this background information by presenting a literature review of the subject areas which impact on EMA training and therefore on the work of occupational therapists in this area. In Chapter Three I focus on the research methodology and describe the process of research undertaken in this study. Chapters Four, Five, Six and Seven contain the research findings and Chapter Eight presents a discussion of those findings, synthesised with the relevant literature. Further, in Chapter Eight I outline the conclusions that I have reached as a result of this research study and include suggestions for future research.

Chapter 2: Literature Review

Glaser (1998), one of the founders of grounded theory methodology, stated:

Do not do a literature review in the substantive area and related areas where the research is to be done; and when the grounded theory is nearly completed during sorting and writing up, then the literature search in the substantive area can be accomplished and woven into the theory as more data for constant comparison (p. 67).

This position supports emergence and attempts to keep the researcher free from any preconceived concepts previously documented in the literature. However, in reality researchers are likely to have studied an area of specialty in order to establish a research interest and, as a result, have already been exposed to a range of ideas relating to the study area (McCallin, 2003).

The need for evidence based practice within the clinical field also leads to researchers embarking on their studies being familiar with literature available from electronic databases, as would be the case here. As mentioned in the previous chapter, I had already been involved in the creation of evidence based guidelines for clinical practice and therefore had reviewed relevant literature on memory rehabilitation prior to making decisions about my research topic. Moreover, in practical terms, a literature review is also a requirement in meeting the needs of a university when seeking permission for a research project and gaining ethical consent, thereby forcing a researcher to have reviewed aspects of the area under study.

Recognising the reality that the researcher is likely to bring a background in professional experience and literature to the study, Strauss and Corbin (1998) revised the original grounded theory approach to literature review. Strauss and Corbin believed that literature is useful at the beginning of a project to formulate questions that act as a stepping off point during initial observations and interviews (1998, p. 51). Following this line of thinking I started my project with a broad knowledge of the literature relating to memory rehabilitation and the use of EMAs. From this point I was therefore able to identify the gaps where further research was required. While I had an awareness of certain concepts related to the topic it became evident through data collection and

analysis that some of these concepts remained and some became redundant, as I stayed grounded in the information received through participant interviews.

As the study continued, further literature was reviewed on wider topics as they emerged from the data and this literature was integrated into the study using the constant comparison methods described in Chapter Three. This then assisted with theoretical sampling and questioning as the study continued. This literature is not examined here as it forms part of the discussion of the findings and will be described in Chapter Eight.

This current chapter gives details of the literature relating to memory impairment following a TBI, approaches to memory rehabilitation, justification for the use of a compensatory approach to memory rehabilitation, and outlines the evidence for the use of EMAs as a tool for achieving greater occupational independence. Finally, gaps in the current evidence are highlighted towards the end of the chapter.

Traumatic brain injury and memory impairment

For the individual with TBI frequent memory failures can be frustrating, embarrassing and even life threatening. These failures limit the independence of these individuals, causing them to rely on a carer or family member for prompting. Memory deficits will affect an individual's chance to return to living independently at home, return to work and pursue leisure pastimes (Fleming et al., 2005), i.e. participation in their daily routines and occupations.

Frequently the types of memory impairments experienced by individuals following TBI involve prospective memory and the ability to recall new information. Fleming et al (2005) described prospective memory as 'the ability to remember to perform an intended action at a specific time in the future' (p. 1). This type of memory is considered to be dependent on the function of the pre-frontal lobes.

The recall of new information is a complex multi-system task for the brain involving aspects of encoding, storage and retrieval. Investigations using functional magnetic resonance imaging have suggested that the skill of recalling new information is reliant on a number of brain areas including left and right pre-

frontal areas, medial temporal lobes and diencephalic structures (Buckner, Koutstaal, Schacter, Wagner & Rosen, 1998; Lee et al., 2002).

Given that both prospective memory and the recall of new information are reliant on the function of the pre-frontal lobes and the temporal lobes it is not surprising that these are common difficulties for people following TBI, as these brain areas are often damaged at the time of injury due to their shearing on the bony prominences of the skull. Fortunately it is common for injured individuals to have other types of memory that remain intact, such as memory for procedures and routines. It is therefore suggested that in memory rehabilitation clinicians should capitalize on these procedural memory skills to effectively treat the client (Kennedy, 2006).

Memory rehabilitation approaches

Memory rehabilitation has been investigated by a number of professions including speech and language therapists, psychologists and occupational therapists, and has tended to centre around two philosophies: remediation and compensation.

Remediation approaches include participation in activities such as memory games, exercises and drills to foster storage, retention and retrieval of information. However, there is little convincing evidence to support the notion that practicing memory tasks benefits overall memory performance or generalises into everyday functional changes outside of the clinical setting (Fleming et al., 2005; Van Hulle & Hux, 2006). Some authors argue that the interdependence of attention, memory and executive functions makes it difficult to independently evaluate and treat a single cognitive skill, highlighting the artificial nature of isolating cognitive impairments during treatment (Sohlberg et al., 2007). The neural circuitry for one cognitive process will by necessity activate circuits for other related processes.

Compensation approaches include the use of internal and external aids to work around the memory impairment. Internal aids include the use of mnemonics and visualization. External aids include the use of environmental adaptations, notebooks, diaries or various electronic devices. In clinical practice, rehabilitation professionals often address memory problems using a

compensatory approach. Compensation strategies are more relevant to everyday functioning; more easily generalised into functional settings and can assist clients with reduced cognitive capacity to improve their levels of independence (Fleming et al., 2005). Furthermore, a recent systematic review for the use of external aids as a memory compensation technique concluded that studies are universally supportive of the general practice of using external aids to compensate for memory impairments (Sohlberg et al., 2007).

Two systematic reviews into cognitive rehabilitation recommended the use of external aids in the treatment of memory impairments as a rehabilitation practice guideline for adults with memory impairment following TBI. This level of recommendation is based on the number of Class I studies or well designed Class II studies that directly address the effectiveness of the memory intervention (Cicerone et al., 2005; Sohlberg et al., 2007).

External memory aids to compensate for memory impairments

Different studies have looked into a variety of EMAs ranging from low-tech journals, diaries or notebooks (Donaghy & Williams, 1998; Fleming et al., 2005; McKerracher, Powell & Oyebode, 2005; Schmitter-Edgecombe et al., 1995) to more high-tech; pocket computers, paging systems and electronic aids (Lannin et al., 2010; Van den Broek, Downes, Johnson, Dayus, & Hilton, 2000; Van Hulle & Hux, 2006; Wilson, Emslie, Quirk, Evans, & Watson, 2005; Wright et al., 2001). Although these authors used a variety of different aids within their studies, all highlight that the use of compensatory strategies requires the client to have some self-awareness and be able to acknowledge the existence of their cognitive problems in order for a successful outcome.

Recognising the potential for EMAs to increase the independence and quality of life of individuals with memory difficulties after TBI, a number of studies have been completed in an attempt to identify which aids are best suited to this population. These studies have predominantly been in the form of single case studies or non-random cohort studies which look at the improvements to function from providing individuals with one specific aid (Fleming et al., 2005; Schmitter-Edgecombe et al., 1995) or compare the outcomes and user satisfaction of different aids (Van Hulle & Hux, 2006; Wright et al., 2001). Only

two randomised control trials exist to date that evaluate the use of electronic aids as an EMA for people with TBI (Lannin et al., 2010; Wilson et al., 2005). The details of all these studies have been combined to form a number of key points, outlined below.

Study participants

The participants within the EMA studies are mostly younger adult males which reflect the demographic characteristics of this population with data suggesting a roughly 2:1 ratio for male: female with TBI, and a peak in incidence in the 15 to 30 age group (New Zealand Guidelines Group, 2006). A wide range of aetiology and pre-morbid details are provided for the participants in the studies. Time since injury ranges from post-acute periods of a few months to chronically affected individuals being supported in the community, years after injury. All the participants are described as having significant memory impairments, usually including prospective memory difficulties. These impairments are reported as affecting their daily occupational performance in a variety of meaningful activities ranging from simple tasks, such as taking their medication, to more complex activities like returning to school or work. Van Hulle and Hux (2006) identified that the heterogeneous nature of this population creates a challenge for therapists who have to create and implement treatment strategies to compensate for the unique cluster of deficits presented by each individual within their chosen activities. They made the point that expecting therapists who work with multiple survivors of TBI to develop totally unique treatment interventions for each individual is not feasible.

The variety of external aids

Studies to date have examined the use of a variety of EMAs. Some have looked into comparisons between similar types of aids such as McKerracher et al (2005), who compared two different formats of memory notebooks with a gentleman with memory problems caused by a TBI, and Wright et al. (2001) who compared 12 individuals' satisfaction with two different styles of electronic pocket computers. Other studies have compared different types of electronic aids with pen and paper style aids such as that by Van Hulle and Hux (2006) who compared the use of 3 different aids using three case study examples who all

required reminders to perform the same task, independently taking their medication. One study compared notebook training with supportive therapy to evaluate the effectiveness of a 9-week notebook training intervention conducted within a group format. This study found a significant difference in everyday memory failures between the two groups, with the notebook group performing more favourably immediately after the intervention. However, this difference was not significant at a 6 month follow-up and it is hypothesised that this may be due to a lack of sustained use of the notebooks over time (Schmitter-Edgecombe et al., 1995).

Which external aid best meets the clients' needs?

Although it has been stated by a number of authors that the use of electronic aids is becoming increasingly popular, as technology advances, there is still debate as to which aids best meet the needs of the individual with a TBI. McKerracher et al. (2005), for example, advocated for the use of less complex notebook-style aids as they are more familiar to people and can facilitate the recall of a diverse range of functional tasks, rather than assisted-technology devices that tend to be more complex and require individuals to learn new semantic information to use them. Wilson et al. (2005) and Wright et al. (2001) took an alternate stance and argued for the use of electronic aids over a paper aid as the electronic device can be customised to suit the client and reduces the memory load required to use it, as on-screen instructions appear to prompt the individual in the device's use. They believed that electronic aids could be used to address the memory and planning problems of a person of any age, as long as they could read, and the aids could be generalised to a wide range of circumstances.

Nonetheless a common aspect to all these studies is that the researchers themselves have selected the aids for exploration and the focus of findings has been on the pros and cons of the specific aid selected to meet the pre-determined needs of the participants. Device selection has therefore been in the hands of the researchers rather than the participants. This presents a problem in itself as Wright et al (2001) acknowledged in the discussion of the success of their pocket computers, 'people prefer to manage their routines post brain injury by whatever methods they used previously' (p. 799). This acknowledges that the client needs

to take part in the selection of a memory aid, rather than being issued with a specific aid by a health professional. The aid a client selects is most likely to be something they are familiar with and comfortable in using. This makes arguments regarding one aid being better than another redundant. If health professionals are to focus on the individual nature of the client then the best aid is the one that the client was previously familiar with, whether that be in electronic or paper form, thereby reducing one potential barrier to the use of EMAs.

Potential barriers to the use of external memory aids

A number of potential barriers to EMA use have been identified by researchers in the literature. The most commonly discussed is that of client insight or self-awareness. The need for assessing and improving clients' awareness of their memory impairments prior to introducing memory aids is well documented (Cicerone et al., 2005; Fleming et al., 2005; Kennedy, 2006; McKerracher et al., 2005; Wilson et al., 2005; Wright et al., 2001). After a TBI, impairments in self-awareness are common and individuals tend to rate themselves as having higher abilities in the areas of thinking skills and behaviour than the ratings of their clinicians or significant others (Sherer et al., 2003). Fleming et al. (2005) described self-awareness as 'a necessary first step in this rehabilitation process' and 'essential for the motivation to participate in rehabilitation and to independently adopt compensatory strategies at home, community or workplace' (p. 2).

A number of strategies have been put forward to manage this particular barrier. In terms of the assessment of insight, the use of questionnaires, interviews and observation of function have been suggested as means to assess a client's beliefs regarding their memory (Kennedy, 2006). More formal assessment tools have been described in some studies such as The Self Regulation Skills Interview (SRSI), which was used in self-awareness training by Fleming et al (2005) to provide a starting point for discussions with clients regarding memory difficulties and rehabilitation. The SRSI is a clinical tool designed to measure metacognition skills after acquired brain injury and includes three components: awareness, readiness to change, and strategy behaviour. The validity and reliability of the SRSI has been tested and it has been found to have

sound inter-rater and test-retest reliability and concurrent validity with other neuropsychological measures (Ownsworth, McFarland & Young, 2000).

Strategies to improve the insight of those individuals who struggle to identify the impact of their memory impairments on daily functioning include individualised education, setting memory goals and monitoring their achievement, creating opportunities for accurate self-monitoring and involving the client as much as possible in decision making (Kennedy, 2006). Creating opportunities for self-monitoring have been attempted in a variety of ways including the use of role-play scenarios (Donaghy & Williams, 1998). McKerracher et al (2005) described 'reality testing' as an alternative to role-play as they argued role-play can sometimes appear too abstract for the client with poor cognitive abilities. Reality testing, as described by McKerracher et al, involves a client being asked to perform significant tasks and experiencing memory failures within these, leading to poor performance outcomes. These experiences were found to greatly improve the motivation of their client to use a diary system.

Willingness, or motivation, has also been highlighted as a barrier to EMA strategies. Wright et al. (2001) noted, in some of their study participants, a general lack of motivation underlying the reluctance to use a pocket computer. They attempted to address this by introducing other activities for which the pocket computer could be used, such as games. Their hypothesis was that the individuals would be encouraged to use the pocket computer more often and they might be more willing to enter reminders into the diary if they already had it in their hands and switched on. Unfortunately, the success of this idea was not reported in their findings. The issue of motivation may also run hand-in-hand with that of insight, as people are unlikely to enter reminders into a memory aid for events that they believe they can remember.

Other potential barriers to the use of memory aids have been documented and include clients' perceptions of the aid. Van Hulle and Hux (2006) noted that 'TBI survivors do not welcome compensatory strategies that make them appear different from other people or even different from the way they were prior to the injury' (p.102) and therefore clinicians must recognise the importance of minimising the 'conspicuousness' of any device that they suggest as a

compensatory aid. McKerracher et al (2005) also acknowledged that there are certain client perceptions that create potential barriers and need to be taken into account. These include the clients 'not wishing to use strategies/aids that draw attention to their problems' and 'feeling as if they are cheating and should not rely on aids' (p. 117). This idea of 'cheating' was also noted by Wilson et al (2005) who found that their pager system was unsuccessful when people perceived it as a retrograde step in their recovery.

A final barrier to EMA use, that has become apparent in more recent literature, is that of cost. With the increasing availability of electronic aids such as personal data assistants (PDA) and smartphones these are becoming increasingly considered as memory aid devices. Cernich et al (2010) identified that cost needs to be factored in to decision making when selecting these types of aids. They estimated that off-the-shelf PDAs range from US\$99-900 depending on the programs required and the level of memory required in operating the features of the device. Smartphones also require phone and data plans that often incur a monthly fee.

Involvement of significant others

Recent literature on cognitive rehabilitation has highlighted the importance of involving the clients' significant others in rehabilitation programs, particularly when preparing for community re-entry. The collaborative effort of these individuals, along with the health professionals, has been shown to help reinforce the compensation strategies that have been put in place (Cernich, Kurtz, Mordecai, & Ryan, 2010). Despite this there are few studies that include details of how the clients' families or significant others are involved in assisting the client to use the memory aid provided. Some studies mention involving significant others, such as the client's spouse, but do not give specific information regarding their involvement (Fleming et al. 2005; Wright et al., 2001). In spite of the suggestion that family members should be involved in rehabilitation in order to ensure successful outcomes, Wilson et al. (2005) found evidence to the contrary. They discovered that the compensatory strategy of pager use was unsuccessful with some individuals whose carers/relatives felt they should be doing the reminding rather than relying on the pager.

EMA training programs

While studies are universally supportive of the use of EMAs to compensate for memory difficulties, there is a significant lack of specific training protocols to allow the positive outcomes of the studies to be replicated in clinical situations (Sohlberg et al., 2007). Only four studies describe in some detail the EMA training program that participants underwent (Donaghy & Williams, 1998; Fleming et al., 2005; McKerracher et al., 2005; Schmitter-Edgecombe et al., 1995). Combining the stages of training from these four articles, results in some clinically useful guidance for implementation of training in EMA use, as outlined below.

Assessment

All four of the studies stated the importance of assessing the level of cognitive functioning of the client with three including details of the psychometric assessments they used (Fleming et al, 2005; McKerracher et al, 2005; Schmitter-Edgecombe et al., 1995). The psychometric assessments used vary widely between the studies with only *The Rivermead Behavioural Memory Test* (RBMT) common in both McKerracher et al. and Schmitter-Edgecombe et al. The RBMT is a commonly used tool designed to predict everyday memory problems in people with acquired, non-progressive brain injury and monitor change over time (Wilson, Cockburn & Baddley, 1991). Prior to initiating the use of an EMA, the test is useful in evaluating the level of memory impairment and the type of everyday memory strengths and weaknesses being experienced by the client.

Although advocated as useful tools in assessing memory and metamemory (Kennedy, 2006), the use of self-rating questionnaires is only mentioned by Fleming et al. (2005). There are a number of these types of questionnaires clinically available, such as the *Memory in Everyday Life* and *Use of Aids and Strategies* questionnaires (Thickpenney-Davis & Barker-Collo, 2007). The aim of these questionnaires is to assist in establishing the specific functional difficulties experienced by the client and the types of aids they are familiar with.

As self-awareness has been highlighted as an important component in the success of memory aid training, The Self-Regulation Skills Interview

(Ownsworth, Mcfarland & Young, 2000) is included in the assessment stage by Fleming et al. (2005). This provided the researchers with the ability to formally evaluate the study participants' levels of self-awareness and gave them a starting point for discussion about realistic goals for their program. The participants in the Fleming et al.'s study also experienced experiential feedback during task performance, which involved the use of self-estimation of memory function before and after participating in activities in an attempt to address any self-awareness issues.

For those study participants with impaired self-awareness of their memory deficits, a number of strategies have been suggested prior to commencing selection and use of an aid. As mentioned earlier, McKerracher et al (2005) completed a period of 'reality testing' with their study participant, during training in the use of memory notebooks. This period involved a list of significant tasks being compiled for their client to complete. The client was then monitored closely and found to miss appointments, lose items and forget important pieces of information. These errors were discussed with the client and this knowledge was found to increase their client's motivation to use the diary notebook. Fleming et al (2005) offered an alternative using video scenarios to provide clients with the opportunity to discuss real-life memory errors, such as forgetting to pay bills and forgetting social arrangements, in a non-threatening way. After watching the video, the client and therapist discussed strategies that could overcome each of the memory problems. Donaghy and Williams (1998) conducted role-play exercises during training to improve awareness; however in other case studies, clients have been unable to cope with the abstract nature of role-play (McKerracher et al, 2005). Kennedy (2006) suggested individualised educational information about the client's specific memory difficulties, and involving the client in setting memory goals as ways of improving self-awareness.

Goal setting

Goal setting is fleetingly mentioned in the memory aid research literature, with some studies making the point that the type of goal the client wants to achieve will influence the choice of memory aid. For example electronic paging systems and wristwatches have been found to be successful in targeting specific

behaviours such as remembering to take medication (Van Hulle & Hux, 2006; Wilson et al, 2005.), whereas more general prospective memory prompts such as remembering important appointments may be better met through the use of notebooks or diaries (Schmitter-Edgecombe et al, 1995).

Training stages

It has been recommended by Donaghy and Williams (1998) and Schmitter-Edgecombe et al (1995) that training should be composed of four stages: anticipation, acquisition, application and adaptation. These stages have been adapted from previous work described by Sohlberg and Mateer (1998). Within each stage the client participates in a combination of didactic learning with the therapist and homework exercises. The anticipation stage involves identifying memory weaknesses, gaining interest in solutions to memory difficulties and demonstrating the need for an external aid. The acquisition stage involves selecting the aid, learning to use it, and establishing a routine. During the application stage the client practices the appropriate procedures for recording information and using the aid through the use of homework tasks and role-play situations. At the application stage, Donaghy and Williams suggested an errorless learning approach to prevent clients from developing bad habits by using their aids incorrectly, "this is important because, in memory impaired individuals, errors become strengthened with repetition and thus are difficult to eradicate" (p. 1065). Finally, during the adaptation stage the client is encouraged to use the skills acquired within novel settings and adapt the aid to meet personal needs.

Re-assessment

The studies also described their re-assessment, as would be expected when investigating the outcome of an intervention. The authors do not suggest that this forms part of the clinical application of the training program; however it would seem logical to assume that therapists would also want to review the outcome of their intervention with clients, particularly at this time where therapists are being increasingly asked to justify their input by providing objective results to funders of services.

Re-assessment following participation in the memory aid training has been completed through different means within the various research studies. For instance monitoring success in functional memory tasks (Donaghy & Williams, 1998; McKerracher et al., 2005), examination of the physical evidence present within the aid itself, e.g. the number of entries in a notebook (Donaghy & Williams, 1998; Fleming et al., 2005), monitoring everyday memory failures (Fleming et al., 2005; Schmitter-Edgecombe et al., 1995) and qualitative feedback from participants regarding benefits and usefulness of strategies (Fleming et al., 2005; Schmitter-Edgecombe et al., 1995). In addition, psychometric assessments were re-administered to establish any change in memory impairment levels. If the level of memory impairment remained static but success in targeted behaviours was seen then the authors suggested that this improvement in function was most likely due to the use of the aid and the impairments were being successfully compensated for.

Gaps in the current evidence

Two recent systematic reviews have collated the evidence for the use of EMAs in memory rehabilitation (Cicerone et al., 2005; Sohlberg et al., 2007). Both reviews recommended that training in the use of external compensatory aids with direct application to functional activities should be a 'practice guideline' for subjects with moderate to severe memory impairments after TBI.

Critical research gaps identified by these reviews are the lack of studies that detail their training methods and the lack of information on factors that lead to long-term adoption of external aids. Although EMAs have been shown to positively affect functional outcomes, critical questions related to device selection, user evaluation and specific training protocols remain unclear. Sohlberg et al. (2007) concluded their review with a list of specific research questions that must be addressed before detailed practice guidelines can be generated. Included in this list of research questions is, 'what are the training components most likely to lead to efficient, durable use of an external aid?' (p. 24).

Summary

This chapter has provided background to the present study by outlining the literature relating to memory impairment after TBI and the evolving evidence for the use of a compensatory approach to addressing these memory impairments. Details of the EMA studies completed to date have been given including the participants within these studies, the variety of aids trialled and the potential barriers to memory aid use described in the literature. The sparse detail of specific training protocols used within the studies has been collated in order to demonstrate the lack of guidance currently available to therapists working in clinical practice, particularly when considering device selection, goal setting, and processes for successful implementation of an aid within the variety of clinical settings that clients may be based. Lastly, the gaps in current evidence as documented in two systematic reviews have been highlighted and provide further justification for this current study's aims, which are to:

- Explore occupational therapists' experiences of external memory aid training
- Identify a process to external memory aid training
- Inform future clinical practice and research by generating a process for external memory aid training
- Provide support for clinicians/service managers in justifying this type of cognitive rehabilitation to funders

The following chapter describes of the methodology used in this research project.

Chapter 3: Methodology and Methods

This chapter begins with an explanation for choosing a qualitative research approach and justifies why grounded theory was selected as the best methodology to meet the aims of the study. The philosophical underpinnings of grounded theory are described and reasons to link myself as a researcher to these philosophies are explained. Next, an overview of grounded theory and the relevance of this methodology to this study are discussed.

The later part of the chapter outlines the methods used in the study to recruit participants, select a sample from these participants, collect the data, and perform an analysis of this data. Examples from the study will be used to help support the description of these methods. The final section of the chapter will detail the ethical considerations relevant to the study and explain how I established rigour throughout the research process.

Rationale for choosing a qualitative methodology

A qualitative research design seemed most appropriate to address the study aims, as a detailed and complex understanding of the issues surrounding the EMA training was required. The study involved exploring the dynamic relationship between client and occupational therapist along with the fluid and evolving process of EMA training. In such a study it was felt that the more rigid and structured format of quantitative methods would not be appropriate. Interactions between therapists and their clients are difficult to capture with quantitative methods that may not pick up on pertinent issues such as intervention with clients who are coming to terms with reduced functional ability or have poor self-awareness of resultant impairments post brain injury. As an occupational therapist engaged in clinical work with a TBI population, I would also be drawing on my own experiences when analysing data, therefore rejecting the traditional ideas of objectivity involved in quantitative research. The overall goal when setting out on this research journey was that the results would have particular relevance for those therapists engaged in clinical work with clients on a day-to-day basis. My intention was that the words and actions of the participants would be heard and bring real meaning and relevance to the findings

for other therapists. This concept is well summarised by Corbin and Strauss (2008) who believed an important reason for choosing qualitative research is 'a desire to step beyond the known and enter into the world of participants, to see that world from their perspective and in doing so make discoveries that will contribute to the development of empirical knowledge' (p. 16).

Even when a researcher decides to use a qualitative approach, there remains the question of which methodology among the many qualitative options best fits the aims of the study. The idea of this study was for theory to emerge from the data collected rather than to test a hypothesis that had already been established from the literature; therefore an emergent research design was required. The main focus of the study was to develop a theory relating to the process of EMA training, rather than giving a narrative of the participants' experiences. Although I was interested in how occupational therapists experienced training their clients, and to hear the meanings that they gave to those experiences, I also wanted to locate those experiences within a larger context and describe a process of memory aid training that included the actions/interactions taken in response to issues that arise during the training. Grounded theory methodology was chosen as an approach to qualitative research that encompassed these requirements.

Theoretical perspectives to grounded theory

One theoretical perspective that has been attributed as underpinning grounded theory is that of symbolic interactionism (Corbin & Strauss, 1990). Crotty (1998) described theoretical perspective as 'the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria' (p. 3). Symbolic interactionism as described by Crotty is based on the assumption that people interact with phenomena in their lives in a way that has meaning to them and deals directly with issues such as communication and interrelationships. Within this study the phenomena would be the memory aid. The occupational therapists are attempting to establish an aid that has meaning for the client in their lives and will be sustained over time. They have developed a range of interactions with the client that are reliant upon their communication and relationship.

Two sociologists, Barney Glaser and Anselm Strauss, developed grounded theory methodology in the 1960s. While each came from different philosophic and research backgrounds their respective contributions were equally important. Strauss came from the University of Chicago, which had a strong tradition in qualitative research, and was inspired by interactionist and pragmatist writings by authors such as John Dewey, G.H. Mead and Herbert Blumer. Glaser came from the Columbia University and was influenced by Paul Lazarsfeld, known as an innovator in quantitative research. The Columbia tradition emphasised empirical research in conjunction with the development of theory. Both the Chicago and Columbia research traditions were directed at producing research that would be of interest to professional and lay audiences (Strauss & Corbin, 1990).

By the early 1990s differences in the grounded theory methods conducted by Barney Glaser and Anselm Strauss started to emerge which were further compounded by their differing career paths with Strauss remaining in academia and Glaser moving on to other endeavours. At this point two distinct versions of grounded theory emerged which became labelled as 'Glaserian' and 'Straussian' grounded theory (Morse, Stern, Corbin, Bowers, Charmaz, & Clarke, 2009 p. 15). The development of grounded theory has not stopped with the original creators but has continued through their students in a distinct 'genealogy' (Morse et al, 2009).

Grounded theory methodology, as described by Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008), has been selected for this study. The Strauss and Corbin approach to grounded theory uses a paradigm (discussed later in this chapter), which offers the novice researcher clear guidance in interpreting data. Although the use of this paradigm has been strongly contested by Glaser (1992), who claimed that it was too structured as an approach and forced analysis rather than having concepts emerge from the data over time, it was hoped that this structure would assist me as a comparatively novice researcher to ensure the rigour of data and results.

Grounded theory methodology as it applies to the researcher

As an occupational therapist I have been trained in the principles and foundations of the profession, and had the opportunity to put these principles into action over my 12 year career. One principle, which underpins the profession and acts as a model for supervisory relationships and ongoing professional development is that of reflective practice. Hagedorn (1997) emphasises the importance of reflective practice in ensuring quality, depth and efficacy of clinical reasoning in occupational therapy. With this background of reflective practice I found the philosophies of Dewey and Mead as cited in Corbin and Strauss (2008) very familiar. Corbin and Strauss (2008) described Mead and Dewey's writings as providing the framework for grounded theory methodology and use quotations from both these influential pragmatists that emphasise the need for self-reflection in pursuing grounded theory. I would consider that this link between the principles of my profession and the framework for grounded theory to be one of the reasons I was drawn towards grounded theory as a methodology.

As a researcher, working within the clinical setting of TBI rehabilitation, I bring to the study my own perspectives, training, knowledge and biases and these aspects of my self have been woven into the research process. This is a process that is encouraged through grounded theory methodology and is what Corbin and Strauss (2008) would call 'sensitivity'. They define sensitivity as 'interplay of researcher and data in which understanding of what is being described in the data evolves until the researcher can finally say, aha, that is what they are telling me' (p. 33).

Through the alternating processes of data collection and analysis, meanings and significance of data become clearer and researchers begin to see the issues from the perspectives of the participants; however Corbin and Strauss (2008) also point out that insights into data do not occur haphazardly but more often they happen to prepared minds. My professional experience, the theories and knowledge I have, enabled me to understand the significance of some things in this study more quickly than if I had entered a field of study with no prior understanding. For example, the terminology used in brain injury rehabilitation is familiar to me and assessment tools used to establish the degree of memory

impairment are tools that I have also used. Corbin and Strauss recommended three points to consider when it comes to sensitivity. The first is to always compare knowledge and experience against data, never losing sight of the data themselves. The second is to always work with concepts in terms of their properties and dimensions as this keeps the focus on the similarities and differences in events and prevents the researcher being overwhelmed by descriptive data. The last point is that it is not the researcher's perception of an event that matters; rather it is what the participants are saying that is important.

With this final point in mind, I decided to take part in a presuppositions interview prior to conducting my own interviews. This had been recommended by my supervisors as a way to explore and make more explicit my own perceptions of memory aid training before asking others about their experiences. By making myself more aware of any biases I may have, I could recognise these should I unwittingly bring them forward during interviews with my participants and spot them during data analysis. This presuppositions interview was conducted with a member of the grounded theory group to which I belong. The interviewer had experience of grounded theory as a research methodology and was aware of my research phenomenon through conversations at the monthly grounded theory discussion group. I appreciated the opportunity to reflect on my own clinical practice with clients and the review of the recorded interview highlighted my views on issues such as client involvement in decision making, the importance I place on family involvement in successfully implementing a memory aid, the need for client insight to develop prior to initiating the use of an aid, and reviewing their performance in previous functional activities within social contexts. The interview helped me identify the multiple conditions in which memory aid training is undertaken, including client based variables such as severity of injury and pre-injury functional ability, environmental conditions such as the staff support, length of stay and resources, and the social context such as availability of family support. As these concepts arose in my interviews with study participants I was able to go through transcripts and check that they had not arisen due to prompting from my biases. This was important for maintaining rigour and will be discussed further in this chapter.

Grounded theory methodology as it applies to this study

As the Strauss and Corbin approach to grounded theory methodology has evolved, it has lead to the creation of a set of 'assumptions' which now lie behind the methods and research strategies (Corbin & Strauss 2008). Of these assumptions there are some that particularly apply to this study:

The first of these assumptions is 'Contingencies are likely to arise during the course of action. These can bring about change in its duration, pace and even intent, which may alter the structure and process of interaction' (Corbin & Strauss 2008, p. 6). This would certainly be the case in most therapeutic interventions with clients after a TBI. Contingencies need to be made as their most common impairments, such as fatigue and reduced attention fluctuate throughout the day, and need to be accounted for when planning interventions and monitored during the intervention.

The second assumption thought to be particularly pertinent to this study is 'Courses of interaction arise out of shared perspectives, and when not shared, if action/interaction is to proceed, perspectives must be negotiated' (Corbin & Strauss, p. 7). As discussed in previous chapters, a number of clients following TBI will have damage to areas of the brain that influence their self-awareness and as a result their insight into their cognitive deficits may be poor. They may have limited insight that memory problems are causing functional errors and blame these errors on external factors. In this way the therapist's perspectives and that of the client may be very different. The nature of this issue is that occupational therapists will need to negotiate with clients in order for them to engage in cognitive rehabilitation.

The next assumption of relevance is 'Interactions may be followed by reviews of actions, one's own and those of others, as well as projections of future ones. The reviews and evaluations made along the action/interaction course may affect partial or even complete recasting of it' (Corbin & Strauss 2008, p. 7). In this time of 'evidence based practice' therapists are increasingly under pressure to justify the interventions they are taking through measuring outcomes. It was interesting to examine how occupational therapists have evaluated their actions with clients and what outcomes they have measured to establish that their intervention had a positive impact on the clients functional abilities. In

particular, it was interesting to explore how the occupational therapists working with clients on an in-patient basis predicted clients' future actions of ongoing memory aid use once they returned home.

Lastly, the assumption of a major set of conditions for actors' perspectives, and thus their interactions, is their memberships in social worlds and subworlds (Corbin & Strauss 2008, p. 7) applies to this study. Occupational therapists may be working alone or as part of a wider interdisciplinary team and it is of interest to establish if these conditions have an impact on the interactions they choose to take with their clients. The TBI population includes people from all walks-of-life and therefore it was of interest to see how occupational therapists incorporated this variability into their memory aid training. The impact of a client's social world would seem to have impact on therapist/client interactions and also on prediction of future use of aids in the community.

Research methods

Participant selection

The participants for this study were recruited from a pool of approximately 70 occupational therapists that are members of the Auckland Regional Neurological Special Interest Group. Members were sent an email explaining the study, its aims and asking for their involvement. A participant information sheet was attached to this email to provide specific details (See Appendix A). Once an occupational therapist had indicated their interest in participating in the study a second email was sent asking them to complete and return a consent form (Appendix B) and demographic data form (Appendix C).

The demographic data form provided information about clinical role, experience and work environment, and was used when seeking specific participants for open or theoretical sampling (described in the section below). See Appendix D for a summary of the participant demographics. Inclusion criteria were occupational therapists working in roles where they provide cognitive rehabilitation to individuals following TBI. Individuals who were being supervised by the researcher were excluded due to the conflict between researcher/participant and supervisor/supervisee relationship.

Initially open sampling (see below) was used to select the first three participants. Theoretical sampling, also described below, was then used to determine participants to be selected for interview depending on the need to explore particular concepts emerging during data analysis. Those participants who were not selected through theoretical sampling but expressed an interest in participating in the study were given the opportunity to attend presentations of the study results and be part of any future research.

Sampling

Grounded theory methodology advocates the use of open and then theoretical sampling (Strauss & Corbin, 1998). In the initial stages open sampling is open to those persons, places and situations that will provide the greatest opportunity for discovery (Strauss & Corbin 1998, p. 206). In this study open sampling was used to select participants who worked in clinical areas where they had the opportunities to train clients of varying abilities in the use of a range of EMAs and under a range of circumstances; thereby, bringing numerous examples of their clinical cases on which to reflect. The first three participants selected using open sampling included occupational therapists that worked across a range of services from post-acute rehabilitation to community rehabilitation, thereby seeing clients as in-patients, out-patients and in their own homes, their local community or work places. They also provided intervention for clients at times varying from less than one month post-injury to over two years post-injury.

The aim of theoretical sampling, as described by Strauss and Corbin (1998), is to maximize opportunities to compare events, incidents, or happenings, to determine how a category varies in terms of its properties and dimensions (p. 202). Theoretical sampling occurs simultaneously with data analysis and guides the need to acquire further information about emerging concepts. For example, following analysis of the first three interviews a concept appeared to be emerging around the durability of EMAs in the long-term, therefore a participant was then sought out who worked with clients at the two year post-injury stage to see if any information could be gathered to add to this concept. Theoretical sampling continued following the analysis of each interview as this permitted me to go to places and people that maximised opportunities to discover variations among, and add depth to, the concepts emerging as data was

analysed. Theoretical sampling continued until saturation was reached, that is, no new data relating to the concepts was emerging and relationships between concepts seemed to have been fully developed. Theoretical saturation was achieved with eight interviews.

Data collection

The first three occupational therapists participated in semi-structured interviews, comprising three to four purposefully broad questions, for example, “Tell me about your experience of EMA training with previous clients, what did you do and how did you do it?” Further examples of these interview questions can be seen in Appendix E. These initial questions gave each participant the opportunity to explore in detail his or her experiences of training clients with EMAs. Questions aimed at creating clarity and greater details were asked as the participants reflected on their practice. Following these first interviews concepts emerged through the data analysis requiring further exploration and the initial interview guides gave way to new questions and concept grids, an example of such a grid can be seen in Appendix F. These grids assisted me to record notes during interviews and draw my attention to particular language that was used by the participants, which related to the concepts. As theoretical sampling continued, questions became more focused towards adding depth, variation, or strengthening connections between, the emerging concepts. For example, as the concept **getting others on-board** started to emerge, questions were more focused on “who else do you involve in the memory aid training?” and “how do you go about getting them involved?”

Interviews were audio-recorded and transcribed verbatim. This gave the opportunity to listen to the interviews a number of times and immerse myself in the information as it was transcribed. Written notes were also taken during and after the interviews, which helped to recall details of the interviews that could not be captured through the recording, such as the non-verbal communication and distractions within the room. This became important in data analysis as the recall of a participant becoming animated and excited about describing certain clients and then quiet and thoughtful about others could give clues to the meanings of the words in the transcript.

Transcripts were returned to the participants via email and they were asked to review their answers to questions and return any comments, questions or elaborations to the researcher. None of the participants chose to elaborate on their answers. Their reactions to the transcripts were positive in terms of their responses to questions but they commented on their surprise at how they 'did not speak in sentences' (Participant 1) or 'went on a bit before getting to the point' (Participant 4). They were reassured that this was the case with all interviews and the information that they provided had been useful.

Data analysis

Once the interviews were transcribed a constant comparative method of analysis was undertaken as advocated in grounded theory methodology (Corbin & Strauss, 1990). Comparisons were considered within individual interviews, across all participants' experiences and also in relation to literature connected to the field of study.

Within the constant comparative method of data analysis, Strauss and Corbin (1998) described a three level system of open, axial and selective coding, which were employed in this study. Open coding is 'the analytic process through which concepts are identified and their properties and dimensions are discovered in the data' (Strauss & Corbin 1998, p. 101). During open coding interview transcripts were examined line-by-line and given labels to capture the meaning of each discrete part, these labels were then compared for similarities and differences and formed into codes. Table 1 on the following page shows an example of this process taken from one of the interview transcripts.

In the next phase of open coding similar codes were then grouped together to form more abstract categories. An example of this would be codes such as 'real life', 'meaningful environment' and 'everyday life' being grouped under a category 'real world'. 'Real world' started as an in-vivo code itself, taken from a number of participants' transcripts, and seemed to encompass the meaning of codes such as those mentioned above.

Table 1: Open coding

Section of Transcript	Labels	Open codes
So when I am using memory aids I am really trying to fit it around them, like their routine, trying to be beneficial for them, try to give them some sense of independence because a lot of them say, you now, I just can't remember what I am doing and obviously if you are trying to increase their engagement well using the memory aid would probably be a perfect way to do that.	<p>Aid to meet the client's needs and routine</p> <p>To be beneficial for them</p> <p>To promote independence</p> <p>Clients report difficulty with remembering what to do</p> <p>Memory aid seen as a way to increase engagement in activity</p>	<p>Tailor the aid to the client</p> <p>Purpose:</p> <ul style="list-style-type: none"> • Promoting independence • To help remember • Increasing engagement

During axial coding these groups were reassembled by making connections between the categories. These connections were examined through a number of analytic tools described by Corbin and Strauss (2008) including: The use of questioning, making comparisons, thinking about the meanings of a word/phrase and looking at language. Further connections were tested through the use of a 'paradigm' and 'conditional/consequential matrix' (Corbin & Strauss, 2008).

The paradigm constructed by Strauss and Corbin (1998) is 'a perspective, a set of questions that can be applied to data to help the analyst draw out the contextual factors and identify relationships between context and process' (Corbin and Strauss 2008, p.89). The basic components of the paradigm are:

1. There are conditions of the interviewee reveals the circumstances or conditions that lead him/her to make a particular response, such as a client demonstrating poor insight into their memory impairment.

2. There are inter/actions and emotions ó these are the responses made to situations or problems, for example, the therapist attempts to improve a client's insight through individualised education.
3. There are consequences ó these are the outcomes of the inter/actions. The client has more understanding of their brain injury and their insight into memory problems improves.

The conditional/consequential matrix enriches the use of the paradigm above by helping to sort through the range of conditions/consequences in which events are located and responded to. As a novice researcher the paradigm and matrix provided me with devices for keeping track of the complex sets of relationships between data.

In keeping with grounded theory methodology, throughout the data collection and analysis, memos and diagrams were kept which helped me reflect on decisions regarding: ongoing data collection, the process of constant comparative analysis, emerging theory development and sampling. Memos are a type of written record that contains the products of analysis; diagrams are visual devices that depict possible relationships between codes or concepts (Corbin and Strauss, 2008). Below is an example of such a memo, written during the comparative analysis of the first three interviews:

Even before the intervention with the client begins the OTs are already aware of barriers they face in providing the best service that is possible, these include: gaps in their own evidence base and knowledge, company structures such as staffing, ACC contracts under which they work, difficulties with accessing more high-tech aids. Barriers with respect to ACC contracts are again considered during client goal setting with the type of contract having a bearing on the OT intervention and anticipated outcomes. When describing their training, OTs have to work through or around a number of barriers which seem to fall into two categories: structural issues (reduced staff support, sheltered rehab environment, poor resources) and client issues (e.g. poor motivation, physical impairments, sensory impairments, reduced insight). ó Memo 15.5.10

This memo helped to direct future questions to participants regarding their identification of, and ability to deal with, barriers to memory aid training. In earlier stages, memos focused on the codes emerging from the transcripts and helped to link these together.

Diagrams were found to be particularly useful in the early stages of analysis for summarizing memos into an easily visualized format or when examining the properties and dimensions of certain concepts.

The use of literature

In an emergent research design, such as grounded theory, the researcher works in a particular way with the literature related to the field of study. Literature is initially used to map the field of study and identify the gaps in the research. At later stages, as the researcher begins to discover emerging processes and concepts, literature becomes part of the method by which these are compared, contrasted, sorted and expanded (Glaser, 1992). For example, the concept of getting other people on-board to help reinforce the memory aid training emerged from data analysis early on. Memos led to ideas of engaging family, particularly, in the client's training; and there was a feeling among participants that this led to better outcomes. A review of literature regarding family involvement in rehabilitation improving outcomes for clients with TBI was then looked at for comparisons with the reports from participants. This added to the depth of information and also highlighted the complexities involved in building relationships with families. Data was then re-examined to establish how these relationships were being built and under what conditions.

Ensuring rigour

I have reviewed a range of interesting literature on the topic of rigour in qualitative research. Many of the articles discuss the debate over how to ensure the quality of qualitative research and divide the opinions into three positions, as summarised by Rolfe (2006):

1. Qualitative and quantitative research should be judged on the same criteria
2. There should be different criteria for assessing rigour of qualitative research versus quantitative
3. It is inappropriate to use any predetermined criteria to assess qualitative research as this makes the assumption of one unified paradigm for qualitative investigation.

As someone new to using qualitative research methodologies I found the above debates interesting but confusing. I can see the need to move away from the positivist criteria of validity, reliability and generalisability as these terms do not appear congruent with many qualitative approaches. However the articles that support the second of the above positions (Bradbury-Jones 2007, Tobin & Begley 2004) use alternative criteria for ensuring rigour in qualitative study such as 'credibility', 'transferability' and 'dependability' but then admit that these new terms are equivalent to the quantitative concepts of internal validity, external validity and reliability. In my mind this only confuses people as to what is actually being referred to. I can also see the point to Rolfe's third position, as I agree that qualitative research should not be referred to as one single paradigm and therefore it is difficult to assign predetermined criteria across the board.

With the above in mind I have tried to focus on my own study and employ strategies for rigour that apply to the particular grounded theory methodology being used. It is proposed that the detailed process involved in gathering and analysing the data within a grounded theory study provides the foundation for rigour (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The constant interplay between data collection, analysis and sampling, as described earlier in this chapter, assists the researcher in staying truthful to the data and ensures theory evolves from the data itself. This system also ensures that negative cases, i.e. data from interviews that does not fit with the developing concepts is considered. Further strategies to ensure trustworthiness within the research, from an interpretive perspective, and based on the rigour literature I reviewed were also considered and are explained below.

Reflexivity

Reflexivity refers to the way in which the researcher and the research process have shaped the data collected, including prior assumptions and experience (Mays & Pope, 2006). As a therapist working in TBI rehabilitation and seeing clients in the post-acute stages, I am engaged in cognitive rehabilitation on a regular basis and this includes training clients in the use of EMAs. I am aware of processes and barriers that influence the training and of literature and evidence that informs my own clinical practice. I have discussed the importance of memory aid training with other members of the multi-

disciplinary team and heard their opinions on the use of aids. I have also reviewed literature specific to the topic of memory rehabilitation and EMAs, in part, as a way of establishing what research has already been done in preparation for writing my own research proposal.

During my research process I have remained aware of this clinical experience and its potential impact on the data. I have openly acknowledged this and shared my position with readers. I have employed a number of ways in which to monitor my personal views and insights regarding emerging themes in the data, including the use of memo-writing and diagramming. I also regularly met with my two supervisors to discuss the research process. I took examples of my coding to demonstrate my analysis and to explore the concepts which I was uncovering from the data. As well as meetings with supervisors, I was a member of a grounded theory research group where students undertaking grounded theory studies, would present and discuss their individual projects. The processes of challenge, discussion and reflection, along with continued individual learning, assisted me to ensure I remained grounded in the data from my participants and did not conceptualise based on my own opinion.

The pre-suppositions interview, which I described in an earlier section of this chapter, also assisted to ensure reflexivity by drawing my attention to my own opinions and potential biases and enabling me to recognise these when they appeared.

Engaging in all the reflexive processes described above, I hope to assure readers that the emerging theory is more likely to be grounded in data rather than due to my own personal views.

Transferability

Transferability or *õfittingnessö* is described by Chiovitti and Piran (2003) as, *õthe probability that the research findings have meaning to others in similar situationsö* (p. 433). In my study I carried out interviews with occupational therapists working in the TBI services. In order to ensure transferability I have aimed to describe the demographic characteristics of the sample, the characteristics of their work settings, the funding systems under which they work and the TBI population that they provide intervention. In grounded theory terms, some theories may be *õsubstantiveö*, whereas others may be considered *õformalö*.

Substantive theories apply to a particular phenomenon within a particular context. Formal theories, in comparison, are less specific to a group or place and therefore apply to a wide range of contexts (Strauss & Corbin, 1998). I aim to generate substantive theory based within a particular context which readers must understand in order to relate this to their own working environment.

Saturation

Using a grounded theory approach, the coding and comparative analysis of emerging concepts as described by Corbin and Strauss (1990, 1998) has led to a saturation point where no new information was being collected. This will be illustrated in the following chapters through the inclusion of extracts from the interviewees themselves demonstrating how a concept emerged or through the inclusion of memos/diagrams showing examples of how topics were coded and categorised.

Review of interview technique

As a novice in the skills of research interviewing, I have requested feedback from my supervisors on a regular basis regarding my interview skills in order to establish the best possible techniques. Supervisors have been able to review the questions that I have been preparing for interviews and give advice on the structuring and phrasing of these. This was helpful in preparing myself for clearly structuring any follow-up questions I might ask when seeking clarity from the interviewees.

Member checking

Following the transcription of each interview it was returned via email to the participant for review and comment. My intention was to address any queries, clarifications or concerns that arose from the participant's review and add their additional comments to the data under consideration. Of those participants who replied to these emails their main concerns were more about the structure of their answers than the actual content.

As part of the agreement with my employer who is assisting me with the funding of my study I have been required to present findings of the study at regular intervals. These presentations have been to the rehabilitation team in

which I work and their feedback on the emerging concepts and processes has been taken into consideration during memoing.

Ethical considerations

Ethical approval for this study was sought through the Auckland University of Technology Ethics Committee (AUTEC) and written approval was received on 12th January 2010 (Appendix G). The ethical principles and requirements are outlined in the AUT Ethics Knowledge Base (2008) and the following applied to this study: informed and voluntary consent, respect for rights of privacy and confidentiality, minimisation of risk, the right to withdraw, cultural and social sensitivity.

Informed and voluntary consent

Potential participants were informed of the study through an information sheet (Appendix A) that was issued to them via the special interest group e-mail contact list, as previously described. Once potential participants indicated that they were interested in participating they were asked to complete a consent form and demographics form (Appendices B and C). Prior to the interviews commencing each participant's understanding of the information and research process was checked and they were given the opportunity to clarify any details and ask questions before proceeding.

Respect for rights of privacy and confidentiality

Participants were informed that their identities would be protected at all stages through the project. Each participant was allocated an ID number. Information relating to the participants has been kept in locked cabinets in my home office or under password accessed computer folders and only linked by the ID numbers. Signed consent forms have been stored separately from the data, in a locked cabinet in the principal supervisors research centre at AUT. No information that could identify an individual participant has been used in report writing.

Minimisation of risk

It was made clear to the participants that should they, during the course of an interview, discuss clinical practice which was clearly in breach of the Occupational Therapy Board of New Zealand's Code of Ethics (2004) the researcher would, in the first instance, provide the participant with advice at the end of the interview. If the issue arose due to poor understanding of current evidence then the researcher would also offer to send the participant appropriate literature on the subject. Should the participant continue to infer that they would practice in an unsafe or unethical manner then the researcher would inform them of the need to disclose the relevant information to their manager in order to protect the public interest. During their interviews none of the participants discussed clinical practice that was considered to be unethical or unsafe.

The right to withdraw from the study

Participants were given the opportunity to withdraw from answering particular questions during their interview or withdraw from the study at any time. However, none of the eight participants withdrew.

Treaty of Waitangi

Prior to completing my application for ethics approval, I discussed the study's implications for Maori with Charmeyne Te Nana-Williams, a Maori Advisor for my employers ABI Rehabilitation Management Ltd. We discussed three aspects of the study relating to Maori, the first being the possibility that participants who volunteered for the study could be Maori, the second being that participants could discuss Maori clients, and the third being the general implications of the findings of the study as they relate to a Maori population.

None of the occupational therapists that volunteered to be interviewed for the study identified as being of Maori descent. This was unsurprising considering the New Zealand Association of Occupational Therapists (2009) reported that the proportion of Maori across the occupational therapy workforce is only 2%. It was therefore felt that the interviews reflected a true picture of occupational therapy interventions.

Participants who discussed Maori clients during the interview process did not make any reference to these clients requiring any alternative considerations

to those of clients from other cultural backgrounds. As cultural difference was not a particular focus of the study, questions relating to this were not asked unless participants raised these subjects themselves as per the semi-structured interview format.

The process of **getting client buy-in** and **getting others on-board** as explained in the findings chapters would appear to embrace the Treaty of Waitangi principles of partnership and participation between the occupational therapist, tangata whaiora (client) and whanau (family).

Summary

This chapter has presented an overview of the grounded theory methodology as employed in this study. An explanation for the use of qualitative research, in particular grounded theory methodology, to meet the aims of the study has been given. In addition the philosophical and theoretical perspectives of grounded theory and their fit with this study have been explained. The methods employed throughout the study to select participants, collect and analyse data have been described, as well as the ways in which rigour was maintained. Finally, ethical considerations have been discussed.

The findings of the research will be presented in the following chapters. To assist the reader in recognising the titles of processes, categories and sub-categories within the findings chapters, processes will be presented in **bold** type, categories and subcategories presented in *italics*. Excerpts from the interview transcripts will be used to demonstrate how the findings are grounded in the data collected. A participant's number, followed by two numbers indicating the transcript page and line from which the data is taken, identifies the source of each excerpt (e.g. Participant 2, 3:16). For ease of reading, transcript quotes have been tidied up, i.e. ums, ahs and repetitions have been removed.

Chapter 4: Developing client insight

Occupational therapists working with clients who have had a TBI often employ the use of EMAs. The findings of this study revealed that sustainable use of an EMA was constructed through a core process of **making it real**. Contributing to this process were three overlapping processes which have been named using the words that the occupational therapists used during their interviews: **developing client insight**, **getting client buy-in** and **getting others on-board**. In the following chapters each of these four processes is described separately, but in reality they do not stand alone; they overlap as the occupational therapists progress through the memory aid training with their clients. **Making it real** is the core process that travels through and encompasses the other three.

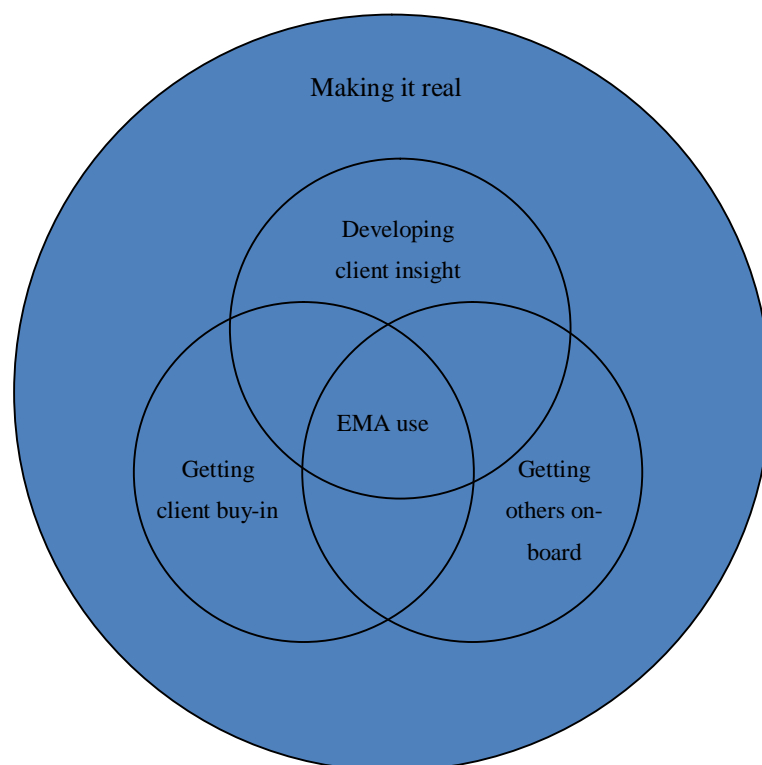
To assist the reader in forming a picture of these four processes and how they interact with one another a visual representation, Figure 3 on the following page, has been produced. This represents three of the processes that are surrounded by the fourth, core process, **making it real**. All processes contribute to the outcome of sustainable use of an EMA by the client, which is placed in the centre of the figure. The overlapping of each process indicates how they interact to produce this final outcome. Where overlaps in the processes occur, these will be pointed out in the presentation of the findings and discussed in depth in Chapter Eight. This visual representation will be referred to, and explained in more detail, throughout the following chapters as the focus changes from one process to the next.

This current chapter explores the process **developing client insight**. It has been placed before the others due to the occupational therapists' beliefs that they must first establish some degree of client insight into their memory problems before the client will engage in using (or **buy-in** to) an EMA. In Chapters Five and Six the two processes **getting client buy-in** and **getting others on-board** are described. Chapter Seven will address the core process of **making it real**.

To assist in making sense of each process and the categories within it, Strauss and Corbin's (1998) conditional paradigm, as described on page 36 of Chapter Three, will be employed as the structure to each of the findings chapters, with each process being broken down into paradigm components: conditions,

inter/actions and consequences. Each chapter will start with a table listing the paradigm components and categories and sub-categories related to each.

Figure 3: Four processes



Developing client insight – an overview of categories

This process is about how the occupational therapists helped their clients to establish a degree of insight into their memory impairments and the impact these impairments would have on their everyday functional abilities. When talking about insight the occupational therapists described levels of insight rather than clients having or not having insight. They also used words such as awareness, understanding and acknowledging when describing what they meant by insight. **Developing client insight** was felt to be an important first step as it led to **getting client buy-in** into the EMA training. An example of this point is captured by Participant 4.

So obviously if someone does not have insight, or they do not really care that they are not remembering, then you are not going to get buy-in for them to use a strategy, and that is often a big barrier. (Participant 4, 3:11)

The categories and sub-categories relating to this first process are represented in Table 2 below.

Table 2: Developing client insight

Paradigm component	Categories	Sub-categories
Conditions	Stage of rehabilitation	Early on
		Later down the track Time in their normal lives
	Severity of injury	Mild injury vs Severe injury
Inter/actions	Assessing	Levels of insight Functional observation vs client report Pre-injury vs post-injury Client self-rating
	Educating	Individualised education Explaining results of assessments
	Experiencing failure	Allowing errors Involvement in meaningful activity
	Supporting client	Explaining Listening Counselling
	Reflecting	Who am I now Accepting changes
	Rapport building	Humour Caring attitude Establishing trust
	Focusing on what the client enjoys	Interesting activity Wanting to achieve
Consequences	Seeing the point	Understanding
		Realising
		Willing to engage

Within the conditions of *stage of rehabilitation* and *severity of injury*, occupational therapists undertook a number of inter/actions with their clients in order to get them *seeing the point* of the memory aid training. The conditions under which the occupational therapists were working will be explained first and are summarised in the table below.

Table 3: The conditions - an overview

Paradigm component	Categories	Sub-categories
Conditions	Stage of rehabilitation	Early on
		Later down the track
		Time in their normal lives
	Severity of injury	Mild injury vs Severe injury

Condition: Stage of rehabilitation

One of the conditions under which **developing client insight** took place was the *stage of rehabilitation*. This condition was one in which the occupational therapists either described clients who were *early on* in their rehabilitation journey or *later down the track*. This condition was evident during interviews with occupational therapists working in the more acute stages, where they felt the clients had had little opportunity to develop their insight into the functional implications of the brain injury.

It is quite early so there is still a lot of grieving and a lot of emotional stuff that is going on before they can even grasp what the brain injury actually means. (Participant 5, 3:3)

Alternatively occupational therapists working in the latter or community stages of rehabilitation felt that client insight had become more developed.

In my experience it is time actually, and it has been really interesting doing this job, being able to follow people from [name of rehab unit] and knowing how they presented at [name of rehab unit] and seeing them six months down the track and seeing the *huge* emergence of insight. (Participant 4, 14:20)

In the initial *stages of rehabilitation* therapists felt clients lacked opportunities to engage in the challenges of their everyday lives. As they moved through the *stages of rehabilitation* they had more *time in their normal lives* and experienced difficulties in returning to activities they could previously manage. This led to some realisation of their memory problems. Participants 4 and 6 worked with clients in long-term rehabilitation services and had experienced clients who were 'trying to live a normal life and then suddenly realising that they couldn't' (Participant 4, 15:12) as they struggled to manage due to memory issues. They talked of these clients becoming increasingly aware of their memory issues due to these experiences.

They have seen a pattern of how things are not working for them currently and they start to get a realisation that something has to change, something has got to be done. They start to think 'oh no, I have to do something about this'. They have had enough experiences that show them this is a problem now. Before they could not see that memory was a problem, now they do, they need to try something. (Participant 6, 22:28)

Condition: Severity of injury

The severity of a client's injury was seen to influence their level of insight and the degree to which the occupational therapists had to focus on developing their insight, as highlighted by Participant 8.

I guess depending on, yeah, depending on the severity of the injury those levels of insight, you know, they can be a higher level or a lower level. (Participant 8, 8:4)

During the interviews the participants mainly referred to clients who had suffered a *severe injury* when they talked about the challenges of developing insight. When they worked with the clients with *mild injury*, less time was devoted to the actions required to build insight, as these clients were more readily able to take this information on board.

Participant 3 is an example of one occupational therapist, who worked across a range of services, offering rehabilitation to clients ranging from concussion to severe traumatic injuries. In her interview there was a notable difference between the clients with a *severe injury* who are described as 'non-compliant with strategies' (3:10) and 'really unreliable' (3:13) and finding the memory aid 'pointless' (8:10), compared to the clients with more *mild injuries*,

whose goals were based around a return to work, and required some EMA training to manage this. Participant 3 struggled to engage the more severely injured clients in memory aid training due to their lack of understanding/insight.

If they cannot understand the purpose behind what you are doing they are not going to be forthcoming to engage in what you want them to do. (Participant 3, 14:29)

Participant 3, along with the other participants, discussed in detail how they would spend time with these more severely affected clients developing their insight through the range of inter/actions discussed in the following sections and summarised in Table 4 below.

Table 4: The inter/actions – an overview

Paradigm component	Categories	Sub-categories
Inter/actions	Assessing	Levels of insight
		Functional observation vs client report
		Pre-injury vs post-injury
		Client self-rating
	Educating	Individualised education
		Explaining results of assessments
	Experiencing failure	Allowing errors Involvement in meaningful activity
	Supporting client	Explaining
		Listening
		Counselling
	Reflecting	Who am I now
		Accepting changes
	Rapport building	Humour
		Caring attitude
		Establishing trust
	Focusing on what the client enjoys	Interesting activity
		Wanting to achieve

Inter/action: Assessing

The first inter/action in which the occupational therapists engaged was *assessing* the level of a client's insight into their problems post brain injury. These *levels of insight* were defined in two ways. The first, more general description of the levels of insight was in three parts: 1) clients had awareness of their obvious physical impairments, 2) awareness of lower level cognitive issues, and 3) awareness of the higher level cognitive difficulties. These three levels can be seen in this excerpt from Participant 8's interview:

You can have insight into the fact that you have a broken leg, or arm or collar bone but no insight into the fact that your brain is bruised and swollen ... you can then have insight into the fact that you have memory problems but no insight into the fact that you have problems with problem solving and sequencing and abstract thinking. (Participant 8, 7:28)

The second way that the occupational therapists defined their client's *level of insight* was more specific to memory impairment and was based around their ability to predict when their memory would fail them. Some clients would deny that their memory was any problem to them at all, others were able to identify specific memory errors when they were discussed or as they occurred, and some could anticipate and plan for any likely failures in memory by independently using a memory aid. Participants 6, 7 and 8 talked about recognizing these levels of insight in some of their clients.

He would acknowledge it in the discussion, he would say 'oh, yeah' and he did kind of acknowledge he did have a memory problem, but then afterwards and while engaged in something else he would not really acknowledge it, he did not really see it, so that was quite a big barrier. (Participant 6, 4:11)

He had extremely poor insight; according to him there was absolutely nothing wrong with him. (Participant 7, 8:10)

You are working with them and you say, 'you know how you missed your appointment last week, what can we do about that, how can we do things differently' and they might say 'well, my memory is not so great'. (Participant 7, 7:11)

He knew and was able to tell me that he had repeated himself, pretty much everything that he had told me 5 minutes before, and he was able to recognise that but he was

completely unable to shift himself from the thinking that he did not need some help to be able to combat that. So he had insight into the fact that his memory was really bad but then that insight did not then tell him that öoh, this [the memory aid] can actually really help.ö (Participant 8, 6:9)

Assessing the level of client insight was done in a variety of ways including *functional observations versus client reports, pre-injury and post-injury comparisons* and *client self-rating*.

Occupational therapists working in in-patient rehabilitation services and community services drew on their skills of *functional observations* to establish the impact of the memory impairments and the level of client insight into their memory impairments. When carrying out assessments they would question the client in order to get feedback on the outcomes the client expected and the outcome that was actually achieved. One occupational therapist who worked with clients on return to work programs reported that she would use a work based functional trial to establish a client's level of insight:

I would obviously go there with him, do an assessment, watch what he does, but if he is not remembering to put, because he just em, what did he do? He works for the [name of company] doing all the food so it is very repetitive but if he could not remember things like that then it is easier to say, look you can not remember doing this so how about we put this strategy in and then that will help you to be able to be back at work and you will be able to remember things and your fatigue levels will be more manageable because you will be resting more regularly. So it was really just a way of him gaining insight into öactually I do have problems and I really need to take this on board and I need to start to implement these certain strategiesö. (Participant 3, 8:22)

Occupational therapists working in in-patient environments would also have the added benefit of numerous staff being able to observe the client in their everyday activities such as self-care and simple meal preparation. In conjunction with their own functional assessments, therapists also gained information from other staff members as to how the client was performing and compared this with the client's reports. Participant 4 was one such therapist, who had previously worked in a post-acute rehabilitation unit. As well as her own assessment she took on-board the observations of others. Here we have an example of the concept **getting others on-board** overlapping with **developing client insight**, as represented by Figure 3 at the start of this chapter.

I think assessing in terms of, I think if you are in an in-patient facility it is reasonably easy because you have got a lot of people watching the client so there is a lot of observation of behaviour which will be incongruent with what the client is saying. So the client will be saying 'I am fine, there is nothing wrong with me' and yet all the therapists and the staff will see things to the contrary. That client might be struggling to recall what they have got to do next or struggling to manage their own fatigue or get themselves sorted for the day in terms of their cares and things like that. So with insight, I think if you are working in that area you know pretty early on, when they are out of PTA obviously, and you are doing your functional assessments and things like that and then you would sit down and chat with the client, yeah, you sort of have to talk with them and ask 'well, how do you think you're going, do you notice any changes?' (Participant 4, 13:28)

Along with these functional assessments and observations some occupational therapists would also ask clients to compare *pre-injury versus post-injury* performance to ascertain if clients noticed a difference when it came to their functional independence and their memory errors.

So whether that might be something like making lunch, something quite basic, something that you kind of know that they are going to have a little bit of trouble doing. Then you can just draw on that, you know, asking 'could you do this before?' (Participant 3, 15:16)

The client's families were also asked to assist with this *pre-injury versus post-injury* performance comparison (another example of overlap with the concept **getting others on-board**, which will be described further in Chapter Six). The therapists would talk to the families and get their opinion on how the client was presenting in comparison to their pre-injury abilities. Participant 4 worked with a client in the community and found a significant difference between the client's reports of his abilities and the reports from the family, demonstrating this comparison.

I think talking to the family as well is quite important. They can tell you how that person is presenting compared to how they normally are. And often, I am just thinking of a particular client who has caused a lot of grief in the community, [name of client], he is very much, 'I am fine, I am fine, I am fine' and the family are like 'gosh he is so different'. (Participant 4, 14:10)

A more formal method of establishing the level of client insight was taken by Participants 5 and 7 who used *client self-rating* scales. These were visual scales, where the client would rate them self from 1 to 10 before and after a memory task. Participant 5 discussed a particular client with whom she worked; this client had the added complication of communication issues and therefore this type of visual scale was useful as the client could point or reply yes/no in response to a number.

I just kind of draw a line and I put a 10 and a 1 and just say öif 10 is really easy and 1 is really hard, where would you put yourself on that scale?ö so she can point or I can say a number and if it is right she will say yes or she will say the number again. (Participant 5, 5: 4)

I try to do it before and after, just to get a gauge. With the memory task I did it before and after with her for that, yeah. So before she was just like yeah 10 out of 10, no problems, then we did a task giving her three pictures or words of objects and she was like öyep, yep, got it, got itö and then I put them in three different places on a page and wrote all these other words and she could not pick out the words, even though we had said it. But, yeah, and then I got her to do it [the self-rating scale] afterwards and I can't remember what it was afterwards but she knew there was a change she knew she was not as good as she previous thought she was. (Participant 5, 6:4)

Once the occupational therapists had established the level of a client's insight through their assessments, they then decided what education was required and began to provide this in a variety of ways.

Inter/action: Educating

Following on from *assessing*, *educating* was the next inter/action taken by occupational therapists when they were **developing client's insight** into their memory difficulties. The sub-categories of *educating* included *individualised education* and *explaining results* from standardised memory assessments.

The participants described their education to clients following their assessment of insight. They believed it was important to try to increase understanding of the memory impairment through education focused on the client themselves, such that each individual client had knowledge of their own brain injury (e.g. the location of the injury), what this meant in terms of the brain's ability to encode, store and recall information and how this would impact

on the client once they began to return to their normal daily activities. The education was also individualised to meet the needs of the clients in terms of their other cognitive limitations. They saw this as a first step to improving awareness.

I think it starts with education. So you have to make sure that your client understands that they have a memory impairment and how memory works and some concepts like prospective memory and the planning ahead and the recording what has happened and the different ways that people can use memory aids but just doing that at the right level for that person. So I do not think you can standardise that stuff. (Participant 4, 10:7)

Some of the participants described how they pitched their education using a number of different approaches to assist the clients in their learning. Participant 4 described her resources for education as a 'little basket' that she drew relevant written information from, as needed.

I think what you do is you have a little basket, a little basket with a different page for each concept and you just take the pages away that are not relevant and then you leave the pages that are in you have got to start with education and make sure that the person understands a little bit about memory and their *own* memory impairment. (Participant 4, 10:12)

Similarly, Participant 8 used drawings and explanations to assist clients in building their understanding. This information could then be referred to by the client at a later date and reinforced with ongoing daily education sessions.

I have nifty little pictures of brains and I mark out the damaged areas and I link that to why there is a memory problem and in simplistic terms I will show how that is the part of the brain that often contributes to memory and I put that in the front of their modified diaries because most people with limited insight will say 'there is nothing wrong with me, I am fine, everyone has memory problems' and I guess, so I will say 'yes, but not everyone has this particular damage on their brain, this is going to make it a little bit harder and that is why this would be really helpful for you if you can, well, if we can make it work for you'. So I do try to increase that awareness and that insight, almost on a daily basis. (Participant 8, 6:29)

Four of the participants (Participants 1, 2, 3 and 4) described the usefulness of carrying out standardised assessments, such as the Rivermead Behavioural Memory Test, to establish an objective measure of a client's memory abilities and

then *explaining results of assessments* to the clients as a way of improving insight. These assessments provided the occupational therapists with useful information regarding the specific areas of memory impairment and they could then educate clients in how the results related to memory function in everyday life.

I might do an assessment, a Rivermead Assessment and you might use it also as an education tool to say 'they look, this test looks at this and this is what it showed'. I would not expect that to solve all of the problems but sometimes it makes a bit of a dent or at least raises the topic of poor memory and the things that I have observed.
(Participant 1, 5:6)

This education may lead to an increase in the level of a client's insight and recognition of the need to establish some strategies to manage their memory impairment. Under the condition of the more *mild injury*, as described above, this was usually the case. However, more *severely injured/impaired* clients would often require further intervention in order to raise their awareness of poor memory function and their need to train themselves in the use of a memory aid to help compensate for their poor memory. Further intervention took the form of allowing the client to experience failure, as described below.

Inter/action: Experiencing failure

Six of the eight participants discussed how they would have the client *experiencing failure* in a controlled way in order to have clients build their insight into the activities that they could no longer perform due to memory impairment. This was discussed in different ways, and was again dependent on the *stage of rehabilitation*, but included the idea of *allowing errors* to occur during the rehabilitation day when a client was in the more acute stages of rehabilitation. These errors included such things as being late for appointments or missing a meal. The repercussions of these errors were what appeared to be of importance as demonstrated in this statement by Participant 2 who described scenarios where the client might 'get into trouble' for their memory impairment which resulted in 'their ears being ready to listen'.

They end up being late, then staff getting upset, or they miss their lunch and the food has been removed and they are hungry, those kind of things. When they really miss important things. (Participant 2, 14:18)

Involvement in meaningful activities was also felt to be important when allowing the client to experience failure. The occupational therapists were interested in engaging the clients in doing, as well as talking about the activities in which memory failure may be encountered as a problem. This point was made by Participant 3 who thought that failure through doing was, for some clients, the best type of therapy to build their insight.

So failure through doing I think sometimes is the best type of therapy and then you can be like well this is why I think we need to be working on it. I think because actually you can see it, they can see it and there is a realization that actually I am not functioning ok, I can talk to people, I look fine, I can walk, but actually when it comes to *doing* I am not able to do what I could do before. (Participant 3, 15:20)

Participant 5 described two different clients whom she *involved in meaningful activity* in order to help them build insight into their memory difficulties. She chose activities that these individuals would have engaged in pre-injury, either because they enjoyed them (using the computer) or it was part of their profession (cooking). The activities were important to the clients and through their involvement in them they began to realise their difficulties and develop signs of insight.

We did some keyboard tasks and I got her to type her name just her full name, just copying it and she could not do it and she was just so overwhelmed and so surprised because she is an avid computer user at home. So that really, so things like that, I think that is what is giving her the insight, it is actually the feedback of when she goes to do something and that gives her the insight. (Participant 5, 4:24)

We did a lot of cooking, she was a chef, so the only way for her to actually realise about the cognitive deficits was to do cooking with her and we made several things which turned out absolute disasters and only then did she realise that I can't actually go back to work, I can't actually cook for people because I am leaving shells in my mixture and beating them in. I tried to point things out along the way so it did not turn out too badly but you know it was only through that that she actually realised. (Participant 5, 6:24)

All the occupational therapists who described using this approach to **developing client insight** also described two further stages of the process which were necessary in order to *support the client* through this process and assist them in *reflecting* on their current level of ability in comparison to their abilities prior to the injury. These next two stages are described below.

Inter/action: Supporting the client

The experience of failure in everyday tasks was noted as being 'upsetting' (Participant 3 and 5), 'emotional' (Participant 3 and 4) or even as making the client 'angry' (Participants 4 and 6). The client, described above by Participant 5, who had engaged in the meaningful activity of cooking as this was part of her job, became upset directly after the activity.

It was quite upsetting for her because that was her life, she loved to cook and loved to entertain people and that kind of thing, but for her that was the only way that she really realised about the deficit. (Participant 5, 6:30)

Participant 8 compared this upsetting and emotional stage of **developing client insight** to a grieving process where clients began to accept the reality of their current situation.

As they start to move through the process they realise that this is actually real and I think that comes from the education but also that natural grieving process. (Participant 8, 7:22)

The occupational therapists recognised the need, at this point, to provide the clients with the support in order to move on to the next stage of *self-reflecting*. This support was offered in a variety of ways including *explaining* the cause of difficulties, *listening* to the client's concerns and offering more formal *counselling*. Participant 3, whose client had experienced memory failure in his attempt to return to work, helped him through his upset by *explaining* why these failures were occurring and what could be done to help.

I could tell he was a little bit upset after we had done that and I just told him why, so reinforced that this is what is happening in your brain, this is what is not working, and this is where we can help you. (Participant 3, 9:16)

Participant 5 identified how difficult this stage could be for both client and therapist and how she drew on a number of options for support including *listening* and the addition of more formal *counselling* when she felt the degree of input required fell out of her ability to manage. She also considered engaging some family support. This is an example of the overlap between the processes of **developing client insight** and **getting others on-board**.

I do find it really challenging but I just try to listen to people and say well what can we do about that, how can we help you to help yourself in that area and what do you need. And I just kind of put it back on them because all some people what to do is go (demonstrates crying client) and have a big cry and I am ok with that but sometimes I feel that it is out of my scope, and sometimes it really is, and I am ok with that and telling people that. I have to say, ölook I am not a counsellor or a psychologist but those services are available if you would like themö. If not and they are set, then we might continue maybe with the family on-board or a support person. I am happy to talk to a support person and say look this is how this person is feeling, because often the families don't realise. (Participant 5, 7:19)

Inter/action: Reflecting

Through the stages of experiencing failure, and being supported through the resulting upset, occupational therapists reported that clients began to ask themselves ‘*who am I now?*’ and *accepting changes* in their level of functioning, as described here.

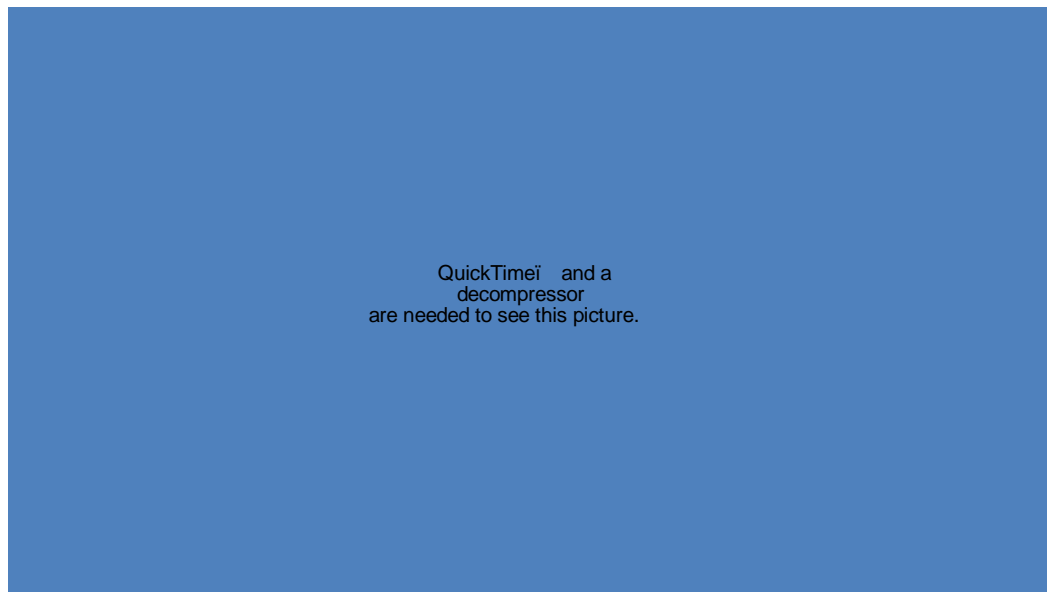
They become quite emotional because they realise that they are not the same person and then it is sort of that whole self-reflection of öok what do I do now, who have I become?ö (Participant 3, 15:27)

There is a bit of natural healing there as well that helps and also just acceptance, a lot of acceptance work, and looking at other people around them that have suffered a similar injury and thinking oh my gosh this is actually real, because I think most people come into it and they kind of think they are different, that it is not going to affect them the same. (Participant 8, 7:18)

It was at this point that occupational therapists felt clients had developed their insight and there was recognition of their memory impairments, and the impact these had on daily activities.

Figure 4 below summarises the inter/actions described thus far and demonstrates the process that the participants described through their interviews. The dashed line is a representation of those clients who fall under the condition of *mild injury*.

Figure 4: A Summary of the inter/actions



The impact of the conditions *severe injury* and *later down the track* on the process **developing client insight** was apparent in the interview with Participant 6 who worked with more severely impaired clients at the later stages of rehabilitation, over two years after injury, in a long-term residential unit. She described trying to use the process summarised in Figure 4 to **develop client insight** and the difficulties she encountered with one particular client who had never moved beyond the stages of *experiencing failure* and *supporting* him to manage his upset. This occupational therapist had therefore stopped this type of intervention and attempted to take an alternative route, which included actions such as *rapport building* and *focusing on what the client enjoys*.

Inter/action: Rapport building

When the process summarised in Figure 4 had been carried out and there had been no evidence of emerging insight, the use of *rapport building* was described by Participant 6. She discussed her use of encouragement through

humour and a *caring attitude* rather than **developing client insight** through re-visiting the same failures and upset over and over again.

The thing is definitely with him he will just respond to being, that encouragement, that cheerful and making jokes, you know, not making a big deal out of things and when things do go a bit wrong you make sure that they get the point that it is serious ðyou could really have got hurt there, and your mum would be so upset, and your sister would be upset and I would be so worriedð that kind of reminds them that lots of people are caring for them, even though they don't feel like it quite often. So it is sort of making sure that they get the point that it is important because everyone cares about them so much. We are really trying to help you. Yeah, I suppose it is showing that care and it is showing but you know ðthat is a bummer that you can not rememberð. (Participant 6, 17:27)

The strategy of *humour* was particularly important in getting her point across to the client but not making him feel bad about it, as that risked the rapport breaking down.

He goes on about ðI'll be fine, I can do it, I can do itð, ðlast week you did not do itð, you know, just making jokes out of things and reinforcing it. It is like having a joke with him and keeping it quite light but making sure that they get the point but not that they feel down about it because then he will get a bit shamed out and then there are more repercussions and he will get offended so the next day he is not even looking at you and he has got quite a bit of attitude. (Participant 6, 18:6)

The other important aspect of the *rapport building* was *establishing trust* within the client-therapist relationship. Here, Participant 6 described the importance of keeping her word in order to establish trust and get the client without insight to engage with her.

So you actually say this is what we are going to be doing and then you have got to really stick to it and if you can't stick to it then you have got to go ok well I am really sorry that this did not happen and it does mean a lot to me and it does mean a lot to you I know, it is a really important thing but I can not make it happen right now. You have to then make it happen as soon as you can in the next day or same day or something and you have got to give them a follow up time of exactly when that is going to happen so you can not just drop it and leave them hanging. They do not cope well with not knowing. You have got to have some kind of follow up plan. Like ðI know that did not happen but we are going to do it nowð otherwise you lose trust if you say something and it does not happen. (Participant 6, 18:23)

Once the rapport had been built and maintained this occupational therapist chose to then focus the client on accomplishing a desired activity and introduced EMAs as secondary to completing the activity.

Inter/action: Focusing on what they enjoy

With her *severely injured* and *later down the track* client, Participant 6 shifted the focus of intervention away from the impairments of insight and memory and on to participation in real life activities. Rather than highlighting failure and building insight, the focus became an activity the client enjoyed doing and external aids were naturally incorporated to achieve the desired outcome. The therapist had to choose an *interesting activity* in which the client was *wanting to achieve* some level of independence.

Here, Participant 6 talked about a client who really wanted to go shopping on his own and enjoyed heading into the town to wander around the shops but forgot how long he had been, what time he needed to be back or where he needed to get picked up.

It is definitely using something that they are already engaged with some kind of activity that actually interests them, there is some kind of point to it. If he wants a ride back and does not want to catch the bus back then he needs to be at a certain place at a certain time so it is a motivating factor. It has to be something that the person is motivated in achieving. You have to bring them back to, so maybe this [using the memory aid] is something that they do not particularly like doing but remember it is going to help you to do this. (Participant 6, 17:11)

Although these were the inter/actions used when the conditions *severe injury* and *later down the track* impacted on the occupational therapists intervention with clients. There was also a feeling, from some of the participants, that even if the clients insight into their memory impairments was not developing at one stage of their rehabilitation it did not mean that this should not be re-visited at a later time, even if it had already been tried and failed. Thereby, returning to the assessing stage and re-starting the process. Participant 4, who also worked with longer-term rehabilitation clients in the community, described clients whose insight was late to emerge and the need for them to get the right intervention at the right time.

There are things that they [the clients] say to me about how they are going and what they understand about their brain injury, they are just a million miles from where they were at (name of previous rehab unit). And it is almost like, well there was not any point in us actually banging our heads against the brick wall back then because they just were not really in the right time and place. But I guess the important thing is that they get the rehab when that insight is emerging and that is when you put in the more intensive community rehab. It is a shame it cannot be quite as intensive as the in-patient rehab, it is almost the wrong way around sometimes. You almost think well can I have more because now is the time, now we can *do* something with this person because they *understand* their brain injury. (Participant 4, 14:24)

Adding these extra components to the developing insight process as shown in Figure 5, results in the following diagram. This diagram demonstrates the conditions impacting on the process of **developing client insight**. The solid black arrows represent the clients who require the full process in order to develop insight in the *earlier stages of rehabilitation*. The dashed arrow shows the route taken by clients with more *mild injuries*, whilst the red lines highlight the process that is taken by the occupational therapists who deal with more *severely impaired* and *later down the track* clients

Figure 5: The impact of conditions on inter/actions

QuickTime[®] and a
decompressor
are needed to see this picture.

The inter/actions described in the sections above lead to one main consequence, which was established from the participants' interviews. The details of this consequence are summarised in Table 5 below.

Table 5: The consequences - an overview

Paradigm component	Categories	Sub-categories
Consequences	Seeing the point	Understanding
		Realising
		Willing to engage

Analysis of the data revealed that the consequences of the inter/actions described above were clients beginning to *see the point* of the memory aid training and therefore also beginning to buy-in to the EMA training program.

Consequence: Seeing the point

Seeing the point came from a phrase used by Participants 6 and 8, when they explained what it was they were striving to achieve with their clients as they progressed through the process of **developing client insight**. This phrase encompassed the ideas of clients having an *understanding* of their difficulties and comprehending the need to use an aid to assist them in remembering important things. When talking of *seeing the point* the participants also described clients who were recognising when they were forgetting things and *realising* that they needed to use a strategy of some kind to address this.

Insight is knowing that if they did this then this is how it would benefit them. If they don't have the insight, then they don't actually understand or comprehend that if they did something, if they did this process, or if they wrote things down, or if they used a diary, or if they use a calendar then it would benefit them in so many different ways. They just don't get that. It is kind of like a "well, what is the point". The, kind of, cogs in the head don't work to motivate them to actually want to do the activity so they lack the ability to see the point, "What is the point?" So insight yeah, insight of the point of why they would be doing it in the first place or it is the recognition after something has even happened that they don't even, some quite often realise that if they had have done that and they look back in the past they can not see, they are kind of like "oh, yeah, I forgot", it is really slow, they kind of get that they forgot "oh, yeah I did not remember that" but they only realise it when you prompt them to actually realise that it was a problem. (Participant 6, 15:1)

Once the clients saw the point of using a memory aid they were more likely to initiate the use of the aid and actively participate in the training program with the occupational therapist.

So the reinforcement really has to come from the client, they are going to have to have some kind of sense of wanting to initiate [the use of the memory aid] and if they find it pointless then there is going to be a lack of doing. (Participant 3, 8:8)

Participant 4 described this as an exciting time as the client now understands their brain injury, they have acknowledged that there is a problem and are *willing to engage* in memory aid training, learning new skills in order to manage their deficits.

Now we can do something with this person because they understand their brain injury. And it is actually quite exciting to see how people change and how they start to engage with therapists and make gains just purely because they have gained that insight, they haven't, their brain injury problems have not gone away but they are starting to learn how to manage them because they acknowledge them. (Participant 4, 15:3)

Returning to a statement from Participant 2, used at the start of this chapter, the clients who now *see the point* have ears that are *ready to listen* and are *willing to engage* in the memory aid training with the occupational therapist.

If you think that your memory is not a problem are you going to work with a diary? You are going to say, *talk to the hand*. If you have insight and you know you get in trouble due to your memory, your ears are ready to listen. (Participant 2, 14:12)

Summary

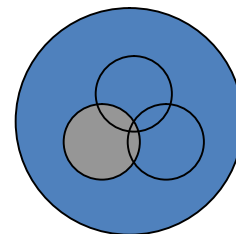
The process of **developing client insight** is a complex one with the clients' *severity of injury* being a condition that impacted greatly on the inter/actions taken by the occupational therapists. A further condition impacting this process was that of the *stage of rehabilitation* as clients in earlier stages were found to be less insightful than those who were later on in their recovery.

Under these two conditions the occupational therapists engaged their clients in a number of inter/actions included *educating*, *experiencing failure*, *supporting* and *reflecting*. When the *severity of the injury* was such that these inter/actions were ineffective the occupational therapists used alternatives such

as *building rapport* and *focusing on what the client enjoys*. Each of these inter/actions has been explained along with their relationships to one another and the conditions.

The range of inter/actions undertaken by the participants lead to the main consequence of *seeing the point*. It is at this stage that the occupational therapists moved on to the next process of **getting client buy-in**.

Chapter 5 – Getting client buy-in



The phrase ‘client buy-in’, used in the naming of this second process, was taken directly from six of the participant interviews (Participants 2, 4, 5, 6, 7 and 8). Client buy-in relates to the client’s level of engagement and participation in the memory aid training. All the occupational therapists interviewed identified that getting the client to actively engage in the memory aid training was of importance when establishing an aid that would be sustainable long-term.

The figure above, and to the right, has been included to remind readers of Figure 3 on page 46 which depicts the process **getting client buy-in** overlapping with the processes **developing client insight** and **getting others on-board**, and surrounded by the core process, **making it real**. Overlaps between **getting client buy-in** and the other processes will be highlighted through the chapter.

As with the previous chapter, the explanation of **getting client buy-in** will begin with a brief overview of the process and its component parts. This will be followed by a breakdown of each stage of the process using Strauss and Corbin’s (1998) paradigm components. Tables will be provided to summarise the categories and subcategories of each paradigm component.

Through the data analysis a number of conditions appeared which impacted upon the process of **getting client buy-in**, these included a variety of *client impairments* that were present following the TBI, the *rehabilitation service structure* in which the intervention took place, and the occupational therapists ability to *access* the necessary aids. Within these conditions the occupational therapists described **getting client buy-in** through a variety of inter/actions.

The first of these inter/actions was *doing the groundwork*, which incorporates actions such as *educating*, *discussing memory aids* with the client and *normalising* memory aid use. A further inter/action, *keeping it simple*, was used where the occupational therapists attempted to break down the complexities involved in memory aid use and fit the aid as best they could to the client’s current abilities. The final strategy was *making the aid meaningful*, which participants did through focusing on functional goals and finding a specific purpose for the aid that related to the client’s real life.

Through their inter/actions the occupational therapists achieved one main outcome, *incorporating the EMA into daily activities*, where the client was motivated and interested in the use of the aid and its potential for helping them return to previous occupations. Ultimately, **getting client buy-in** was seen as the therapists finding ways to get the client engaged in the EMA training such that they could begin to work together on solutions to the memory problems.

The conditions, inter/actions and consequences of the process **getting client buy-in** are summarised in Table 6.

Table 6: Getting client buy-in – an overview

Paradigm component	Categories	Sub-categories
Conditions	Client impairments	Psychological
		Cognitive
		Physical
Inter/actions	Service structures	Type of contract Organisational processes
	Accessibility	Organisational resources
		Funding for aids
		Client's budget
	Doing the groundwork	Educating
		Discussing previous use of aids
Consequences	Keeping it simple	Setting-up
		Normalising
	Making it meaningful	Fitting the client's abilities
		Developing key points
Consequences	Incorporating the EMA into daily activities	Breaking down complexities
		Focusing on functional goals
		Using purposeful activities
Consequences	Incorporating the EMA into daily activities	Motivated client
		Interested in promoting independence
		Excited by EMA itself

These paradigm components will provide the structure to each section of this chapter.

Condition: Client impairments

Table 7 below gives an overview of the conditions and associated categories and sub-categories.

Table 7: The conditions – an overview

Paradigm component	Categories	Sub-categories
Conditions	Client impairments	Psychological Cognitive Physical
	Service structures	Type of contract Organisational processes
	Accessibility	Organisational resources Funding for aids Client's budget

The most commonly discussed *client impairments* seen to impact the occupational therapists EMA training were *psychological* impairments. These included post-traumatic stress (Participants 1 and 4), anxiety (Participant 1, 3, 4 and 6), anger (Participant 4), depression (Participant 4 and 6), and grief (Participants 5 and 8). The impact of these psychological impairments was clients feeling overwhelmed and unable to actively engage with the occupational therapists or with any memory aid that they were attempting to use.

People who are depressed and really anxious or are under stress because there are a lot of other things going on, I just think that that is often one of the things that goes out of the window because their brain has become less organised and therefore it becomes difficult to be externally organised and that is what we are asking them to do so I think that is a big consideration. (Participant 4, 12:3)

We have had people when they are 5 days post injury, sometimes it is two weeks, 10 days, but it is quite early so there is still a lot of grieving and emotional stuff that is

going on before they can even grasp what [the injury] actually means. (Participant 5, 3:2)

Anxiety plays in there as well, overwhelms them quite easily so then they can't engage as well because they are too kind of worried and concerned, then the mind fills up with things too fast for them that they can't actually focus. (Participant 6, 10:4)

In addition to these *psychological* impairments there were also *cognitive* and *physical* impairments that impacted on the memory aid selection and training. The *cognitive* impairments that were most mentioned by the occupational therapists as impacting clients ability to complete EMA training were attention and cognitive fatigue. Three therapists noted they had to take these impairments into consideration when deciding on their inter/actions with the clients. For example Participant 1 stated:

You might look at other areas of cognition so you get a good idea of where their overall cognitive level was already before you start. So looking at what their attention is like, what their fatigue is like or are they going to be able to read and interpret what is on the memory aid. (Participant 1, 8:10)

Participant 5 considered fatigue to be a barrier to EMA training that impacted her clients' ability to buy-in to a group based memory rehabilitation program that she had put together for clients in her in-patient rehabilitation unit. She described two different clients who both struggled to engage due to their fatigue, along with other complexities in their conditions.

She would just be so fatigued. Which is another thing that I find really impacts on the memory strategies and how effective they are in being implemented by clients is what their fatigue levels are like on the day and, you know, yeah, just how receptive they are to what we are doing. (Participant 5, 2:18)

She had a lot of fatigue and well, her condition was quite complicated she had a lot of muscle rigidity. She would get into really weird postures on the bed and be like (demonstrates posture) and that would stress her out so I don't think she benefited as much from the group as she would have liked to. She was really keen to be in the group and participate but, yeah, if she was in pain or if she was tired or had limited energy, there were all kinds of things that impacted on her coming. (Participant 5, 15:3)

While discussing the clients with whom she had included in her memory group, and attempted EMA training with, Participant 5 also noted that more

clients were being seen with *cognitive* issues such as aphasia and apraxia, which made memory aid interventions more of a challenge.

And we are getting a lot more clients with severe aphasia as well and apraxia, which is another dynamic that is really quite challenging to work with the clients but also for them in terms of their communication. And also that link between what is actually the apraxia and what is the other things, like you know, for example memory recall, because when you ask them to do it they know and they are like *ōhí ō*, it is like they don't remember to do it but they know how to do it, you know. (Participant 5, 1:18)

As well as the *physical* impairments mentioned by Participant 5 on the previous page, which included rigidity, pain and difficulties maintaining posture; other *physical* barriers to memory aid use were evident in the participants' interviews, such as not being able to use the upper limb for writing or severe visual problems when reading (Participant 1, 12:24). These added complexities to the memory aid selection and training which the occupational therapists had to take into consideration.

In addition to the complexities created by the *client impairments*, further conditions generated by the structures, processes and resources of rehabilitation services within which the therapists were working impacted EMA training.

Condition: Service structures

The participants in the study worked across a variety of rehabilitation services ranging from post-acute in-patient rehabilitation to long-term residential and community support services. The nature of TBI rehabilitation in New Zealand is such that services are funded through the national Accident Compensation Scheme (ACC). Each rehabilitation service operates under an ACC rehabilitation contract with each *type of contract* having particular operational guidelines such as Concussion Service (July 2010) or Integrated Rehabilitation Services for Traumatic Brain Injury (January 2010). The occupational therapists considered the *type of contract* they were working under to be a barrier to their intervention with clients. Firstly, it was noted that the contracts were restrictive in terms of the time they allowed to work with the clients. Participant 3 worked under a Concussion Service contract and therefore

was designated six, one hour, sessions in which to work with her clients. She found this restrictive in a number of ways:

You can not go so much into detail and it is kind of working out what is their priority so like there is so much to cover in six hours, based over six weeks, so it is like öso what is your priority, is it your fatigue, is it your memoryö. So it has really got to be client based with that. As a therapist it is like öoh, we can do all this stuffö but realistically it is not going to happen in six sessions, six hours. (Participant 3, 11:23)

Participant 7 worked for a community rehabilitation service providing rehabilitation under the ACC Training for Independence (July 2009) contract. She found that this *type of contract* required her to measure functional change in clients and this could be difficult with the complex nature of the clients that she was seeing. In one case she felt that **getting client buy-in** took time but was not something that she could measure for the öfunderö (ACC). She felt that if she was unable to demonstrate functional changes she would be unlikely to receive permission to extend the rehabilitation period for her client.

For this chap who had the hypoxic injury, with ACC you have 3 or 6 month contracts and you are looking at how much progress you have made in that time, have you got anywhere. And for some clients it can be a really subtle shift like the only difference is you are actually getting a little bit more buy-in and they are actually more welcoming of you. That is really difficult to show in a contract where you are being asked to show a functional change, and for other clients you have actually made a shift, you know, they were not able to do this and now they are doing that. At the end of the day the decision is down to the funder but that is kind of, you know sometimes you are looking at real subtle changes and that is what we are not being funded for now. (Participant 7, 13:16)

Participant 3 also described difficulties in **getting client buy-in** as she was required to focus on particular aspects of rehabilitation as dictated by the ACC contracts. This limited her ability to set client-centred goals and make rehabilitation as meaningful as possible for the client.

I think if it is not their goal, so if they cannot understand the purpose behind what you are doing they are not going to be forthcoming to engage in what you want them to do. So I think that goes back to being client centred but of course working to the guidelines of ACC their goals have to be kind of fixed around a certain kind of domain or area í it is mainly based around productivity. So engaging back in work or getting back into some sort of study. You know, it is like that is already set and so that is what you need

to tailor when you are speaking with the client. So you kind of influence their goals in some ways. Which is not really good to admit but it is reality (laughs). (Participant 3, 14:29)

The condition *type of contract* demonstrates the funder's impact on the occupational therapists work but there was also a variety of conditions that were placed upon them due to the organisation for whom they worked. These conditions have been labelled *organisational processes* and had an impact on the occupational therapists ability to carry out their EMA training with clients. Participant 5 worked in an in-patient rehabilitation unit and found that *organisational processes* such as room bookings and the timetabling of clients frustrating. She was aware that some professions traditionally did not take part in the timetabling and saw clients as they were able to which, at times, clashed with her allotted time with the client.

We have our timetables so it is pretty good because if I have a session then I have that person for that time. It is more just the people who do not run on the timetable so the social workers, the nurses, doctors and dieticians and staff like that. Like yesterday I had a session with a lady at 3 and I go in there and the social worker is in there and she was like 'I just need a little bit more time' and I was like 'alright, I will come back in 10' but you know, fortunately I had the flexibility to do that yesterday but I don't always have that, you know, and the client has a timetable and everyone knows this so it is a case of well check what do they actually have on now. (Participant 5, 13:15)

Participant 6 identified that **getting client buy-in** was easier if the EMA fitted with the day-to-day *organisational processes* within her residential unit, such that the use of the aid could be integrated into routines like the daily orientation activities staff completed each morning with clients.

If it is a process within the company that has to happen then that tends to happen quite well but if it is not part of an agreed process then it is more difficult. If it is an individual basis kind of client then it is much more difficult. If it is an overall thing that everyone does then it is easier in residential. (Participant 6, 19:23)

The *organisational processes* and limits on length of stay were another condition under which the occupational therapists had to work; as demonstrated by Participant 5 who felt pressure to focus her therapy on the physical aspects of rehabilitation rather than the cognitive ones, in order to ready her clients for

discharge. She felt frustrated that she had to refer people on to other rehabilitation services to address the memory difficulties they were having, rather than addressing these herself.

The other thing is that now we are all having these conversations about how long people stay here and it is all getting shortened. So to try to fit in 8 sessions on memory, purely, when we have been told our focus is to get them home and get them home safely, you know, which definitely includes part of that memory training but what I find as a bit of a barrier is that cognition and speech deficits become secondary to physical. If people can walk and they can get to the toilet, it does not matter if they can not sequence the task or remember what they are doing or, you know, can not communicate. It is not that they do not think it is important but if they are physically well then they can be going home and getting out-patients for those other things. (Participant 5, 15:18)

Outside of the organisations' structures and processes there were also resource issues that impacted on the occupational therapists' clinical decision-making. These resource issues went beyond the organisations and incorporated the clients' own resources and the funder's ability to supply the required aids. This formed a condition on the occupational therapists' memory aid training that was one of *accessibility*.

Condition: Accessibility

Accessibility to different kinds of aids was identified as a condition to **getting client buy-in**, particularly when it came to selecting the most appropriate aid to suit the clients' abilities, goals and functional needs. *Accessibility* could be limited either through a lack of *organisational resources* or a lack of *funding for aids* through ACC.

Participants 1, 2 and 7 felt it was important for the clients to trial the use of an aid before either having clients purchase the aid themselves or applying for permanent funding through ACC. This was felt to be particularly important if the most suitable aid was a more expensive, electronic one. This opportunity was, however, limited by the *organisational resources*.

I guess we did not have the money or the resources available to provide the alternatives to the standard diary or check list or things like that, which has been a problem from time to time definitely. (Participant 1, 12:24)

I think it would be helpful if we had a range of things to trial with people but often what happens is we don't have the trial ones so we have to apply for funding and you kind of get a one off chance to get it right and, you know, it could be an expensive piece of equipment as well. I guess there is a little bit of hesitancy on my part to go down that path unless you are really sure it is going to work. (Participant 7, 5:4)

When applications for *funding* had been made to ACC, the occupational therapists found that the funding was unavailable or the process of accessing the funding took a long time, which meant clients had to continue their therapy input without the aid most suited to their needs.

Barriers, I guess sometimes it can be financial, I guess for some people electronic devices are actually best and getting funding for those is not easy and some people, they can't afford it themselves. I think that is a big consideration, a big barrier for some people. I think that is where we are lagging behind in New Zealand compared to some countries. There just has not been the investment in that stuff, yeah, because I think they can be really good for some people. (Participant 4, 12:11)

Just accessing the resources can take quite a while, you know it can take weeks and then it is all over by then. (Participant 6, 19:14)

If *accessibility* to the most suitable aid was limited through lack of funding from either the rehabilitation service or ACC, the therapist might look into the clients buying the aids themselves; but in most cases the *client's budget* was also limited. This, in turn, limited the type of aid available to low-tech aids such as diaries, notebooks and calendars, which suited some clients but not others.

You know what the problem is at the end of it. I think it is money. Because everyone can afford a diary but they can't afford all these wonderful devices so what happens in the end, you go back to calendars, you go back to diaries because they can't afford other things. (Participant 2, 5:14)

Money. They cannot afford it, they can not get to the shops. Or they have expenses and there is something else they want to buy. They do not have enough money to get the cell phone they want because they will not get the budget one. Yeah, money is quite often one [a barrier]. (Participant 6, 19:10)

Working within the conditions of *client impairments*, the *service environment* and *accessibility* of the most suitable EMAs, the occupational

therapists carried out a number of inter/actions or strategies to establish client buy-in with the EMA training. These inter/actions are summarised in Table 8 below.

Table 8: The inter/actions – an overview

Paradigm component	Categories	Sub-categories
Inter/actions	Doing the groundwork	Educating Discussing previous use of aids Setting-up Normalising
	Keeping it simple	Fitting the client's abilities Developing key points Breaking down complexities
	Making it meaningful	Focusing on functional goals Using purposeful activities

Inter/action: Doing the groundwork

Doing the groundwork encompassed a number of actions used by the occupational therapists to introduce the clients to the idea of using an external aid to support impaired memory function. These actions included *educating*, *discussing previous use of aids*, *setting-up* and *normalising*. Participant 7 talked of a time before she became aware of the importance of *doing the groundwork*. This was a time where she worked in an in-patient rehabilitation unit and her process of issuing a memory aid involved simply taking a diary from the store cupboard, issuing it to the client and telling them to start using it. She found this to have very little success.

Initially, the whole thing was that you gave them a diary, and you took one out of the cupboard, threw it at them, and no surprise, they did not want to use it. (Participant 7, 1:11)

Participant 7 indicated that from her experiences of working with clients in the community, carrying out actions such as *educating*, *setting-up* and

normalizing helped with **getting the client buy-in** to the EMA training and establish the most suitable aid with which to carry out the training.

The first thing you would do is rush in a say, õright you need to use a diaryö but you have to do so much groundwork before you get there and the diary is not always the right thing either. That was the other thing, you know, it was always a diary (laughs) and for some of our clients that is just not going to happen. (Participant 7, 6:27)

All the occupational therapists talked about providing some kind of *education* to clients regarding memory and the use of memory aids. Some of this *education* overlapped with what was provided during the previous process **developing client insight** (Chapter Four). However, this education differed in that the clients were aware that their memory was an issue and they were looking for solutions to solve their memory related problems; they were, therefore, already beginning to take an active role, and considering the idea of memory aid use.

The therapists did not have a standardised way of providing this education. It took a variety of forms and at times included the use of metaphors to explain complex memory processes.

The one that I think the most, they understand the most is the computer; your memory is like a computer. They follow that quite easily because they can understand that. (Participant 2, 15:21)

The therapists also used theoretical models to explain memory processes and where clients' difficulties lay.

We use the Braintree model, well it is actually Sohlberg's model. So we talk about attention first of all and give them education on that and then work our way up the triangle. (Participant 7, 6:6)

The education was done during one-to-one or group settings. Where Participants 2 and 5 found group sessions useful was in the sharing of ideas and strategies between the group members and development of peer support. Participant 5 described her group as having a focus on education, support and feedback.

There was definitely a big education component, like each session would be like a recap of the last session and what you did and we would often give them tasks to take away

and see how people got on implementing strategies, was it useful, was it not, any feedback. And then we would have a group discussion with some tasks and also some education on things like environment, the different strategies and it is all split up over the different days. (Participant 5, 16:11)

The education lead to the clients being able to select an aid that they thought was most suitable for them to begin the training with. Therefore it was the client making the selection, not the occupational therapist, this was perceived to help with **getting client buy-in**.

So you discuss and describe memory problems if they have the cognitive ability to understand. You go through all the steps of the memory problems and then afterwards, if you explain all the possibilities, and they can choose one [a memory aid] themselves and you can take it further with them. (Participant 2, 2:16)

I guess I have done quite a lot of education around what an external memory aid is and kind of said like these are the options you could use so what works for you? So it is kind of like giving, that was with my [name of work area] clients, it was kind of giving them the education and then giving them options and saying look what works for you? (Participant 8, 2:22)

Another aspect of *doing the groundwork* was the therapist *discussing previous use of aids* with their clients. It was felt that if a client used an aid prior to their injury, which worked for them, they were most likely to use this type of aid again. Participant 4 described the importance of this conversation with clients as she had experience of being wrong when assuming which aid might best suit a person.

I talked to him about his previous use of aids, a diary or how did he used to remember things in the past, before his brain injury did he have a way of organizing things. It turned out that he had used a diary in the past but not in the recent past but he was quite good with writing things down, he was quite comfortable with writing and using pen and paper which I was very surprised about given the person's background. So I think that is why, yeah, it was really good to talk to him about it rather than make any assumptions because if I had looked at him and looked at him on paper I would have perhaps not thought he would, you know, an ex-gang member who was a P-cook, you would not expect to be someone who was good with writing. (Participant 4, 3:14)

Participants 5, 6 and 7 indicated that discussing pre-injury EMA use was beneficial as they could then re-introduce the clients to aids that were already

familiar with. This reduced the need for the client with TBI and limited cognitive capacity to learn something new; instead they could rely on old memories of procedures and habits. There was also an aspect of *normalizing* the aid, as it was previously a part of everyday life and not something new that they had to now use because of their injury.

Like if they are going to go shopping what do they do? Do they have a list, do they just remember it, do they group it by fruit and veg, you know, how do they remember things usually in day-to-day life. And I try to use what they are familiar with, if it has been working for them, but if it is completely new for them and they are really impaired then it is totally like starting again. (Participant 5, 2:21)

If they have used a diary prior then they may use one again, so if it is a pre-injury habit it is more likely to happen hence it is really good to do a pre-injury history and get to know the person. (Participant 6, 20:16)

Whether people have used them in the past or not and how they have used them. So someone like a businessman might more easily adapt to using a diary for memory problems than someone who has never used one before. (Participant 7, 3:7)

Some occupational therapists reflected on the way they involved family members when gathering this pre-injury information on use of memory aids. Participant 1 explained that involving family members could help with getting a thorough understanding of what EMA options might be suitable for the client and this might make the client more willing to engage in the training.

I'd probably get more accurate, reliable information that would not just be from the client but from the family and friends as well and it might open up more avenues for different things that you could use. It might get the client more on board and he would be willing to give things a try. I guess it is just making sure that you have done that section thoroughly. (Participant 1, 16:10)

Setting-up the EMA was another part of *doing the groundwork*. The term 'setting-up' was used by three participants (Participants 4, 7 and 8) to describe how they interacted with the client and got them to consider and rehearse the practical aspects of using a memory aid. This involved a degree of client participation in the decision-making and participants tended to describe their interactions at this stage as 'working together' or 'doing it with them'.

The participants indicated that this stage of *doing the groundwork* was often impacted by the condition *client impairments*, which had to be taken into account when considering the practical aspects of EMA use for each individual client.

There is probably a stage of setting it up and you are doing that with the client so you are talking about 'how do you want to do this, what is going to be best for you'. Sometimes that person is not actually able to do that so you are actually saying 'this is what I have developed for you' and you are pitching it at that level. It totally depends on the client but ideally you are doing it with them. So, yeah, you are setting it up with them. So you are teaching them by explaining it, by getting them to do stuff, by getting them to explain it back to you, to try and make sure that they understand it, getting people to demonstrate it to you. (Participant 4, 10:30)

The participants talked about particular clients where they had to set-up an aid in a particular way in order to work around the *client impairments*. Participant 7 talked about the difference in *setting up* a diary for clients with severe injuries, and therefore reduced ability to attend and process large amounts of information, versus a client with a concussion who was more able to cope with these demands.

The other thing to think about is the layout of the page, do they want to be able to see the whole week or do they want to just see a day at a time and work on that. That often depends on the severity of the injury because people who have got a really severe injury often can only concentrate on one day, what they have got on today and what to do this morning, whereas some clients with concussion benefit from seeing a whole week and being able to see at a glance what they have to do throughout the week. (Participant 7, 3:24)

Participant 8 discussed a client who had difficulties with planning and organising his memory aid use and the need for her to spend time with him arranging his memory aid in a way that suited him best.

I have sat down with him and got a completely new folder and got him to come up with headings that he felt would best organise all the items and we went through it together and organised all that information so it was user friendly for him, it was not someone else's way of organizing things and that worked quite well. (Participant 8, 5:10)

Participant 7 described in detail the actions involved in *setting-up* with one of her clients who had chosen to use a diary as his memory aid. First she described having the client think through practical considerations, such as which memory impairments the diary would help to compensate for, how he would like to record items in the diary, how he would carry the diary, and where it would be kept.

You might want to use it with a to-do list or whether you want to use it as a journal to record what you have done, or whether you want to use it to record appointments that kind of thing. Just getting the clients to think how and why they are using the diary and what their specific problems are. (Participant 7, 3:1)

The other thing is looking at the size of the diary and how they are going to carry it. So are they going to have a big one that they leave on their desk and they do not take with them, probably not very effective, or are they going to have one that they are going to take with them, and if they are, do they have a bag, do they have something to carry those kind of things. And I found for a lot of the younger male clients the dairies that have a pencil or a pen in the spine of the diary are really effective so then they do not have to think about how they are going to write something down as well. (Participant 7, 3:13)

Second, Participant 7 described how she would get the client to practice particular aspects of using the diary and build this into therapy sessions. This included practicing techniques like writing and ticking off lists or encouraging the habit of referring to the diary at particular times. She could monitor the success of this through the practical activities that she set the client.

It is building into your sessions how to use it. So you are not just expecting them to go away and use the diary. I have had things where I have asked clients to phone the office at a certain time on a certain day and leave a message that has been left in their diary so maybe every day there is a different time with a different message. Just getting them in to the habit for looking at the diary or if they have got appointments making sure they are in the diary. (Participant 7, 3:6)

The final aspect of *doing the groundwork* was the effort made by the occupational therapists to *normalise* the EMA for the client. This was done in a variety of ways including, as mentioned earlier, using an aid that the client had used previous to their injury and therefore was not out of the ordinary. Another

form of *normalising* was participants modelling EMA use themselves, thereby making the use of an EMA seem ordinary.

I mean I always use my diary and I always model using my diary with clients and always say to them, öit is not just the people with memory problems that use it, I would be lost without itö. If they ask can they have an appointment next week I will always get my diary out and use it, and constantly talk about memory and the fact that it is not fool proof for any of us. (Participant 7, 6:3)

The other form of *normalising* used by the occupational therapists was personalising the aid for the client by having them shop for the aid of their choice and make the decisions about aid selection, or personalize certain aspects of the aid such as how it was organised or accessorised. This is shown in the following examples with the participants discussing how personalising can be done with a variety of aids including mobile phones and memory files.

I think a part of that was getting the right lanyard for him to carry his mobile phone on. I had not quite realised how the lanyard part was such an expression of your individuality. So instead of shopping for a mobile phone we ended up shopping for the lanyardí That was a huge part of actually getting him to carry his phone about with him. (Participant 7, 11:13)

I organise it initially for them and, as I say, as it starts to get old I change it up and make it a lot more personalized because they don't know until they try how they want it to be organised. But you definitely need to have that personal factor, it needs to be relevant to them and to work for them, and it is really funny, I am just reflecting on this now, but every person has been different, the things that they need and the things that they like have been different, you know, like one client just really wanted a big chunky file that had a lot more space and a lot more organisation and then I have had another client not so long ago who just wanted it really concise and small and as little information as possible. (Participant 8, 5:18)

By *normalising* or personalising the aid in this way the occupational therapists aimed to achieve a greater level of client buy-in with the use of the aid, and ultimately this assisted the client in meeting some of their memory goals such as recalling what they had done or needed to do in the day, as expressed by Participant 8:

I am hoping that I will achieve a greater level of participation for that person in using that particular memory aid and that effectively they will be able to, they will be able to use it to remember their daily events. (5:29)

Inter/action: Keeping it simple

Keeping it simple was a strategy that the occupational therapists used to encourage client buy-in. *Keeping it simple* involved the therapists ensuring that the education they completed, the discussions they had, the aid that was selected and the use of that aid, were all at a level suitable for the client within the condition of the *client impairments*. An element of *keeping it simple* used by the occupational therapists was using aids that the client was familiar with and in this way using previously learnt skills, procedures and habits rather than attempting new learning. This inter/action was explained in *doing the groundwork* where the occupational therapists established the aids a client was familiar with by *discussing previous use of aids*.

Keeping it simple was important to the therapists, as they did not want to overwhelm the clients with aids that were too complex for them to use. They felt this was likely to lead to failure and therefore reluctance to use any aid long-term. Even if the therapist was certain the client could cope with the demands of an aid they had to take on board the clients' perceptions of their own abilities and pitch the aid at this level.

Not making the task too big that it is actually beyond their [the clients'] interpretation of what they can manage, even if you think that they can and they actually can. If they do not think they can do it then you are building them up, there is too much pressure and they are more likely to fail. (Participant 6, 17:17)

The ways in which the occupational therapists kept it simple included choosing an aid *fitting the client's abilities*, where possible *developing key points* to give to the client as written instructions and *breaking down any complexities* of an aid to enable the client to cope with the information processing. Participants 3, 4 and 6 discussed components of each of these strategies.

Participant 3 made decisions about *breaking down any complexities* of the aids she gave to clients in the community in order for the aid to *fit to the clients' abilities* and help increase their engagement in everyday life.

So when I am using memory aids I am really trying to fit it around them [the client], like their abilities, trying to be beneficial for them, try to give them some sense of independence because a lot of them say, you now, I just can't remember what I am doing and obviously if you are trying to increase their engagement, well using the memory aid would probably be a perfect way to do that. Yeah, so it is just knowing, when do you set the whole big picture and when is that going to work and when do you break it down into tiny little steps and use daily planners. (Participant 3, 5:17)

Participant 6 *breaks down the complexity* of diary use for one of her clients in a slightly different way by altering the lay out of the diary. Instead of a daily book-style diary she simplified the aid by creating a week-to-view style planner, which could then go on the wall.

If it was not a daily diary then I would maybe do something slightly more basic like a one week timetable thing recording the pattern of things that they do, I do a weekly planner basically and have it up on the wall. Divide it and then put in appointments. (Participant 6, 8:3)

Participant 4 described the strategy of *keeping it simple* for those clients who had chosen to use a diary as an EMA but had cognitive difficulties and could not necessarily process and manage full diary use alone. She described *breaking down* the use of a diary into one or two specific purposes and then *developing key points* that she wrote down for her clients in order to make the diary simpler to use. Participant 4 also established a routine for the client in the use of the diary.

Some people need very set guidelines, they need everything written out for them like the steps of how to use a diary and they need to have a real routine about it. So you have got to look at the function, how independent is that person, how much are they going to be able to do themselves. So, yeah, taking into account their cognitive abilities. So some people will be quite high functioning and can use a diary in quite a complex way and other people need it to be much more structured and much more simplified out for them and they need to have a constant routine for how they are using it to be able to do it. (Participant 4, 2:21)

By *keeping it simple* the occupational therapists created aids for their clients that were user friendly and met the needs of the client without becoming an added burden on their cognitive, physical or psychological abilities.

Inter/action: Making it meaningful

All of the occupational therapists talked about the importance of *focusing on functional goals* that had been developed with the client, and practicing the use of the EMA by *using purposeful activities* in order to establish and maintain client buy-in. The main purpose of this focus on goals and purposeful activities was to make the training meaningful to the client. Participant 7 made this point after discussing the amount of groundwork she had carried out with a particular client in order to understand what was important about memory aid use to him.

I guess that little tangent that I just went off on was about what is *meaningful* for them [the client]. I guess that it is not about what is meaningful or important for us but trying to find some way of finding what is meaningful for them on some level. (Participant 7, 11:24)

Some of the occupational therapists related the use of the memory aid to the higher-level goals that clients had set themselves at the start of their rehabilitation such as being able to return home or get back to work. The therapists broke down these larger goals into component parts to show how the memory aid could assist with achieving aspects of these.

Take it back to their goals and hopefully one of them is about memory (laughs). öWell you know in the beginning when you talked about goals and you said that this was really important to youí ö Yeah, I just tie it back and often we get those really big goals, öI want to go homeö, öI want to walk againö, you know those are the two most common goals. So it is like öin order to go home and to be safe at home and do some of those things you want and need to be able to do we need to look at thisö and mostly I have not had anyone totally decline and not want a bar of it. (Participant 5, 11:3)

Other therapists set more specific memory goals with their clients that were related to the memory impairments experienced by the clients and could be directly met through the use of the memory aid they were learning to use. Participant 1 gave an example of this when discussing a client she worked with who had the very specific memory goal of remembering to take his medication on time. Because the client could see that a memory aid was a way of achieving this goal, the therapist did not have any difficulty with the client **buying-in** to the memory aid training. He began to trial the use of the aid after the initial set-up

and achieved a greater level of independence prior to going home and having to manage his medications on his own without help from a nurse.

We talked about the pros and cons of forgetting your medication and taking it on time and stuff like that and I had to go through with him what all his meds were as well. He had to know everything. So I did lots of education around that to begin with and then I sort of said 'hey I have created this chart, I have got an idea, do you want to listen to it?' and he was quite open minded about listening to my suggestions. (Participant 1, 4:1)

He had to sign, because it was the RN in the house or staff in the house that would of course give him the meds, but he had to sign on the chart when he had taken them and he had to train himself to check his chart. (Participant 1, 2:21)

Focusing on functional goals set by the client also had an impact on the type of aid the occupational therapists selected to use. Some aids could meet a goal better than others.

A cell phone perhaps would not be that great for working on some goals like trying to remember where you put your glasses before you went to bed, I mean that is no good is it. So I do not think that there is going to be one aid that is going to be able to address every goal you can think of. (Participant 2, 15:14)

When the clients were unable to see a link between their functional goals and the memory aid there was a lack of buy-in, and training tended to be unsuccessful, as in a case recounted by Participant 3, who talked about a gentleman whose main goal was to return to work. Trying to base her EMA training on discussion, testing and other activities had no impact on **getting client buy-in** with the memory aid as he was unable to see the point of the training.

So we have really talked about memory, we have done tests with him that show him his memory is really poor but for him I don't think it is his goal. His goal is to go back to work so that is why he is not really using any of what we are telling him. So we are coming to this point with ACC that we are going to have a case conference and seeing where we are going to go forward with him. So he is probably not the best example to use but he is an example of somebody who is not using what we are doing so it is just not working, no matter how many different strategies we use, they have not been implemented. (Participant 3, 3:19)

When therapists discussed their EMA training with clients *using purposeful activities*, those activities that were of interest or related to aspects of their home, social or work life, were the preferred medium for training. It was found that client motivation was linked to achieving these activities and therefore the client would buy-in to memory aid use in order to accomplish the desired activity. This is where **getting client buy-in** is strongly linked to the core concept **making it real**. Participant 6 demonstrated this point when discussing clients with mild brain injury who lived at home and want to go back to work, and those who were based in a residential service, had more severe injuries and multiple impairments, whose goals were to recall when their visitors would arrive.

Some are real motivated to get back to work so therefore they even push way beyond what you would recommend in order to get themselves back faster, if that work ethic is there, if it is not there in the first place and they don't actually want to get back to work in the first place then they drag it out. (Participant 6, 10:1)

If they want to remember the activities that are important or of interest to them. They might be motivated by it [EMA use] if it involves family, õoh, I can't wait for my family to comeõ then they will remember the family are coming, you can not even wipe it out of their brain. (Participant 6, 9:6)

With more severely impaired clients the use of repetitive practical sessions of the aid, *using purposeful activity*, helped the client to recognise the correct use of an aid and the benefit it could bring to achieving a positive outcome.

It is like practical sessions over, and over, and over, and *over* again because, if you think they are not accustomed to that, you think how many times you have to *convince* them to use it. (Participant 2, 5:27)

Although all the participants talked about *focusing on functional goals* and *using purposeful activity* in order to engage the client in the EMA training, there was no specific point during **getting client buy-in** that could be identified as the best time to introduce client goals or purposeful activities. Participant 1 was the only therapist who appeared certain of the stage at which she would introduce goal setting with a client. This came after assessment, establishing the level of insight and education. Knowing the client goals and the activities in

which the client needed to use the aid then assisted Participant 1 in selecting the most appropriate aid.

I definitely always start with assessment and education. Now that assessment could be a standardised measure like the Rivermead or it could be checklists and I always try to get as much information as I can into their own insight into their impairments and what they have noticed and get them to identify their goals as much as they can. Then always lead on to some education about what memory is and how the impairment came about and the different things they can do about it. Then, I guess trying to define what memory aid they use often depends on their goal. (Participant 1, 7:16)

The three inter/actions *doing the groundwork, keeping it simple and making it meaningful*, were taken by occupational therapists in order to establish client buy-in with the EMA training. The consequences of these inter/actions was an aid that began to be incorporated into the clients' everyday activities. In some cases clients began to generalise the use of the aid to assist them in managing their memory impairments within their everyday home, work and social lives. The consequence *incorporating the EMA into daily activities* and the categories and sub-categories related to it are summarized in Table 9 below and described in detail in the following section.

Table 9: The consequences – an overview

Paradigm component	Categories	Sub-categories
Consequences	Incorporating the EMA into daily activities	Motivated client
		Interested in promoting independence
		Excited by EMA itself

Consequence: Incorporating the EMA into daily activities

In the absence of any definitive measures, the occupational therapists judged the likely sustainability of an EMA by observing the consequences of their training including the clients' use of the aid, how quickly they adopted it, and how willing and motivated they were when *incorporating the EMA into daily activities*. Participant 5, for example, would decide how sustainable an aid was going to be by looking at subjective measures like how well the client

ögrasped itö, öused itö, öknew itö and öliked itö, if they knew öit was going to be good for themö then they would use it (Participant 5, 19:29).

Signs of a *motivated client* were noted in a variety of ways but generally included the client showing initiative or effort in the use of an EMA, not being a passive learner but taking an active role, and taking responsibility or öownershipö of the aid.

I donö think it [motivation] came from me, it came from him. He was annoyed about his memory problems and so it was my job to help him solve that problem. Yeah, the motivation did not come from me it was his motivation. It was very much a team effort, it was working together. (Participant 4, 4:19)

Well, they have taken ownership of it, they are self-initiating to use it, if they are not self-initiating then it [sustained use] is not likely to happen but if they are self-initiating and they can give examples of how it has benefited them then that is a good factor. (Participant 6, 21:19)

In some cases the clients were not only interested in *incorporating the EMA into their daily activities* as taught to them by the therapists, but also began to demonstrate how they were *interested in promoting their independence* by adapting the aid and generalising it to other situations outside of those taught to them in formal therapy sessions.

She would often come back, one of the ladies, and she would have made it her own öI took this idea and I have done this with itö and she really made it her own and that was really encouraging because these are just tools and these are ideas. (Participant 5, 16:28)

The participants talked about clients they had worked with who had become increasingly interested and, at times, excited by the use of the aid and how it could be used in daily life to promote their levels of independence. These tended to be the clients with the milder injuries and therefore the conditions of *client impairments* were not seen to impact on their ability to anticipate how the aid could meet their more abstract everyday goals in life. Participant 6 described her clients in the concussion clinic, who had fewer issues with cognitive or physical impairments, who had worked through the process of memory aid training with her and could now see the benefits of adopting it within a number of daily living areas.

They really responded well to the diary but they had enough awareness that they would actually benefit from it and then they could, initially but sometimes they didn't but with a little bit of practice and they were a lot more open to suggestion and they would give it a go because they found that the state they were in at the time, that at that point they knew they had to get better, they would try anything. So they were really open to strategies, so yeah, so they were quite happy to give it a go and then they started to realise the benefits of it and then they could see their progress because initially they couldn't, all they could see was 'I am screwed and what am I going to do now?' (Participant 6, 5:7)

If they show some excitement about the fact that they are using it and they can show some consistency that they have used it for a number of weeks or months and they seem interested and they see it is helpful for them. (Participant 6, 21:22)

This interest was different when observed in the clients with more severe impairments who struggled to see beyond the aid itself to the bigger picture of how the aid might improve independence. These clients were *excited by the EMA itself*. Their excitement was based around having something new that they felt was a good fit with their abilities and their self-image. Participant 6 discussed a client with a severe injury and long-term impairment whom she was working with in her residential service. This client engaged well with a mobile phone as things involving electronics and technology excited him.

He really engaged with the phone at putting numbers in and we could call him or text him. It was a very helpful thing to be able to contact him and for him too. He learnt how to use the mobile phone really fast so memory aid wise learning the electronics and learning how to enter things and that kind of memory practicing that was really good. (Participant 6, 4:1)

A similar experience is described by Participant 7 who talked about her younger clients getting excited by new, modern gadgets that made them look good in front of their friends, and as a result were more likely to use the aid longer term.

If they are excited about some kind of new toy or some new phone that is coming out then they are more interested and likely to use it lots more if they can show it off to their mates, if it is going to make them look good, yeah they quite like that idea, they are like more engaged. (Participant 7, 20:18)

The consequence of *incorporating the EMA into daily activities* was particularly impacted upon by the condition of *client impairments*. Although clients with both mild and severe impairments could become *motivated* to use an EMA, it tended to be for different reasons. The clients with the milder injuries were interested in how the EMA could promote their independence in their functional goals and could think of ways to adapt the aid to meet their ongoing needs. The more severely impaired clients were often more interested in using the EMA because it excited them to have a new modern gadget, or something that they could show other people and suited their self-image.

Summary

Getting client buy-in is about the therapists finding ways to get the client engaged in the EMA training such that they work together on solutions to the memory problems and establish long-term use of a suitable memory aid.

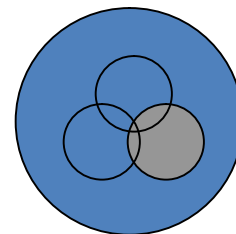
This chapter has explored the process of **getting client buy-in** by firstly describing the conditions that impacted upon the process. The condition *client impairments* had a significant impact on this process. Other conditions included the rehabilitation *service structures* within which the therapists had to work and the struggles with *accessibility* to the necessary aids.

Within these conditions the occupational therapists attempted to get client buy-in through a variety of inter/actions which included the essential first step of *doing the groundwork*, followed by *keeping it simple*, where the occupational therapists broke down the complexities involved in EMA use and fit the aid as best they could to the client's current abilities. The final strategy was *making the aid meaningful* by focusing on functional goals and finding a specific purpose for the use of the aid that the client could relate to.

Through the above strategies, the occupational therapists hoped to achieve one main consequence, for clients to *incorporate the EMA into daily activities*. This indicated to therapists that the EMA was likely to be sustainable long-term.

The following chapter examines the process of **getting others on-board** which is the third of the overlapping processes.

Chapter 6 – Getting others on-board



Getting others on-board was the third process to emerge from the data. The phrase ‘getting on-board’ was used by five of the participants (Participants 1, 2, 5, 7 and 8) and describes a process in which the occupational therapists began to recruit other people, such as rehabilitation staff members, family and employers, to assist in completing the EMA training with the client.

One condition that impacted on this process was the *properties of the staff*, such as their reliability, consistency and understanding of memory aid use. Other conditions included the *family set-up* and the amount of *therapist’s time* available to communicate with other people.

The main inter/action that the occupational therapists used in this process was *recruiting*, a word used by two of the participants in the study (Participants 4 and 7) when it came to summarising what they did. Recruiting took the form of *educating* the individuals, asking them directly for help, getting them actively *joining* with the rehabilitation journey and general *relationship building*.

The consequences of having other people on-board were *regular reinforcement* of the training components by all those involved, getting *feedback relating to real life* use of the aid in everyday activities, and *sustained use* of the aid once the client left the rehabilitation service.

These conditions, inter/actions and consequences of **getting others on-board** are summarised in Table 10 on the following page. As with previous chapters this chapter is structured using the paradigm components, starting with an explanation of the conditions.

Table 10: Paradigm components of getting others on-board

Paradigm component	Categories	Sub-categories
Conditions	Properties of staff	Reliability
		Availability
		Consistency Understanding
	Family set-up	Family support Availability
	Therapist's time	Billable time Time to educate staff
Inter/actions	Recruiting	Educating Joining the training Relationship building
Consequences	Regular reinforcement	Repeating Prompting Normalising
	Feedback relating to real life	Feedback on use at home How the aid fits with real life
	Sustained use	Continuing rehabilitation providers Carry-over with natural supports

The conditions – an overview

The three conditions influencing this process are the *properties of staff*, *family set-up* and *therapist's time*. As the conditions indicate, other than the occupational therapists, the two main groups that were brought on-board to assist the client in the memory aid training were the rehabilitation staff and the client's family. Each of these groups brought their own set of conditions. These conditions are summarised in Table 11 on the following page.

Table 11: The conditions – an overview

Paradigm component	Categories	Sub-categories
Conditions	Properties of staff	Reliability
		Availability
		Consistency
		Understanding
	Family set-up	Family support
		Availability
	Therapist's time	Billable time
		Time to educate staff

Condition: Properties of staff

The occupational therapists would ask other staff within the services they worked to assist them and the client in the memory aid training. The staff involved differed depending on the service that the therapist worked in, but the staff most discussed by the participants were either support staff, such as therapy assistants, rehabilitation assistants and health care assistants, or other members of the therapy team, such as physiotherapists and psychologists. Referrals to alternative therapy teams were also discussed, particularly at times when the clients would transition from in-patient rehabilitation units to home.

Members of rehabilitation staff had certain properties that the occupational therapists discussed as either barriers or enablers to the clients training. The first of these properties was the *reliability* of the staff members in carrying out the training activities that had been set by the occupational therapist. Some of the therapists described situations where they would set plans for support staff to prompt and encourage memory aid use with the client in their rehabilitation setting at certain points in the day. An example of this could be seen in the interview with Participant 8 who regularly set clients up with a memory diary and tried to get her whole team on-board in assisting the client in using the diary to record events during the day. She then prepared structured activities for support staff to review the diary at the end of the day to aid the clients' recall of the events.

Generally it involves the whole team being on-board, reminding the client what they need to do, but on top of that it involves an actual activity of sitting down and going through that information because it is all very well writing it down but to go through it again at the end of the day and review what they have done and actually talking through that sensibly and logically and helping them make sense of that information and then organizing it is a whole other activity. So that takes you know a good 15-20 minutes with a staff member in the house and so an activity, a rehab activity, needs to be written up so they know how to do that, and that is monitored by the therapists on a weekly basis. (Participant 8, 3:27)

The therapists experienced some support staff who could be relied upon to complete the tasks at the right times and provide good feedback on the client's performance; other staff were not so reliable. This issue of *reliability* led to inconsistencies in the training received by the client and frustration for the occupational therapists, as noted by Participant 1 in her post-acute rehabilitation service.

There is not enough consistency, you might get really great use in the morning with a good morning staff and then in the afternoon and evening it just does not happen. I have probably found that most times, when it is most successful, the clients are more driven or not as impaired because they are able to make use of their strategies without any other input from any other staff which is really sad and goes against everything that you are meant to be doing at [name of rehab unit]. (Participant 1, 13:21)

Participant 6 also talked of her frustration at the lack of consistency in the training she put together for clients in her residential service.

With staff, particularly, it is more like trying to build it into their [the client's] routine, it depends on staff as well. Some staff miss it and don't ever do it and other staff it is very much, they will say 'oh yeah I have done that yep, we are going to do this and do this next' and there are some staff that are really consistent with it and will prompt the client regularly every morning after their shower or before breakfast, some time around that morning routine. (Participant 6, 10:15)

As well as the *reliability* of staff in carrying out training activities with the client, they also had to be available at the right times. Staff *availability* was reported to be difficult due to the demands of other clients who required their basic care needs to be met. This was seen as being out of the control of the staff and part of the day-to-day reality of working in a rehabilitation unit.

We have a lot of clients that really need a lot of care, hoisting and those kind of things so then the memory aid is not really going to be on their list of importance so it goes to that second place. So that is not their fault, it is not an attitude problem. (Participant 2, 12:1)

Availability issues were also caused through the daily roster of staff shifts and staff shortages. Some participants gave examples of training that had worked well, when they had got staff on-board who were available at the right times for the client.

And I had to get the house staff on board as well. Luckily there was one regular one who worked there Monday to Friday during the morning shift. And because she was really good that made a big difference as well, she was more reliable. (Participant 1, 4:8)

Participant 6 tried to arrange activities for the client when she knew staff would be available in the same location as there were other daily activities scheduled for that time such as meal preparation.

In the afternoon while staff are, well staff and hopefully client are cooking dinner. Then that would be quite a good time for him to sit down at the table as the staff were sort of in the same area and they would sort of talk while they prepared. So if it is a time where the person is engaged and in that location anyway so environmentally it is kind of easier as they are around at that time anyway so it is kind of built in and gives them something to do. So you have to think about what time of the day is the most easiest and when is it going to most naturally occur. (Participant 6, 10:24)

When other therapists became involved in the EMA training the occupational therapists found they had to liaise closely with these people to ensure *consistency* in the information and support that the client was receiving, otherwise this could lead to clients becoming confused or overwhelmed by conflicting messages from the professionals around them.

I used a colour coding system, then that worked and it was really beneficial for him but then what happened was that he was also seeing a psychologist at the same time and she tried to implement a program for him so like, you know, I am using the weekly planner as a memory guide but hers conflicted with the one I had done so he did not know what to follow and then that really just threw him out of kilter so he did not know what to do, he got really lost. (Participant 3, 4:7)

This was particularly important for those occupational therapists, like Participant 3, who worked in the community and did not monitor her clients on a daily basis. She found that getting the psychologist on-board helped to reinforce *consistency* in terms of memory aid use for her clients.

So ideally, I think, in that situation it would have been good if the therapists had said "this is our goal" and she would be like well "this is our goal" and kind of communicated a little bit more effectively just so that he could have still been in this routine and it would have been working for him. (Participant 3, 10:20)

This type of inter-disciplinary communication was also noted to promote *consistency* for the clients in the in-patient settings. Participants 2 and 5 described the need to ensure other professional staff were providing the same consistent message regarding memory aid use to the client throughout the day. For Participant 5 this involved educating the psychologist, nurses and social worker in the strategies required, and for Participant 2 it was the physiotherapists and the activity coordinators who could then integrate the use of the aid into their scheduling with the client. The occupational therapists in the in-patient settings also tried to promote *consistency* in memory aid use when it came to the point of transitioning the client from their in-patient service to out-patient or community services. They would refer on to these other therapy teams and give details of the EMA training so there was ongoing monitoring and adaptation of the EMA by a professional with a similar background to themselves, thus providing consistency in the training as the client moved through the services.

Yeah so, you know, I feel like I can hand over [the EMA training] to out-patients and be like, well this is what we are working on and you guys can just review it, see how they are going and check it is working for them. (Participant 5, 11:17)

A lack of *understanding* was also noted by the participants as contributing to staff failure to get on-board with the EMA training. Difficulties with *understanding* were reported in both support staff, who would neglect to carry out the training activities with the client, and other therapy staff, who would interrupt training sessions or plan sessions that conflicted with those of the occupational therapists.

You might set up an aid like a checklist, a diary or something and the client really needs the rehab staff in the house to support them with it, while they are learning and practicing, and they just don't do it. It's because of lack of time or lack of an understanding of why it is important. I am not really sure what else, it could be many things but, yeah, it just does not happen. (Participant 1, 13:5)

I have become a lot more assertive now! But I do talk to people a lot more now and you just have to otherwise it [interruptions] just keeps happening, and it will keep happening but I just try to educate people around why it is important that we have these sessions. (Participant 5, 14:6)

When the staff who were assisting the client with their memory aid developed an *understanding* that the EMA could have potential benefits for them, as well as the client, such as the client requiring fewer prompts to complete activities during the day, they would become increasingly interested in getting on-board with the memory aid training. Participant 6 noted that a particular client would become agitated if not orientated to the day and time and the memory aid training served a purpose in preventing the staff from having to deal with his agitation. Staff were, therefore, encouraging him to use the aid as it reduced the likelihood of them having to manage his outbursts.

So they can constantly go back to that [the EMA] because throughout the day he will be saying that he needs to do something and he will be off track so it gives him and the staff, so it is of valued interest to both parties really to keep him orientated so they can keep him on track. It is then less likely that there is going to be outburst or frustration and things. So I suppose it helps both people. When it is not a necessity and it does not actually help the staff or the client then it does not tend to be done. (Participant 6, 12:4)

Other than the staff within the rehabilitation services, the main group of people that the occupational therapists involved in **getting others on-board** was the clients' families. These family units varied and the structure or set-up of the family group was a second condition that impacted on the process of **getting others on-board**.

Condition: Family set-up

When the participants were discussing getting families on-board with the EMA training they talked of involving the clients' partners, parents and wider family members. *Family support* varied across clients. Some clients had

particularly supportive families who were keen to get involved in the rehabilitation. Other families were unable to be so supportive. Some clients did not have any family to support them. Participant 1 described clients who had particularly supportive family who would be present regularly and get on-board with the idea of using a memory aid to help the clients in their daily life.

I think really good and motivated family and friends that at the weekend or when they come to visit really get on-board with the goal and the concept of using the memory aid. Often you hear families referring to how the memory aid could be used in their life back at home, you know when you go to the movies at the weekend or you want to go back to work because of course they have a good understanding of what the person's life was like before and that really helps to reinforce why it is important to practice at [name of service] even though it is not their real life it still has a link to their overall goal of getting back to their life as it was before. (Participant 1, 14:4)

The support of families could depend on the ability of the family to understand the concept of the memory aid and what the aid was meant to achieve, their ability to take on-board the information being given to them and learn the skills to help encourage the client. Participant 2 talked of the need to consider this family function before attempting to get them on-board.

What I find sometimes, it is depending on the family function. I think so. If you have a high functioning family the handover is better but if you have a family that really does not have the ability to buy-in to it themselves you are going to have anyway more of a problem even on the level of the family. (Participant 2, 8:22)

The case was similar for one of Participant 5's clients who had a husband who provided very practical support in some areas but struggled to understand the need to get involved with the memory aid.

So I find with family, if they are not on-board and really understand what is actually happening and why they need to be involved then that carry over is quite hard. It is like that person needs that other support to help implement whatever strategies have been recommended, you know. I mean he is very good with the practical stuff and the logistics, you know, he has had a ramp made and rails installed and that kind of stuff but when you need him, this is not where he thinks he needs to be. (Participant 5, 5:16)

Having family *available* to get on-board with the interventions was another condition for the occupational therapists. Some clients did not have

family nearby and therefore had to be able to manage alone. This caused Participant 6 difficulties with the moderately impaired clients she used to see in the community who would have benefited from supportive family around them.

The moderate ones from (name of service), some of those did not engage in using a diary. I think it seems, especially if they are based at home, and there is no one at home prompting them to do it then they generally don't, I have not found that they have the motivation or memory to even do it. (Participant 6, 7:27)

The participants reported there were times where the family was there to offer support but were not *available* at the times that the occupational therapists could interact and engage with them, often due to work commitments.

I find it really challenging when their spouse works full-time, that is when it can be. Because the times when I have found when it really works is when they work different hours and they can actually come along to some of the therapy sessions so they know where things are at and that kind of thing and they can actually be a part of the rehab process as well with that person which I think is really helpful but it is not always possible. (Participant 5, 8:12)

To meet this challenge the therapists in the in-patient setting had to plan in advance and set-up meetings with family when they knew they were able to attend, or they might hand over information to night staff to pass on to the family when they arrived in the evening. If therapists were working in the community they would leave written information for the family.

Sometimes [there is] a partner, but normally that partner is at work. If they are a younger client so say from 16, yeah age 16, then normally they would have a parent there or someone sitting in, otherwise when you are seeing them one on one I just use written, so I will write down the key points of the session and then I will write down what I want you to follow up on. That is for the client but also for their support person so that they can be like ok this is what we did in the session and this is what I am supposed to do. (Participant 3, 7:22)

Attempting to involve families and other staff during the process of **getting others on-board** called for the occupational therapists to allow time in their schedules to meet, talk and build relationships with these people. This formed the third condition of *therapist's time*.

Condition: Therapist's time

Participants discussed time limitations and the impact these had on getting staff to understand the needs of the client training and the amount of one to one time they could spend with families. Community therapists discussed the impact that their contracts with ACC placed on their time to engage with families. There was a desire to spend more time with the families and contact them via telephone if they were not at home when the client was being seen but this was difficult as the therapist, or company they worked for, would not be paid for this time. Participant 3 discussed this in terms of managing her *billable time*.

If the support person is not there it is not like I then go and make a telephone call to their partner and say 'look this is what I need you to do' and a lot of that is just about time. So that would be an ideal situation, if we were allowed to have a little bit more time but working on ACC, you know, they are quite strict. So you have 60 minutes, you spend 60 minutes with the client and the rest is non-billable. (Participant 3, 7:27)

So you are trying to make the most out of your day. Making sure that it is billable. So as a therapist who did not have that pressure of course you would ring the family and say 'hey this is what we have done, this is what I want you to follow up on and this is the goals that we have set this week can you please reinforce it' but, no, I can not say that I do that. (Participant 3, 8:2)

The participant interviews also revealed a common dilemma in affording the *time to educate* other rehabilitation staff in the use of the memory aids and how to encourage use of the aid with clients. They felt this was difficult to manage when they had multiple demands placed on their time. Participant 2 talked about this in detail, describing the need for her to juggle many work demands and her inability to continue to lead the other staff and 'push' through the memory rehabilitation to completion.

I think we can get side tracked sometimes because if you work here there are so many components that you work on that sometimes it might happen with me that you work so hard on memory and then something else comes up for that client and you get side tracked. I would say it is easy to happen. So if you want to work on memory you have to focus so hard on pulling it through. If other priorities come along they side track you and then it stops. And I have found sometimes, it is not only with memory 'you push, and you push and you pull everyone through but if you stop everything stops. (Participant 2, 13:21)

Time had to be provided to the staff members, whom the participants were attempting to get on-board, in order for these staff members to be clear on the use of the memory aid, the prompting required for the client, and the goals that were trying to be achieved. The participants also had to make time to get feedback from staff members and discuss how to grade the activities in order to encourage more client independence. This was an issue for the participants working in both in-patient and community settings.

What is sometimes really hard for the therapist is, it is like having a second client because you have to follow up, you have to say how is it going? So it is extra work on top, if that makes sense. (Participant 2, 13:4)

So it is teaching the living skills coach öök this is the system that I am going to try with this person, can you please prompt them and then we will reduce the prompts and we will see how much we can reduce the promptsö. (Participant 4, 7:12)

Despite this time pressure the occupational therapists still made considerable effort in **getting others on-board** as they recognised the positive long-term implications of this process. They used a number of strategies in order to get others involved, which have been conceptualised as an inter/action of *recruiting*.

Inter/action: Recruiting

The inter/action of *recruiting* incorporated a number of activities that the occupational therapists used to get both staff and family members on-board. Although only mentioned by one participant (Participant 3), these activities also applied to employers during a client's return to work program that incorporated the use of EMA training. The summary of inter/actions can be seen in Table 12 below.

Table 12: The inter/actions – an overview

Paradigm component	Categories	Sub-categories
Inter/actions	Recruiting	Educating
		Joining the training
		Relationship building

Only two therapists mentioned a specific point in their EMA training where they would begin to recruit others and get them on-board. Participant 2 thought that this was best done towards the end of the rehabilitation stay in the unit, when the client was preparing for discharge.

I think as they near discharge to hand over to the family but I don't see the need initially for the family in the beginning. Later, yeah. But, you know, you can give them the info, if they have an appointment and they know to go along in the diary or how you would like them to note it in the clients diary so that might be a good point to start. The family for one education session, if they use a diary how would you like them to fill in the diary with the client. (Participant 2, 7:17)

Participant 5 thought that she should 'firstly find out if it is going to work for [the client] and they are going to use it before saying to [the family], hey look and offering them some education regarding the use of the aid and ways they could assist the client in their training (9:5). The other six therapists merged their process of **getting others on-board** with **getting client buy-in** as they saw the positive effects of the reciprocal relationship between these two processes. **Getting others on-board** complimented **getting client buy-in** due to the reinforcement and relationships that were built.

Recruiting was felt to be important in overcoming some of the barriers to EMA training, particularly that of limited formal therapy time, and also to promote positive consequences such as repetition of the training components and sustainability of the EMA.

Because working in the community it is sometimes quite hard to gauge if it is working. You know it takes a while to gauge and then you run out of time. So you need to make the most of the time you have got. So you do need to recruit other people in on it. (Participant 4, 7:24)

Recruiting was done in three different ways. *Educating* was the most commonly discussed strategy for recruiting people. The therapists working with other rehabilitation staff would set up the activities to be performed with the client and try these multiple times with the client themselves before passing this over to the staff. The activities in which the staff members were being educated were different depending on the goal of the EMA use. The examples here reflect two very different ways in which staff were involved in memory aid training,

each requiring a different sort of education to be carried out by the therapist. There were times when the therapists were educating the staff in ways to assist the client in their use of an aid within a functional activity, and then there were times when staff were educated about standing back and not prompting the client to increase his use of the EMA rather than maintaining dependency on the staff members.

For example with cooking or shopping, take shopping, we will go with them for a month or a few sessions and set everything up. Like with setting the shopping list and the menus and then you hand everything over. So then we have a good discussion with the rehab coaches and it will be the same for memory. So from the moment you did determine what kind of strategy you want, you will get them on board then to reinforce it because we don't have time. (Participant 2, 5:2)

I talked to the staff in the house and told them not to remind him of his appointments and he was to remember himself. And I was like purposefully like putting stuff on his timetable like "meet me at this time in this room" and I was not going up to his room to find him, he would have to come down and find me. So I did little tests like that and tried to have the staff not prompt him, and that took a little while to train the staff, of course. (Participant 4, 5:15)

Educating family was done in a similar way so there was no difference in the level of detail that therapists would go into for either family or staff. Education to either group involved discussing the use of the aid, the goals it aimed to achieve and the level of support required. The condition of *family set-up* had an impact on the amount of education that could be provided and to who this could be provided by.

Talking to them, educating them and asking for their help, that is what I have done and of course it depends on the family as to whether or not they follow through with that. I mean most are pretty good. (Participant 1, 14:17)

Participant 3 was the only occupational therapist who regularly worked on return to work programs with her clients. These programs incorporated EMA training if this was appropriate for the client. Participant 3 discussed education in the work place with colleagues, and managers. These were her alternatives to rehabilitation staff and families as these were the people available to her and her client within this context.

You have already met their manager, supervisor or their team leader or some of their work colleagues. So you are in the office when you are assessing them anyway and you can say, 'oh, look, this is what she needs to be using to help with this or that' and the team leader normally follows through with that. (Participant 3, 12:13)

The occupational therapists described moving *educating* beyond the level of purely information giving and discussion with families, into more practical activities where they involved the families in using the aid themselves or got them *joining the training* with the client and assisting with the training exercises and EMA use. Participant 5 thought this was of value as it gave the client and family something to share and a common goal in the rehabilitation process, 'it is important for the person that they actually just have someone to share their journey with that has known them previously' (Participant 5, 8:9). Participant 8 discussed a specific example where she had the family *joining* in with the use of the 'modified diary' during the weekend leaves that her clients would take to their homes as they prepared for discharge.

Getting families on-board with that, especially if they are going home. I have sent people home before with their modified diaries if they are going on weekend leave and getting them to prompt the clients to be recording and sometimes families have been writing in there for the client to go back over later and recall which has been quite cool and has worked well. So there is quite a lot of training and coaching involved, not just for the client but also for the family and the other people involved with the modified diary. (Participant 8, 4:6)

Participant 3 would also have colleagues of the client returning to work *joining* in with the memory strategies that she put in place. In this way she encouraged, not only the client, but also other workers to build new work habits that supported the client's impaired memory function.

There is a lot more people within the workforce that can help out even like with taking phone calls, asking people then to put it in a email just to confirm that you have got the points right and kind of just a reinforcement of what you have just talked about, and it gives them more time rather than just a conversation on the phone and having to blurt out answers which could be wrong. (Participant 3, 12:17)

Relationship building, outside of the EMA training, was also seen as being important in order to establish a good rapport with clients' families and explain the rehabilitation processes in general. The participants' perception was

that this was not only down to the occupational therapists themselves, but felt to be a necessary action for all the rehabilitation staff to engage in and present as one cohesive unit, thus bringing the family on-board as part of the team.

I think it also depends... what kind of relationship they [the therapist] establish with the family because that is really important, not that other members of the team can't have a relationship because obviously people connect with different people. In terms of how I go about it, usually I meet the family member either during the day, when they first come in. A lot of people when they know that their family member or loved one is being transferred here then they will come in on the first day just to help settle them in or they will come in later that night and in that case the night staff will meet them. We try to always organise our meetings so that someone can attend, whether that is early morning or late in the afternoon, to try to accommodate as best we can. (Participant 5, 8:21)

By *recruiting* other people into the EMA training, the occupational therapists aimed to achieve a number of outcomes including *regular reinforcement* of the EMA on a day-to-day basis when the therapist was not around, *feedback* in regard to the use of the EMA in real life situations, and *sustained use* of the EMA when the client was no longer involved in rehabilitation. The consequences are summarised in Table 13 below and explained in detail in the following sections.

Table 13: The consequences – an overview

Paradigm component	Categories	Sub-categories
Consequences	Regular reinforcement	Repeating Prompting Normalising
	Feedback relating to real life	Feedback on use at home How the aid fits with real life
	Sustained use	Continuing rehabilitation providers Carry-over with natural supports

Consequence: Regular reinforcement

Reinforcement was a word used by four of the participants (2, 3, 6, 7) when explaining why they carried out the process of **getting others on-board**. Although the other participants did not use this exact word they all talked of the need to have family or staff *prompting* the client, *repeating* the instructions regarding the use of the EMA and encouraging the client, which were then grouped together during data analysis to form the more abstract category *regular reinforcement*. Within this category is also *normalising*, this is where the families or staff integrated the use of the EMA into the clients' lives such that its use became a normal everyday activity for everyone; therefore reinforcing the EMA for the client as they saw everyone around them engaging in the same behaviour.

Repetition was an important consequence of **getting others on-board** for the occupational therapists, as they were aware that clients with brain injury, and particularly those with memory problems, needed regular repetition of instructions in order for these to be learnt. They were unable to supply this level of repetition in the time they had available to work with the clients. The therapists also felt that this *repetition* was best done when clients were engaged in their daily activities thereby reducing the need to generalise the EMA use from the therapy session into real life situations.

We don't always have the time and that is where we need the staff to reinforce it because the one off session with us is not going to work so we have to have the staff to buy in and they need to pull it through for us because they need to practice it daily. It does not matter what strategy and external aid you are going to use you have to practice it daily with a client and as an OT you know we don't have time so the rehab coaches need to support us. (Participant 2, 4:14)

Well if you have got a memory problem and you are asking someone to remember to use something, yeah, it needs to be reinforced and it needs to be at the time. We only go once a week for an hour most of the time and it is not enough. It is far more successful if you have got someone being prompted everyday. (Participant 7, 10:27)

Participant 7 recalled two particularly impaired clients whom she had attempted to establish EMA use with over a period of three months; but this training had not progressed as she had hoped. She therefore recruited the help of

supported living coaches who could be with the client on a daily basis and provide repetitive learning opportunities for them.

I have had a couple of hypoxic clients more recently where we have had supported living involved and it made a huge difference because it is the same thing. You have someone there everyday who is prompting them and they are learning by repetition. Which they can actually do, whereas, if you are leaving them with a memory aid and coming back in a week, or three weeks later because they have forgotten twice that you are coming and it is just not going to work is it? when it comes to someone who is that damaged it comes down to the everyday prompting into a routine and it is amazing at how well someone can do with that. (Participant 7, 12:29)

The *prompting* clients got from others to use their EMA was another aspect of the *regular reinforcement* that was achieved through **getting others on-board**. This *prompting* was not as specific as the repetition described above. *Prompting* came in a variety of forms from both staff and family, and also from work colleagues in Participant 3's case.

You have already met their manager, supervisor, team leader or some of their work colleagues? and you can say, this is what she needs to be using to help with this or that and the team leader normally follows through with reinforcing that. (Participant 3, 12:14)

Making sure that the other people working with them know they have a diary and are prompting them to use it as well, they have got it with them, putting their appointments in it. (Participant 7, 4:13)

The people who have got good family support always do better and we know that but partly because, yeah, when we are using an aid, if they can reinforce it at the time, everyday, it is much, much better. Other team members, if you have got someone who has an OT, a physio and a speech therapist then you know they are going to get at least three prompts a week to use their aid. (Participant 7, 10:15)

Although the participants did not use the word *normalise* there were descriptions of occasions where the family as a whole had got on-board with the use of a memory aid. This then became natural behaviour within the household and the client used the EMA as everyone else did. Participant 4 described an occasion where the whole family involved themselves in the use of a whiteboard that she had put in place for the client on their return home from a rehabilitation unit. Her initial concern was that this appeared a little 'institutionalised',

however, she saw the client begin to use the whiteboard more spontaneously as a result.

I can think of a client who was discharged from (name of rehab unit) and the whole family uses the white board (both laughs), it is like in the centre of the living room and it has got all the kids school stuff and then the client's stuff and it is actually really good, you know it is really functional for everybody. (Participant 4, 7:27)

As well as providing a variety of ways to regularly reinforce the memory aids that had been put in place, the occupational therapists found that **getting others on-board** provided them with a way to get *feedback* on how the client was managing to use the EMA in real life.

Consequence: Feedback relating to real life

This feedback could be *feedback on use at home* and came from family when the client was at home or on home leave from a rehabilitation unit. It could also be from other people such as employers who could give the therapists an idea of *how the aid fit with real life* situations. Participant 4 noted that this was particularly important with an EMA where there was no physical evidence of its use that could be reviewed when the therapist saw the client.

I think as a measure of feedback because once you are in the community you might only see a client once a week, if that. I was not asking [the family] to prompt or help necessarily but it was saying to them 'look this is what this person is meant to be doing, can you watch if they are doing it or not' because I guess with some memory aids you are not going to have physical evidence as well. You know, some people could be using a to do list on a white board quite well but it gets rubbed off and then you don't see it. (Participant 4, 7:4)

It is getting them to use it in real, everyday life and then when you are having your sessions it is reviewing that and seeing how it is going and getting feedback from the other people that you have got to buy in to the system as well, yeah. (Participant 4, 11:14)

Employers, yeah, often employers, often getting them to see how the aid fits in with the person's job and what they actually need to be doing, and making sure that the diary is working in with that and is not an extra thing to do. (Participant 7, 10:22)

This feedback was valuable to the therapists as they could then revise the EMA training where they needed to, depending on where there had been success or failure in EMA use at home or in other real life situations.

[The family] may be able to say they used at this time and it as good for that but it was not so good for this, maybe we could look at something different for this part of whatever it isö. (Participant 5, 9:7)

Consequence: Sustained use

The final consequence of **getting others on-board** was *sustained use* of the EMA long-term. It is not practical for occupational therapists to be working with clients over long time periods. Invariably, the organisation they work for or the funding body that contracts their services sets the rehabilitation timeframes. This limits most therapists to a working duration of, at the most, 6 months with any one client, usually less. At this point the therapists must decide if there is further progress that can be made through referrals to alternative formal rehabilitation providers or if carry-over of the progress made can be sustained through the use of natural supports such as family and friends.

All the participants were aware that whatever memory strategies they put in place they would not be there in the long-term to ensure that the strategies continued to be used by the client. Some participants had the option of requesting funding for *continuing rehabilitation providers* so when one therapist stopped they were able to hand over to another such as in the case of a client transitioning from in-patient rehabilitation to community or out-patient services. The in-patient therapists felt more comfortable in these situations that they had set the client up with an EMA that could be monitored and adapted as required by a professional in the community who came from a similar background to themselves.

The community therapists would just be able to pick up, like [the client] already had something started so they could pick up where I left off and adapt it for what he was doing in the community and help him with that. (Participant 4, 4:24)

Most of my clients, like if they have those kind of deficits, I would be referring them to out-patients so I would put that in my report and they will get followed up. (Participant 5, 11:12)

The community occupational therapists, who were then taking these clients on, found that it was easier to carry on and sustain the use of an aid that had already been introduced in the in-patient setting rather than having to start from scratch.

Normally they have come from an in-patient place, not so much a hospital but more rehab then usually they have the diary and they know how to use it a bit better which kind of helps a lot more. And they have kind of set all their rehab up already. So they have a rehab folder, they know, they kind of get the gist of it a little bit more. So if we are just seeing someone just in the community it is like you are going to have to start from scratch with all this but you are on restricted hours so yeah it is kind of a little bit trickier. So people that have come from in-patient kind of already know what the therapy is going to be about. (Participant 3, 16:27)

By **getting others on-board** who were a natural part of the client's future the therapists aimed to achieve some *carry-over with natural support* in place. Participant 2, for example, invited the family of the client in for an education session towards the end of their rehabilitation stay for the specific reason of ensuring that the use of the EMA would 'continue' once the client left her service.

If the client still needs, they always need prompting, most of them so if you want to continue [the family] need to know how to use and how to prompt the client. Because if they are not going to do that it is going to fall over anyway and they are going to stop using it. (Participant 2, 7:28)

When no family or natural supports were available, either due to complete lack of family support or the inability for family to attend therapy appointments along with the client, the occupational therapists were concerned that this carry-over would be unachievable and there was less likelihood of achieving a sustainable memory aid for the client.

Because there is no reinforcement, the families are not supportive, it is really unlikely that [the client] will start implementing what we have tried to put in place with memory aids and things like that. (Participant 3, 2:20)

I do think the reinforcement in the community is probably one of the important reasons why things do not work because it is just not there and if the family are not there at the

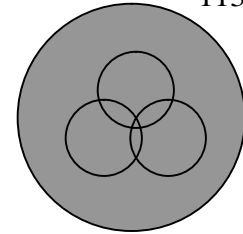
appointment then that is really up to the client but if they have got motivation issues or initiation problems then who is there to tell them what to do? (Participant 3, 18:6)

Of the three consequences described in the process of **getting others on-board**, *regular reinforcement* appeared to be the most important to the participants as they felt the repetitive training and prompting would lead to increased independence in the use of the aid. *Feedback* from family was particularly useful when clients were trialling the use of their aids at home and the therapists needed some idea of how things had gone in real life situations. A further consequence of *recruiting* other people into the EMA training was an increased likelihood of *sustained use* long-term.

Summary

The consequence of *sustained use*, along with *feedback relating to real life* and *regular reinforcement* were achieved during the process of **getting others on-board**. This process involved occupational therapists in the one main inter/action of *recruiting*. The therapists described a range of barriers and enablers that surrounded their inter/actions and impacted upon the consequences, these became the three conditions: *properties of staff*, *family set-up* and *therapist's time*.

This is the third process, which alongside **developing client insight** and **getting client buy-in**, comprises the three processes that sit centrally in the figure of concepts at the start of each chapter, and described on page 46. The chapter that follows describes **making it real**, the core process which surrounds the other three.



Chapter 7: Making it real

This chapter is divided into two sections. The first describes the core process **making it real** as a single process, as has been done in previous findings chapters. The later section of the chapter then explores the reasons for **making it real** being chosen as the core process and gives details of its interaction with the other three processes **developing client insight**, **getting client buy-in** and **getting others on-board**.

The diagram above is now completely shaded to indicate that **making it real**, as the core process, encompasses and travels through the other three processes. The links between all four processes, **developing client insight**, **getting client buy-in**, **getting others on-board** and **making it real** will be discussed towards the end of this chapter.

All eight participants discussed the need for the memory aid training to be made *real*. This was expressed in a variety of ways including the need for the training to be based in the clients *real world* (Participants 1, 6, & 7) and for the training activities to be based on the clients *real life* activities (Participants 1, 4, 5, 6 & 8) or *everyday life* (Participants 3, 4, 5 & 6). The need for EMA training to be *real* stemmed from the idea that this would create a training program for the client that was *meaningful* (Participants 4, 7 & 8) and *purposeful* (Participants 2 & 7). It also assisted the therapists to establish an aid that would fit with the activities that a client was to perform when they returned to their real lives and therefore be a useful and habitual tool to that individual rather than an added task or burden. This, in turn, was believed to create sustainability of the aid over a long-term period.

As in previous findings chapters, this chapter will discuss each paradigm component, condition, inter/action and consequence individually. An overview of the **making it real** paradigm components, their categories and sub-categories can be seen in Table 14 on the following page.

Table 14: Making it real – an overview

Paradigm component	Categories	Sub-categories
Conditions	Environment	Community In-patient
	Personal characteristics	Age Employment/Education Social/cultural
Inter/actions	Creating real life	Simulating real life environments Replicating everyday activities
	Being in real life	Community settings Returning to work
Consequences	Sustained use	Fitting with clients real life Integrated with routine Using long-term

The conditions impacting on making it real – an overview

The conditions that were identified as impacting on **making it real** were the rehabilitation *environment* (i.e. hospital ward, rehab unit, client's own home) and the *personal characteristics* of the client, which included dimensions of the client such as their *age*, *employment* and *social/cultural* group. These conditions are represented in Table 15 below.

Table 15: The conditions – an overview

Paradigm component	Categories	Sub-categories
Conditions	Environment	Community In-patient
	Personal characteristics	Age Employment/Education Social/cultural

Condition: Environment

The *environment* in which the EMA training took place was perceived by participants to impact the process **making it real**. As previously discussed, the participants came from a range of clinical areas including post-acute rehabilitation units, slow-stream rehabilitation services, community rehabilitation teams and residential units. When discussing how they could make EMA training real for their clients the participants tended to talk of two distinct environments, *in-patient* or *community*, that either enhanced or hindered the process of **making it real**.

Making it real was perceived to be easier in the *community* environment where the client could engage in their usual everyday activities, rather than in the *in-patient* environment where the clients were surrounded by the structure of the service. This structured *environment* included regular routines, timetables on walls and scheduled rest breaks, which were not a part of regular life outside of this environment. The staff within the *in-patient environment* also provided structure and prompting through their own routines and supportive caring habits. This *in-patient* structure was thought to reduce clients' need to use their memory skills due to the incidental support around them; therefore **developing client insight** into how their memory impairments would impact on their lives became difficult. There was also thought to be a lack of incentive for clients, within these structured and routine environments, to initiate the use of a memory aid due to the surrounding external prompts.

They come from a very sheltered hospital or rehab environment where you know everything is, you know, lunch is at 12, tea is at 5, afternoon tea is at 3, everything is so structured for them that there is not much challenge for their memory in those kind of situations. So if you are going to do memory aid training in those situations, you are going to have to try and replicate the real everyday life. (Participant 4, 9:5)

I think getting them involved in real, meaningful activities is a lot harder to do in an in-patient setting. I think it is much, much easier in the community. I do think that is something that [occupational therapists] should do automatically but I do think it depends on the environment you are trying to work with them in as well. I mean when I worked in the sub-acute setting it was much harder and you are almost trying to get them to use the diaries before they leave to go home and that is probably too early for a lot of our clients. (Participant 7, 15:27)

The EMA training that took place in the *in-patient* environment included the use of specific aids to meet the clients' needs within such an environment, but were not suitable for use at home. Participant 8 discussed this issue when describing the limitations of her 'modified diary' when it came to discharge.

I think [a modified diary] works really well in a very structured and routine environment like this with everyone telling you to write things down but this is not normal life. Depending on the client, I mean a very, very structured thinking person might adapt really well to that and like to use it but the majority are not. So I think it works like in the very acute stages while they are here but in the long term I think there would be other things that would be more effective. (Participant 8, 9:20)

In-patient therapists tried to solve this problem by taking clients out of the units and into the *community* where they could begin to engage the client in real life activities relevant to their lives at home.

I usually start to trial it on the ward and then see about ultimately trialling it at home as that is where they are going to be discharged to so you not only have to make sure it works here but also that it works in a real life environment, not in a fake environment like here. (Participant 5, 10:27)

For clients who were already at home and having the therapists come to see them within their natural, *community* environment, there was a perception that **making it real** was easier to achieve.

If they are out in the community, as part of your training you want to be working with them in real life situations and using scenarios like 'I am going to ring you up and make an appointment for this time and we will see how you have recorded it and we will see if you get there on time and got to the right place' you know all those kind of, actually testing someone out and doing it repeatedly, giving them lots of practice in using that particular aid and seeing how it actually works, for the client and for the therapist just to get a good gauge on how it works. (Participant 4, 9:11)

Regardless of the rehabilitation *environment*, in which the occupational therapists worked, there was an agreement that the *community* environment facilitated the process **making it real**. This meant that therapists working in the *in-patient* environments had to create opportunities similar to those that would be experienced by their clients in the 'real world'. As well as taking into consideration the *environment* in which the training was occurring, the

occupational therapists also had to account for the *personal characteristics* of their client.

Condition: Personal characteristics

When **making it real** the participants discussed the need to consider *the sort of person* the client was. This included characteristics such as *age, employment or education, and social/cultural background*.

Age was the most common characteristic that participants discussed. The *age* of the client appeared to give participants some indication of the type of aid that would best suit them in their *real life*. As Participant 4 explained, 'you might not give a mobile phone to a 65 year old because they would say oh, that is not me' (8:11). This was in contrast to statements about younger clients and their ability to embrace new technologies that could be adapted to become memory aids.

I think, with the iPhone age, especially when working with younger clients who are used to using cell phones and things like that, they can definitely be utilizing that [as an EMA] and linking it back to real life. (Participant 8, 8:13)

In addition to *age*, participants considered other aspects of how an aid might best fit with a client's life including the kind of *employment* a person had. The activities and setting involved in a person's *employment* appeared to dictate the most practical aid for selection and the type of training that would take place. Participant 4 explained this by using examples of a 'big burly builder' and someone employed in the 'corporate world'.

I sort of discovered that it was important to take into consideration before even recommending an external memory aid to someone was actually to look at the type of person they are, how old they are what kind of job they might have done before and just look at the sort of person that they are and what is actually going to be realistic for them to use. So, you know, if you have got a big burly builder, you are not going to get a big burly builder walking around a construction site with a big heavy paper diary. He might use a little notebook in his back pocket or he might use a cell phone. Or someone who has been in the corporate world might just use technological things and they might be returning to work and therefore focusing on what they can use on their computer or on their phone and things like that so that is going to be much more appropriate for them. (Participant 4, 1:20)

In the examples above, the *age* and *employment* status of the clients predicted the type of aid that the occupational therapists might select for the clients to begin their training. Participant 7 made the point that similar aids may be appropriate for people with different *employment* or *education* backgrounds, however the training that takes place would be very different.

If you have someone who is a businessman and an executive in a company, what you are asking them to do and to remember is at such a different level to someone who is 15 who has dropped out of school. And you might use exactly the same aid but use it in a very, very different way. (Participant 7, 15:23)

These conditions not only affected the selection of the most appropriate aid but also the content and structure of the training that would be carried out.

The other *personal characteristics* of the clients that participants described included the clients' *social/cultural* backgrounds. These dictated the acceptability of certain aids within the client's society. Participant 3 demonstrated the importance of using an aid that was natural to the client and his/her social group.

So we tried to do the weekly planner and he would need reinforcement for that but then I always just noticed that his phone was always with him he was trying to text, he'd text me. So I was like well, it is more functional for you to use something that you just naturally use everyday, so his cell phone is with him everyday, than it is to take this planner around. You know he is quite young, he doesn't want to be with his friends and saying 'oh, hang on I just need to check what I have been doing' and pulling out a calendar. (Participant 3, 9:26)

Taking the *age*, *employment/education* status and *social/cultural* background of the client into consideration during the process of **making it real** was thought to be as important a consideration as that of the client's level of impairment.

I have worked across from people who have had a very mild concussion to people with a very serious injury and across different socio-economic groups as well so from people who, like a young Maori teenager, say through to someone who was a businessman before they had their injury and I think that is where the biggest difference is in what you use and how you use it and how you introduce it. (Participant 7, 1:18)

The *personal characteristics* of a client, along with the *environment* in which they were participating in their EMA training, formed the two conditions influencing the process of **making it real**. Under these conditions the participants described a number of inter/actions that they employed in order to make EMA training real for their clients.

The interactions in making it real – an overview

Through data analysis the inter/actions discussed with the participants in the study were abstracted into two distinct inter/actions: *creating real life* and *being in real life*. These two inter/actions were particularly dependent on the condition of the *environment* in which EMA training took place; for example, if a client was situated in a rehab unit then real life opportunities had to be *created* for the client to gain insight, and then tested out and practiced using their memory aid. In the community setting the client was in a situation of *being in real life*; therefore opportunities were taken by the occupational therapists to have the client engage in real activities within the home, social or work context in order to train them to use the aid. These inter/actions and their subcategories are represented in Table 16 below and explained in the sections that follow.

Table 16: The interactions – an overview

Paradigm component	Categories	Sub-categories
Inter/actions	Creating real life	Simulating real life environments Replicating everyday activities
	Being in real life	Community settings Returning to work

Inter/action: Creating real life

Involving the client in real life scenarios was perceived to be one of the best ways to ensure that the EMA training suited their needs. It was also thought to be a way of **getting client buy-in** as it became more obvious to the clients how the aid could be used in their lives; rather than talking about memory aid use, they could actually experience it and establish the benefits for themselves.

You can do like a practical session because I think, as you know for yourself, if they hear [about the EMA training] it will go in and then out (gesturing to in one ear and then out the other) but if you do a practical somewhere along the line it might become more real for them. (Participant 2, 7:9)

When the participants were trying to establish what was *örealö* for the client it was very individualised and based on the client's previous life roles and activities. Establishing what was *örealö* was done during initial assessments where the therapists would collect information on the client's home, work and social life and the environments in which they carried out their daily routines.

We talk about the home environment set up and do the old *ötell me what a typical day is like for youö* and then try to find something around that, so find out what are they doing. (Participant 5, 9:20)

When working under the condition of an *in-patient environment* the participants would try *simulating real life environments* by removing structured prompts and **getting others on-board** such as the rehabilitation staff in order to *create real life* scenarios. The therapists would then set the clients tasks to achieve within this less supported environment in order to get them using the skills they had developed in their EMA training more practically.

The next stage is actually trying to simulate that real life and getting them to do little exercises, which are going to give them practice. So in an in-patient [environment] that can be relatively easy because you can control what your other therapists do and say, hopefully. So for some clients you could take the timetable off their wall and you could say *öright, you don't need that because that is not real life. So next time you go to the gym, you take your diary and you ask the physio when your next appointment is and you write that down in your diaryö*. It is getting them to use it in real, everyday life and then when you are having your sessions it is reviewing that and seeing how it is going. (Participant 4, 11:7)

The participants also described the ways in which they would try *replicating everyday activities* in order for the clients to experience using their memory aids within relevant daily tasks, including cooking, shopping and using public transport. These activities were usually graded in a way that the therapists could monitor the clients use of the aid, adapt it and review with the client before moving on to more complex scenarios.

I would trial it on the ward or in the community, take them to the shops and do some shopping with them, do some errand tasks either here, well I start them off doing them here because sometimes it is a bit overwhelming going straight out into the community because a lot of clients do not want to go, like if I talk about going on a shopping trip they are just a bit apprehensive, so we just start off doing things in the kitchen and then we just go up to [name of local area] shops and then on. (Participant 5, 10:17)

If you have really a high functioning client who is able to use the bus you write a scenario and instructions for them to be at an appointment somewhere at a particular time but it is like mock sessions, like a true story that they have to relate to. (Participant 2, 6:29)

Through *creating real life* activities, and incorporating the EMA training within these activities, the participants began to establish if the aid would be suitable for the client long-term, even though they were not at a stage where these real life activities could actually begin to happen. As in the following situations described by Participants 1 and 7, where they *replicated daily activities* that a client would have to complete at work in order to train the client in using their EMA, even though they were not ready to return to work at the time. Returning to work was their overall goal and therefore the training was focused on this purposeful activity as a way of **making it real** and **getting client buy-in**.

I have also tried setting out all the training tasks or education based around work or whatever it is that they are motivated to go home to and base it on whatever their goals are too. So set up a scenario perhaps where they are back at work and they need to practice things. So goal focused definitely and as relevant to their life out of [name of rehab unit] as much as possible. (Participant 1, 7:1)

Coming up with [activities] to get them in the habit of using [the diary] really because it takes a while to get into the habit and often in the beginning they do not have a lot of use for the diary, they do not have many appointments, they are not going back to work, or, you know there is not a lot of people coming to see them so you almost have to create those opportunities to start with, which is where doing things like getting them to ring the office come in. It is a bit like the exercise for the exercise sake, whereas if you have got real opportunities that is often a lot better. (Participant 7, 4:16)

Despite the participants efforts to *create real life* they still believed that EMA training was best carried out when it was based within the client's real environment and real daily activities. This was illustrated by Participant 7 who

described EMA training with a client whilst working in her previous job at an in-patient rehabilitation unit.

One of my chaps was a plumbing apprentice so in his diary we had lots of activities for him to do around ringing around and getting different quotes for materials. So it was kind of real but it was not hugely purposeful, whereas when you actually have to do that it is purposeful and it is just that difference between trying to *create* a real world and actually *being* in the real world. It is just chalk and cheese. (Participant 7, 16:17)

For this reason, where the conditions made it possible, participants moved away from *creating real life* and on to the second inter/action *being in real life*.

Inter/action: Being in real life

When the participants talked of EMA training *being in real life* they mostly discussed situations based on either *community* or *work* related activities. The therapists chose *community settings* and activities that were relevant to their client to trial the use of an aid and then continue EMA training through ongoing practice in these settings.

I always do kind of practical training sessions where you go out into the community or do something with a purpose to use the diary or use the checklist or whatever it is that has been introduced. (Participant 1, 8:14)

I think like that functional setting and that community setting can actually, putting people in that situation and saying like, giving them some tasks that they would normally do, this is how it can help, like maybe that device or aid is not normal but the setting is so it just makes it more real life. (Participant 8, 8:23)

Even the therapists working in the community settings with clients in their own homes found that there was little opportunity for the client to practice using their memory aid until they returned to some kind of work. Participant 7 discussed a client who had participated in EMA training to establish the use of a diary/notebook but then found that there was little use for this aid until he started a voluntary work placement. It was through this placement that he really began to use the aid in the way it had been intended. The training had a purpose that had not been previously apparent to the client.

He always had his diary with him he just did not actually use it for anything but he did not really have anything to use it for either. That went on for quite a while and then we managed to get him a voluntary work placement and then suddenly he really realised why he needed to write things down. He was having to take orders and things and once he had finished each order and things he would come back and stand at his desk and just stand there and sort of vacantly wait there for someone to come and tell him what to do. And so one of the things we started doing was having in his diary a list of go and ask so-and-so what to do next. So I guess one of the big difficulties was that there was no purpose for using the diary, no meaningful activity for him to use it for until he got a job really. (Participant 7, 9:11)

Returning to work was a popular goal for a number of clients, however it was not until the *return to work* programmes began that clients started engaging in the EMA training and there was a purposeful outcome to integrating the aid into everyday work activities.

He was sitting at home not really doing very much, not really going out, all he wanted to do was go back to work and there was not any use in him using a diary until he did get back to work and then that gave him the drive because he actually needed it for an activity and I guess that is the thing. There needs to be something around it for them to need to use it and often we are involved at a time when they are not going back to work so you are trying to put stuff in place almost before they need it and that is really difficult. (Participant 7, 10:1)

Participant 6 described experiences of working with clients who had a history of attempting EMA training in the past that had failed while they were in *in-patient* units, as they could not see any meaningful purpose to making the effort of using an aid. These were clients who were now a few months post-injury and looking at *returning to work*. Participant 6 re-introduced the use of memory aids with these clients, even though it had not been successful in the past, as the clients now realised the benefit of these aids in completing their work activities.

I guess it is important to go back and re-attempt things. Even if they maybe did not engage in the first few months perhaps at 6 months down the line they get enough realisation, maybe they start to do a job and they were not at work before so they did not see the point, it is only when they start working. So you can re-introduce or bring memory aids in at any point as soon as you see the need for it and they might not

necessarily think of it straight away. So it is still good to reinforce it and to bring it back again even if they have already tried it. (Participant 6, 22:17)

The consequences of making it real – an overview

Through the inter/actions of *creating real life* and *being in real life* the occupational therapists aimed to achieve *sustained use* of the aid by the client. There were three aspects to sustained use that became apparent through data analysis. For the use of an aid to be sustained it had to be *fitting with the clients real life*, it had to become *integrated with routine* and the clients had to show signs of using the aid *long-term*. An overview of the consequences to **making it real** is presented in Table 17 below.

Table 17: The consequences – an overview

Paradigm component	Categories	Sub-categories
Consequences	Sustained use	Fitting with clients real life
		Integrated with routine
		Using long-term

Consequence: Sustained use

When the participants described their purpose for focusing on the clients' real lives or everyday activities, their ultimate goal was to ensure *sustained use* of the aid by the clients. Creating aids for clients that were 'applicable to their life at home' and they would not 'throw them on a pile of papers in their room when they got home' (Participant 8, 9:16). When participants explained how they knew an aid was going to be sustainable they talked about seeing an aid *fitting with a client's real life*, an aid that was not an added burden to functioning in the clients' normal lives and assisted them in completing meaningful occupations. Seeing the client recognise the value of the aid in achieving these occupations was also a sign of a good fit.

Because it has to be meaningful for them to want to use it, and it has to be appropriate to them, it has to be valuable to them in their own life. They have to be able to see themselves using it. (Participant 4, 8:10)

Participants recognised that each client was an individual and getting the aid *fitting with a client's real life* meant that the focus of EMA training might be different for each client as each one might want to achieve something slightly different or go about daily activities in an alternative way to the last client. This was where **getting others on-board**, such as clients' families, who knew the clients and how they carried out their day-to-day activities in their natural environment pre-injury, could help with creating training that was as real as possible.

Everyone is completely different so you do not have a formula for each client on how to make it real so it is pulling on different resources that the clients have and the families have and then pulling it into the training and getting it to fit what they would normally do. (Participant 8, 11:23)

Without this *fit*, participants expressed concerns that the EMA training would be unsuccessful, the aid would be useless in the clients' real world and never get used. Participant 5 related this to her own use of memory aids comparing what she used at work to what she found useful at home.

They are not going to use [the EMA] otherwise, I wouldn't, I would never use that at home, my diary, I am a list person and that helps me and for some people that (indicates the diary) really works and some people it does not. So you want it to be helpful and for people to use it, it has definitely got to fit in with them and their lifestyle. (Participant 5, 9:29)

Two of the participants (Participants 7 and 8) described 'yes!' moments where they observed their clients beginning to spontaneously use their memory aid in simple daily activities, like noting down their next appointments, without prompting from the therapist. These moments indicated to the therapists that the aid had started to be *integrated with routine* and were the first signs that training had been successful.

The first sign is when you go to see a client and they have got whatever it is, whether it is a kitchen timer or a diary or whatever, they have got it out and they have it ready for your session. So it shows that already there is a link there that is kind of the beginnings of it and having something that they are actually going to use. And then, when you are ringing someone up to make or change an appointment and they say, 'I am just going to

get my diary that is when you go öyes!ö or öI will just check the calendarö or whatever it is they are using. (Participant 7, 14:9)

The participants would observe other client behaviours as the aid became more *integrated with routine* that indicated spontaneous use of the aid and successful completion of everyday activities.

They have just got it all locked in but you could actually see with the turning up to appointments, are they doing the functional things that they need to on an every day basis. So if the wife has asked the husband to go and get something from the dairy or do something during the day, are you doing it, did you write it down? Has it become routine to use the aid? (Participant 3, 19:26)

Having completed EMA training within the client's real life environment and using everyday meaningful activities, in an effort to **make it real**, the participants reported that aids were then *fitting with clients real life* and they observed aids become *integrated with routine* for the client. This further indicated to the participants that they had established an aid that the client would be *using long-term* as it had become practical, useful and habitual.

Well it has to be functional and practical for the person to be able to use it on a long term basis and what you are aiming for is for that to become such an integral part of the persons daily routine and their daily life that they don't even realise that they are using it, it is just completely habit formed. That is what your aim is. So you want it to be a long term thing and for it to be a long term thing you have to give them lots of practice using it in real everyday life situations. (Participant 4, 9:1)

You know it works and they are happy with it and then you know you are on a winner and that is hopefully something that is long-term. But if you have not done that process, if you have not tried it out in real life or if you have not tried to simulate real life as much as possible in the in-patient environment then you don't really know if it is going to be something useful for them. (Participant 4, 9:24)

The three outcomes of *fitting with clients real life*, being *integrated with routine* and *using long-term*, contributed to the occupational therapists perceptions that the EMA training had been successful and that **making it real**, along with the other three processes **developing client insight**, **getting client buy-in** and **getting others on-board** had assisted them in establishing *sustained use* of the memory aid for their client.

By **making it real** the therapists were aiming to complete EMA training that the client could relate to as being useful to them in their own lives and therefore establish *sustained use* of an aid. This was felt to be more difficult in the *in-patient environment* where opportunities for **making it real** had to be *created* through alterations to the environment or mock scenarios. **Making it real** was perceived by the participants to be easier in the *community environment* where they could use *being in real life* as their strategy for EMA training and engage the client in meaningful daily activities.

Throughout this chapter a number of references have been made to the other three processes **developing client insight**, **getting client buy-in** and **getting others on-board**, showing the overlap between the core process **making it real** and these other three. The next section details the relationships between all four processes.

The interplay between making it real and the other processes

When analysing the data from interviews it became apparent that **making it real** was not a stand-alone process but one that was integrated within all the other processes and seemed the most important aspect to the EMA training for the occupational therapists. Without **making it real** there would be no experiential learning for clients during the process of **developing client insight**, which was one of the common inter/actions described by the participants. **Making it real** brought meaning to the memory aid training during the process of **getting client buy-in**, without this participants found clients difficult to engage. **Getting others on-board** often assisted the participants to learn more about the clients real lives and bring this real life into the EMA training. In this section the integration of **making it real** with each of the other processes is explored in detail, starting with the first process **developing client insight**.

Where **making it real** and **developing client insight** most significantly overlapped was during the **developing client insight** inter/action of *experiencing failure* as described on page 56 of Chapter Four. During this inter/action the therapists engaged the client in real life activities that they could relate to. They then allowed them to experience some degree of failure within these activities and supported them through this with explanations for the failure. This was felt

to be an important step in assisting the client to build their insight into their memory impairments and the effect that these impairments would have on their daily occupations.

It was during this inter/action that the therapists had to bring in **making it real** to establish what activities the client could relate to. In some cases it was work related activities like using a computer, and in others it was home related activities like making a meal. Here the participants used the **making it real** inter/action of *creating real life* alongside *experiencing failure*.

[The client] was a chef, so the only way for her to actually realise about the cognitive deficits was to do cooking with her and we made several things which turned out absolute disasters and only then did she realise that 'I can't actually go back to work, I can't actually cook for people because I am leaving my shells in my mixture and beating them in'. I tried to point things out along the way so it did not turn out too badly but, you know, it was only through that, that she actually realised. (Participant 5, 6:24)

The **making it real** inter/action of *being in real life* was also evident when participants described clients who did not develop their insight until they were out of the *in-patient environment* and back in the *community*.

Some of them don't really realise the consequences while they are in [name of rehab unit] and it is probably not until they get out into the real world that they realise things could really affect them with their memory. (Participant 1, 12:20)

The process **making it real** came into play when the participants were **getting client buy-in**, particularly when they engaged in the inter/action of *making it meaningful* as described on page 85 of Chapter Five. It was here that the participants focused on involving clients in purposeful activities based on their functional goals and previous life roles.

I think if we are talking about getting buy-in from the client for the strength of the memory aid and the use of the memory aid, it has to be something almost natural from their previous life. Whether it is taking them into a natural task, or their natural work or home environment. (Participant 8, 12:1)

When the participants did not manage to establish a link between the client goals and the EMA training they experienced clients who were not buying-in to the training as they were not able to see the point of it. 'They have to see

the need for the aid really otherwise they are not going to use itö (Participant 2, 5:27).

The purposeful, real life, activity that the client wanted to return to was also a predictor for which aid to use to best meet this goal.

[Selection of the aid] depends on the goals you are working on, so a cell phone perhaps would not be that great for working on some goals like trying to remember where you put your glasses before you went to bed, I mean that is no good is it. So I do not think that there is going to be one aid that is going to be able to address every goal you can think of. (Participant 2, 15:14)

Therefore, **making it real** had an impact on client engagement and selection of the aid. Some client goals were specific to memory, such as remembering to take their medication, and others were broader goals such as socialising with friends. The focus on real life goals, such as getting back to work, assisted with client motivation and **getting client buy-in**.

I find that if we implement something with a [return to work] client they are likely to remember it because they want to get back into work, you know, their motivation is there and it is really a high value for people to get back to work it is giving them that sense of independence again. So if we set them goals or we say ölook this is what I think you should be usingö they will give it 100%, you know, they will engage a lot more and they will really try, whereas with some of the other clients if it seems pointless then they will be like ömm, nahö. (Participant 3, 12:2)

Making it real overlapped with **getting others on-board** in three particular ways. **Getting others on-board** like the client's family helped the occupational therapists to establish what was real for the client in their everyday life. The therapists not only asked the client what their life was like previous to their injury but also discussed this with family to get a thorough picture.

I like to get more accurate, reliable information that is not just from the client but from the family and friends as well and it might open up more avenues for different things that you could use. (Participant 1, 16:9)

Getting others on-board also assisted with the making it real inter/action of *creating real life* as staff within the rehabilitation services needed to get on-board when trying to reduce the amount of prompting and support the client received in an attempt to create a more realistic, and less structured,

environment. Staff also needed to be on-board when prompting the client to use the aid consistently during practice tasks such as recording their next appointment.

If you have got someone who has an OT, a physio and a speech therapist then you know they are going to get at least three prompts a week to use their aid. (Participant 7, 10:17)

Family also helped to create links between the client's real life and the EMA training, taking place within the *in-patient environment*, thereby assisting in the process of **making it real**.

Often you hear families referring to how the memory aid could be used in their life back at home, you know when you go to the movies at the weekend or you want to go back to work because of course they have a good understanding of what the person's life was like before and that really helps to reinforce why it is important to practice at [name of rehab unit] even though it is not their real life it still has a link to their overall goal of getting back to their life as it was before. (Participant 1, 14:5)

Getting others on-board such as family and employers assisted with **making it real** as these people could provide the occupational therapist with valuable feedback about how the aid met clients' needs in their real life when the therapist was not present. Using this feedback the therapists could then review and adapt their EMA training to better suit the clients' needs.

It is getting [the client] to use [the EMA] in real, everyday life and then when you are having your sessions it is reviewing that and seeing how it is going and getting feedback from the other people that you have got to buy-in to the system as well. (Participant 4, 11:14)

Making it real assisted the occupational therapists to **develop the clients' insight** through engaging them in real life/meaningful activities, which they were allowed to fail and reflect upon. It was the concept of **making it real** that assisted the occupational therapists in the second process of **getting client buy-in** by relating the aid to previous life roles and giving the aid a purpose that related to real life. Finally, it was through **getting others on-board** that the occupational therapist could create the real life environments and scenarios in which the client could practice their memory aid use and be given the support of

others around them. For these reasons **making it real** is believed to be the core concept that travels through and encompasses the other three.

Summary

This chapter has explored the core process **making it real** in terms of the conditions impacting upon it, the inter/actions taken by participants and the consequences of these interactions. The two inter/actions of *creating real life* and *being in real life* are chosen by occupational therapists to establish a memory aid that can be successfully integrated into a clients life, become habitual rather than an added burden, and reduce the impact of their memory difficulties on everyday activities. The participants also anticipated that the process of **making it real** would result in sustained use of a memory aid over time.

The latter section of this chapter has examined the interplay between **making it real** and the other three processes **developing client insight**, **getting client buy-in** and **getting others on-board**. What has been demonstrated is the interweaving of **making it real** throughout these other three and the importance of **making it real** throughout the entire EMA training program.

In the following chapter the findings from this study are discussed in relation to current literature. Reference will be made to the literature that was described in the literature review chapter to demonstrate where research gaps have been filled and questions posed by previous researchers have been answered. Application of the findings to clinical practice will be suggested. Finally, the strengths and limitations of this study will be discussed and directions for further research proposed.

Chapter 8: Discussion

The aim of this chapter is to consider the findings of this study in relation to current literature and to outline the implications this study has for clinical practice and furthering the evidence for EMA training. The discussion then turns to the relative strengths and weaknesses of the study, in particular the ways that rigour has been maintained through the research process. Drawing on literature reviewed in Chapter Two, and literature that has been accessed as data analysis evolved, the gaps that have been addressed through this study and the research questions that have been answered will be considered. Areas for further study will also be suggested. This chapter will conclude with a review of how the study aims have been met and summarise how the study findings have added to the body of evidence regarding the use of EMAs following brain injury.

The following sections review the findings and discuss how they relate to existing literature. The names of the four processes: **developing client insight**, **getting client buy-in**, **getting others on-board** and **making it real**, are used as section headings to assist with the organisation of information. Within these sections I have chosen to focus the discussion on particular aspects of my study findings that address the gaps in current EMA literature, overcome barriers to EMA training documented in previous literature or identify tensions between this study and relevant rehabilitation studies from a wider context. Ultimately I have aimed to provide useful insights for future clinical practice and answer the study question ‘how do occupational therapists successfully train a person to use an EMA after a traumatic brain injury?’

For ease of reading the same formatting has been used within this chapter as the previous findings chapters. Titles of processes will be in bold type and the paradigm components within the processes (conditions, inter/actions and consequences) will be italicised.

Developing client insight

The term ‘insight’ was used when explaining the findings of this study, as this was the terminology preferred by the participants when they described clients’ abilities to understand their memory impairments and comprehend the

impact of these impairments on everyday activities. Many terms have been used in previous literature to describe similar deficits in clients' insight, including unawareness, lack of insight, reduced self-awareness and anosognosia (Anderson, Doble, Merritt & Kottorp, 2010; Brown, Lyons & Rose, 2006; Dirette, 2010; Halligan 2006; Port, Wilmott & Charlton, 2002; Prigatano 2005, 2009; Stroud, 2009).

Halligan (2006) described insight as a 'frustrating construct' and 'difficult to characterise and define in scientific or functional terms' (p. 456). Halligan made the point that 'the situation is not helped by the often uncritical adoption and interchangeable use of different operational and functional terms ranging from direct phenomenological experience (consciousness, self-consciousness, awareness) to the more reflective monitoring capacities of ongoing experiences (insight, metacognitions)' (p. 456).

When the process **developing client insight** began to emerge from the interview data, I searched the literature for information that would support or give an alternative perspective to my findings. Similar to Halligan (2006), I found the terminology frustrating and confusing. Numerous papers used different phrases to describe the same construct, for example, Port, Wilmott and Charlton (2002) used the phrases 'lack of awareness' and 'impaired insight' interchangeably throughout their study. Prigatano (2005) explicitly stated the intention to use 'anosognosia' and 'impaired self-awareness' interchangeably throughout a review of rehabilitation for people with disturbances in self-awareness after TBI, but then also integrated the word 'insight' into the definitions of these two terms.

The term 'self-awareness', rather than insight, has been adopted most often in the literature but has been defined in a number of different ways including 'an integration of both thoughts and feelings such that a person is able to perceive the self in relatively objective terms whilst maintaining a sense of subjectivity' (Anderson, Doble, Merritt & Kottorp, 2010, p. 23) and 'conscious knowledge of one's abilities and the impact of these abilities on daily functioning' (Dirette, 2010, p. 310). Brown, Lyons and Rose (2006) added to the complexity of these definitions by documenting that 'self-reflectivity is an important process involved in the development of self and is understood to be

one of the many mental processes that are encircled by the term self-awareness (p. 938). As can be seen by these definitions, in some cases self-awareness has been defined as objective knowledge of abilities and at other times the definition involves a more subjective component of feelings or reflections.

For the purpose of this discussion chapter, and in the knowledge that there is confusion over the clarity of terminology, particularly when referring to self-awareness, I have chosen to carry on with the term insight. This stays true to my participants' words and fits with the perspective taken by another occupational therapist, Dirette (2010), who attempted to simplify matters and used 'lack of insight' to describe 'general loss of knowledge about one's self without necessarily identifying the aetiology of impairment' (p. 310). Taking Dirette's perspective fits this situation as participants in my study did not explicitly identify the aetiology of their clients' lack of insight but described limitations in a variety of different areas including: neurological abilities directly related to the brain injury, reduced psychosocial abilities, psychological issues (anger, frustration, denial), and a range of non-medical issues such as the environmental impact on abilities. A combination of any or all of these issues could have led to a client experiencing difficulties with insight into their memory impairments.

Developing client insight was the first process presented in the findings chapters. It was positioned first as participants in the study felt that **developing client insight** was a necessary stage prior to introducing compensatory aids or EMA training. Without insight the participants reported clients who would not engage in memory rehabilitation, as they could not understand the benefits of participating. This finding is consistent with the previous literature relating to the use of EMAs. A lack of insight is one of the most commonly documented barriers to successful memory aid training with a number of authors having documented the need for assessing and improving the client's insight into their memory impairments prior to introducing memory aids (Cicerone et al., 2005; Fleming et al., 2005; Kennedy, 2006; McKerracher et al., 2005; Wilson et al., 2005; Wright et al., 2001).

When identifying the participants' interactions within the process of **developing client insight**, *assessing* was the initial interaction taken. In talking

about *assessing*, the participants discussed establishing their clients' levels of insight. These levels were described in two different ways. The first description was one incorporating three levels which appeared to be hierarchical in nature: 1) clients awareness of obvious physical impairment, 2) awareness of lower level cognitive issues such as simple processing and recall, and 3) awareness of the higher level cognitive difficulties such as prospective memory and executive function.

The insight levels described by the participants are similar to those developed by Stuss and Anderson (2004) who outlined four levels of insight related to distinct brain regions. Stuss and Anderson's levels are also arranged hierarchically starting with more knowledge-based aspects of insight, located in the posterior regions of the brain to more abstract aspects of insight located in the frontal regions. These four levels were reviewed and adapted by Dirette (2010) for the purposes of a theoretical based guideline for enhancing client insight after brain injury. The four levels are labelled according to the category of ability that each level addresses. Level 1 – Arousal and attention, is the beginning of insight development where the client can demonstrate basic attention and orientation. At this level they will have no internal model of self and the external surroundings. As they progress through this stage the ability to focus and maintain attention for processing information will develop. Level 2 – Sensory and motor, is knowledge-based insight, with which the client can explain specific sensory and motor abilities. Level 3 – Cognitive, is performance based insight into cognitive abilities. Unlike motor skills these abilities are not readily observable and have to be experienced by the client engaging in some kind of action. Finally, Level 4 – Psychosocial, is performance-based insight of the implications of psychosocial abilities integrated with a realistic view of the world.

The three levels of insight described by participants in this current study are similar to levels 2, 3 and 4 as described by Dirette (2010). The participants do not mention developing insight at level 1; this is perhaps due to this level being at a more acute stage of recovery and none of the participants interviewed worked with clients at this stage. From my own clinical experience of working with clients at this acute stage, the focus of occupational therapy intervention

tends to be aimed at the management of specific impairments such as tone and reducing the risk of secondary complications such as biomechanical changes in joints and muscles or altered spatial perception. Considering more complex cognitive skills such as insight when a client is in a state of low arousal or disorientation is not a priority at this time. This clinical opinion is supported by Powell and Malia (2006) who suggested a model of cognitive rehabilitation that starts with addressing attention and information processing deficits before moving to higher levels of cognitive abilities.

Data analysis of the combined reports from participants identified a second, alternative, way to assess clients' level of insight that was more specific to memory impairments and was based around the clients' abilities to predict when their memory would fail them. Participants recognised that some clients could identify memory deficits only when they were discussed at length with the therapist, others could identify their memory errors as they occurred in activities and address them at this time, and others could anticipate and plan for likely memory failures before an activity was performed. These latter clients were the ones who had most success in utilising a memory aid. An earlier study of self-awareness by Crosson et al (1989) discussed a similar multilevel process of emerging awareness that incorporated intellectual, emergent and anticipatory awareness of deficits. Although this model is useful for identifying the level of awareness at which a client sits, it has been criticised for not addressing the issue of how an individual moves from one level to the next (Stroud, 2009).

Stroud (2009) suggested that a model for clinical practice is required that assists clinicians to develop strategies for moving a client through the multiple levels of insight. One such model is that by O'Callaghan et al (2006), who proposed that clients become aware of their own deficits through experiences in real-life situations, where they can get feedback from the environment and people around them. Surprise and anxiety may accompany these experiences, which should be relieved through explanations by clinicians and building understanding. It is likely that this will also be followed by feelings of loss, anger and perhaps denial. Stroud recommended that rehabilitation should provide an environment that supports clients through the process of acknowledging deficits by offering respect, providing explanations and helping them deal with

the resulting emotional impact. Finally, clients begin to accept their changed ability to perform previous activities and become aware of their need to establish new ways to accomplish these.

The model by O'Callaghan et al. (2006), the principles for addressing insight outlined by Stroud (2009), and the qualitative work and resulting theoretical guidelines established by Dirette (2002, 2010), all acknowledge that the client's experience in real life activities is essential for building insight. *Experiencing failure* was an inter/action that emerged from the participants in this study when discussing how they went about **developing client insight** and an area in which the two processes **developing client insight** and **making it real** merged. Six of the participants involved their clients in meaningful activities and allowed them to experience memory errors such as being late for a meal, missing appointments, incorrectly following a recipe and being unable to use a computer. The therapists then supported the clients in understanding the cause of these errors. This intervention has been used in previous studies of EMA use such as that by McKerracher, Powell and Oyebode (2005) who engaged their client in a two week period of 'reality testing' (p. 119) in order to highlight the impact that memory problems had on his daily life. During this time they monitored his performance in completing a list of significant tasks and found that he missed appointments, lost several items and forgot important pieces of information. The client's knowledge of these errors was reported to greatly increase his motivation to use an EMA.

This reality testing approach has come under criticism from authors who have ethical concerns regarding the emotional impact on clients. Prigatano (2009) expressed particular ethical concerns around the individual with TBI who pursues a return to work or school and experiences significant failure. 'Inevitably they may become angry and depressed, even though they may not understand why they fail' (p. 609). Prigatano emphasised that proper management of the impaired insight of these individuals is imperative to avoid 'considerable psychiatric consequences' and 'devastating effects for the patient and family' (p. 609). Dirette (2010) advocated for the use of functional activities to achieve improved insight, but also stated the importance of the timing and structure of rehabilitation opportunities, as psychological distress rather than

insight could easily follow exposure to the difference between current and expected performance.

The participants in this Masters study reflected these concerns citing experiences of clients becoming upset, emotional and angry when experiencing failure in meaningful occupations. They acknowledged the need for clients to be given support similar to that required when experiencing any grieving process. The inter/action of *supporting* included supportive listening, assisting clients with reflection on their current ability and formal counseling. This support was not only provided by the occupational therapists; they reported bringing in other team members to monitor the clients mood, such as psychologists, and also suggested engaging the family in supporting the client. This would be in-line with the recommendations from Dirette (2002) and Stroud (2009) who advised that building insight through experience and supported failure should be accompanied by careful psychological monitoring, and a team approach as being crucial to ensure that physical, functional, social and psychological needs are met during this time.

Evidence from longitudinal studies that examine the development of insight after TBI has suggested that there are improvements in insight over time, particularly in the behavioural and affective domains (Dirette & Plaisier 2007; Hart, Seignourel, & Sherer, 2009). These longitudinal studies recommended the need for effective interventions for persons with impaired awareness and for flexible timing of rehabilitation efforts but do not give particular reasons for why this increase in insight occurs over the one-year study period. Reasons for increasing insight over time can be found elsewhere though, such as a qualitative study by Brown et al. (2006) that suggested clients undergo a process of *rediscovery* after brain injury and this is seen as the product of the individual and their social and physical environments. Brown et al. used an interpretative phenomenological approach to investigate the process through which a person with a brain injury develops insight into their difficulties. They found that, during rehabilitation, clients found their knowledge of physical difficulties became clear to them and were beginning to inquire about cognitive difficulties. On their return home these clients attempted to return to previous activities, such as integration with their family, and began to discover further difficulties in

cognitive and emotional domains, which had not previously been envisaged. Brown et al. emphasised that the feedback and support of family or significant others was essential during this discovery process.

The results from Brown et al. (2006) study, support the approach taken by the majority of participants in this current study by suggesting that the development of client insight is due to the client experiencing difficulties within their natural home and community environment and receiving feedback from family and significant others on their mistakes. This appears to indicate an example of overlap between the two processes identified in the current study: **developing client insight** and **getting others on-board**.

Despite the majority of participants in this study describing their experiences of client insight developing over time with experience and support there were some participants who experienced clients that did not develop their insight over time despite multiple real-life experiences of failure and ongoing support from rehabilitation staff and family. These participants predominantly worked with clients who were two years post-injury and had ongoing chronic insight and memory issues due to severe brain-injuries. They reported significant issues in using the 'reality testing' approach to **developing client insight** and found that the nature of their clients' injuries was such that they did not develop insight, regardless of the number of failures experienced. Concern for these clients' psychological wellbeing grew as this method showed no signs of positive results and therefore alternative approaches were employed. Rather than attempting to highlight failures to develop insight and then move on to engaging the clients in EMA training, these participants found they had more success by shifting their efforts with the clients to inter/actions of *rapport building* and *focusing on what the client enjoys*.

The inter/action of *rapport building* was described by participants in this study as providing these severely impaired clients with the knowledge that there was a trusting and caring relationship. The participants then noted that the client began to take note of therapists' advice, despite an ongoing lack of insight, as maintaining this relationship was of importance to them. Supporting evidence for this inter/action is provided by Prigatano (2005) who discussed clients with 'a complete syndrome of impaired self-awareness' where 'very little can be

done to improve their awarenessö (p. 25). With these types of clients Prigatano recommended building a ðtherapeutic allianceö. Once this alliance has been established it is believed that the client ömay make better choices, even though their self-awareness fails to improveö (p. 26). The importance of building a therapeutic alliance is discussed in more detail in the **getting others on-board** section of this chapter.

The inter/action of *focusing on what the client enjoys* involved engaging the client in activities that they took pleasure in and they felt were a part of their self-identity. EMAs were then naturally incorporated into the activity in order to achieve the desired outcome. Here, rather than focusing on impairments of memory and insight the occupational therapists took a more global perspective and focused on the client's participation in his/her natural environment to determine what was relevant and important to him/her. This inter/action is an alternative to those found in the previous literature regarding **developing client insight**, which has tended to focus on the client's impairments and building their knowledge of how these impairments impact on their daily activities. Participants in this study suggested that, with the more severely impaired and chronically affected clients, this impairment-focused approach did not work. They therefore adopted an alternative approach by focusing on client participation and using occupations that assisted the client to maintain his/her preferred self-identity, such as a young man being able to get into town on the bus and wander around the shops alone, maintaining his feelings of freedom and independence. Memory aids were then incorporated as a natural way to complete the occupation, rather than the aid being framed as a way to compensate for impairment.

Implications for clinical practice

This study identified **developing client insight** as an important first step in EMA training, which aligns with previous memory aid literature. The ways in which the participants in the study assessed and described their client's levels of insight are similar to those depicted in models proposed by previous authors, although none of the participants made reference to their knowledge of these models. This demonstrates the relevance of these hierarchical models to clinical practice. In order to move from one awareness level to the next, the literature

advocates for clients to experience failure in selected tasks in order to identify errors and then be provided with support to understand these errors and come to terms with their new sense of ability. This was the common approach used by participants in this study in their attempts to develop client insight. Addressing the issue of poor insight through this supported failure approach has sparked debate into the ethical dilemmas of such an intervention. Participants talked of experiencing this first hand and the need for a team approach (including family members) to manage any psychological trauma that may be experienced by clients.

In general the findings from this study concur with previous literature investigating approaches to improving insight and implementing EMAs following TBI. Where this study adds to the current evidence is in the management of those clients with a severe injury and chronic memory problems that demonstrate limited gains in their insight when engaged in the above approach. These are the group most likely to develop psychological trauma through ongoing attempts in using a supported failure approach. Rather than focusing on the impairments of insight and memory, the occupational therapists focused on client participation and encouraged clients to participate in activities they enjoyed and saw as important. The participants then framed the EMA as an adjunct to achieving the desired outcomes within these activities, rather than a way to compensate for memory impairment. This approach was felt by the participants to lead to less emotional distress for the severely brain-injured client as the focus had moved from continuous highlighting of an impairment to increased participation in meaningful occupations that clients felt important to maintain their self-identity.

Getting client buy-in

The process **getting client buy-in** is similar to that described by Schmitter-Edgecombe, Fahy, Whelan and Long (1995) who referred to an initial stage of 'anticipation' in their EMA training, which was a group based notebook training program. The goal of this anticipation stage was to 'pique interest in possible solutions to memory problems: concretely identify memory weaknesses and demonstrate need for an external aid' (p. 486). This anticipation stage was

completed over the first three group sessions and incorporated tasks that defined clients' specific memory skills and deficits and taught procedures for recording items into the notebooks.

Unlike Schmitter-Edgecombe et al. (1995), the participants in this Masters study did not pre-define the memory aid that would be used by their clients and therefore the **getting client buy-in** process also incorporated the decision making around the type of aid to be used.

Although client participation in rehabilitation is described as important to learn the skills required for returning to independent living, studies conducted from this perspective are sparse (Aadal & Kirkevold, 2011). In an attempt to address this, Aadal and Kirkevold (2011) conducted a study to develop a model aimed at systematising health professionals' efforts to promote client participation and learning during the initial intensive rehabilitation phase following TBI. In order to develop, conduct preliminary testing, and then evaluate a model for neurorehabilitation, Aadal and Kirkevold took a humanistic perspective to their research and used a variety of qualitative methods including ethnographic data collection from case studies, semi-structured focus group interviews, and action research techniques. Aadal and Kirkevold's research identified similar conditions to this current study when considering ways of **getting client buy-in**. Their model for promoting client participation considered the need for professionals to address the client's specific learning abilities and provide rehabilitation contexts conducive for participation (p. 16).

Aadal and Kirkevold's (2011) consideration of clients' specific learning abilities took into account challenges to learning including deficits in perception, attention, memory, language, emotion and physical status, which may be present following a TBI. Similar considerations were taken by participants in the current study, who identified *client impairments* as a condition to **getting client buy-in**. Through data analysis three categories of impairment were evident, these being *psychological*, *cognitive* and *physical*. These impairments required close examination prior to the therapists deciding on their inter/actions with clients.

Aadal and Kirkevold (2011) made particular reference to the psychological and emotional impairments of clients, 'Emotional aspects in the learning process during rehabilitation after a TBI invoke special attention

because they influence patient attention and executive and memory functionsö (p. 4). This was seen to be the case in this study too, with participants citing *psychological* impairments like anxiety and depression as being the most common to have a negative impact upon their EMA training.

Within Aadal and Kirkevold's (2011) model for promoting participation and learning, the second consideration is the rehabilitation context or 'environmental framework' (p. 4). They incorporated resources and the physical and psychosocial environment into this one contextual consideration. In comparison, this current study has identified two separate conditions: *service structure* and *accessibility*. The latter of these, *accessibility*, refers to the resources available for the funding of EMAs and is addressed under the resource aspect of Aadal and Kirkevold's 'environmental framework'.

The former condition *service structure* pertained not just to the physical environment but also to the inherent organisational processes present within a rehabilitation service. This condition is not covered in the model proposed by Aadal and Kirkevold (2011) which would appear to be a critical omission as the organisational processes identified, such as limits on length-of-stay, discharge planning and timetabling, are likely to be present in any rehabilitation service and impact on the ability of professionals to engage their client in therapies.

Service structure can be seen as a condition to client participation and satisfaction elsewhere in literature. When considering how to assess quality of care Donabedian (1997) refers to organisational 'structure' and 'process' as two of the three categories that require consideration. The third category is 'outcome' which denotes the effect of the service on the health status of the client, including changes in client knowledge, behaviour and satisfaction. Using Donabedian's structure, process, outcome model, and applying it to this current study it can be seen that the structural conditions of material resources (access to aids, funding) human resources (therapist's time) and organisational structure (physical environment) and process conditions (length of stay, discharge planning, timetabling) impact on the outcome of change in client behaviour, i.e. client participation in EMA training.

In an attempt to address the conditions of **getting client buy-in**, as described above, the participants used three main inter/actions, the first of these

was *doing the groundwork*. One component of *doing the groundwork* was the need to discuss clients' previous use of memory aids. The gathering of this pre-injury information was done with the client and also with the family, demonstrating an overlap between the two processes **getting client buy-in** and **getting others on-board**. Participants found these discussions useful in identifying aids that the clients were familiar with and had worked well for them prior to their injury. They would then re-introduce the same or similar aids and use these in the EMA training. This acknowledges concerns that were discussed by Wright et al. (2001) when evaluating the success of pocket computers as EMAs. They recognised that 'people prefer to manage their routines post brain injury by whatever methods they used previously' (p. 799). If these aids were previously a part of everyday life for the client then they were not seen as labelling their impairments or drawing attention to the fact that they had a brain injury. This issue has been highlighted as a potential barrier to EMA training by McKerracher et al (2005), who noted that clients do not wish to use strategies or aids that draw attention to their problems.

Another aspect of the inter/action *doing the groundwork* was *normalising* the memory aid for the client. This was partly achieved through using an aid that the client had used prior to their injury. Another form of *normalising* was the occupational therapists modelling the use of memory aids themselves, such as getting their diaries out when scheduling appointments. This modelling of good cognitive strategies demonstrated to the clients that memory aids were a part of general everyday life for people, whether or not they had a brain injury. In this way the participants here were addressing another barrier to EMA training that has been documented in previous literature, that of the client feeling like they were different to those around them, they were cheating in some way by using an aid and that the use of an aid would reduce chances of further recovery (McKerracher et al., 2005; Van Hulle & Hux, 2006; Wilson et al., 2005).

Using an aid that was previously a part of everyday life for the client also had benefits for simplifying client learning. In most clients with memory loss procedural memory is spared. Procedural memory is the stored knowledge related to the acquisition of learned skilled activity, such as using a cell phone; it is developed through repetition and practice. These stored memories of

procedures evolve into routines that are retrieved automatically in response to a specific stimulus (Grieve, 2008). By using an aid that has been in some way habitual to the client previous to their injury then this procedural memory can be utilised. For instance one participant described a client who continued to carry around his cell phone and text his friends regularly as he had done prior to his injury. By utilising this habit and previously learnt skills in navigating the cell phone functions, the client was able to learn to use the calendar on the phone to assist him in remembering appointments. This approach proved to be more successful than learning to use other, less familiar, aids.

In addition to *doing the groundwork*, all the participants in the study talked about the importance of setting functional goals with the client and placing EMA training within purposeful activities that related to these goals. Through abstraction of the data relating to these discussions the inter/action *making it meaningful* was formed.

The topic of goal setting is not well documented in previous literature relating to EMA training. Only three studies refer to goal setting in the context that the memory goals set by the client will have an influence over the selection of the most appropriate EMA to meet those goals (Schmitter-Edgecombe et al., 1995; Van Hulle & Hux, 2006; Wilson et al., 2005).

The findings of the current study indicated that participants set goals with their clients in two ways; the first was a focus on the higher-level goals that were set at the start of rehabilitation and then breaking down these goals into component parts, which incorporated the need for a memory aid. These goals included: to go back to work and to live alone at home. Alternatively, therapists set more specific memory goals with their clients that were related to the memory impairments experienced and could be directly achieved through the use of an EMA. These goals included: to remember to take my medication on time and to remember my next appointment. Where clients could not see a link between their functional goals and the EMA training the participants reported a lack of client buy-in.

There is evidence to suggest that the process of goal setting can provide an ideal opportunity for clients to engage in their rehabilitation. In a qualitative study, Conneeley (2004) explored the use of collaborative goal setting from the

perspectives of the professional staff, patients and relatives. One conclusion from this study was that involvement in the process of goal setting appeared to act as a strong motivator to engage in therapy (p. 251). A systematic review of the use of goal setting in rehabilitation by Levack et al. (2006) described one of the major purposes of goal setting as improving client outcomes, which is achieved in part through enhancing client motivation. The studies included in this review were those reporting an original randomised control trial involving adult research participants, where the goal setting approach was included as one of the independent variables under investigation.

In terms of the effect of goal setting on client motivation and treatment participation, the results of the review by Levack et al. (2006) suggested that:

There is some limited evidence that goal planning improves adherence to treatment regimes over the duration of a whole rehabilitation programme and strong evidence (for populations of people with acquired brain injury) that prescribed, specific, difficult goals result in better immediate performance on motor and cognitive activities (p. 746)

This finding would seem to particularly support the participants in this study that chose to set prescribed, specific memory goals in order to motivate and engage their clients in the EMA training.

There is also support for those participants who chose to focus on higher-level goals. This support comes from studies into life goals and their relation to rehabilitation. Life goals are described as the desired states that people seek to obtain, maintain or avoid, and an important motivational force that contributes to health and wellbeing. The motivation of a person to participate in rehabilitation depends on the concurrence between the treatment goals and the individual's life goals (McNamara, Durso & Harris, 2006; Sivaramen Nair, 2003; Sivaramen Nair & Wade, 2003). Sivaramen Nair (2003) conducted a literature review on life goals and their influence on the rehabilitation process. Thirty-nine articles directly dealing with the subject were included in the review. The results confirmed that the incorporation of a client's life goals into a rehabilitation program resulted in better outcomes for clients with various physical and psychological disorders.

Implications for clinical practice

Getting client buy-in is a process that focuses on the occupational therapist's ability to engage the client in EMA training. Conditions impacting on this process included *client impairments*, *service structure*, and *accessibility* to the appropriate aids. These conditions are similar to considerations in other studies that have attempted to create models for neurorehabilitation that facilitate client participation and learning. Each of these conditions should be taken into account when planning EMA training in order to promote client participation within the constraints of client's reduced learning abilities and the limitations of the rehabilitation service.

Participants' inter/actions with clients during the **getting client buy-in** process addressed a number of barriers that have been reported in previous EMA training literature, particularly clients' negative perceptions of using a memory aid such as the aid making them look different to other people, feeling like they are cheating, feeling different to their pre-injury selves. Being aware of these likely barriers and addressing them through *doing the groundwork* resulted in more positive responses by clients and more successful use of the aid. Another useful aspect of *doing the groundwork* is establishing memory aids that have been used by the client previously and the benefits of clients utilising procedural memory during their training with these aids.

All the participants attempted to increase the clients' engagement in EMA training through the use of goal setting. Some participants chose to set higher-level goals related to lifestyle and others chose to set specific memory goals. The evidence for goal setting in rehabilitation and its effect on client motivation and participation is still being explored in the literature, however there is support for both of the approaches taken by participants resulting in potential positive effects on client outcome. Linking the clients' functional and meaningful goals to EMA training is an important aspect of **getting client buy-in** and one that was thought to lead to more likely sustained use of the EMA.

Getting others on-board

Despite participants in this study describing the need to have other people support them in the EMA training and, in particular, recruit family and

employers to assist in generalising EMA use into the home and work environments, this is not well addressed in previous memory aid literature. Four studies investigating the use of external aids make no mention of including any other person but the research team and the clients (Donaghy & Williams, 1998; Kennedy, 2006; Wilson et al., 2005; Wright et al., 2001). Two of the studies include family in the assessment and evaluation aspects of their research through the use of questionnaires or checklists to measure everyday memory errors pre- and post-intervention (Fleming et al., 2005; Schmitter-Edgecombe et al., 1995). Only two studies report actively including family in aspects of the EMA training, one of these is a case study by McKerracher et al. (2005) who involved their client's partner during the 'reality testing' phase of their training program. This client was an out-patient in a neurological rehabilitation unit and as such it was essential for his partner to be involved when monitoring and recording daily memory errors at home as the clinical team were not present. Although these authors highlighted the importance of repetition in the use of the aid during the training they only completed these repetitive training tasks on the days that the client attended their out-patient appointments rather than having them done on a daily basis at home with his partner. The success of McKerracher et al.'s EMA training is limited in its generalisability outside of the rehabilitation setting, and this is perhaps why. Fleming et al. (2005) noted the importance of including the client's significant others in training sessions with the aim of increasing generalisation to the home environment but do not give specific details of how this was carried out in their study.

Only one study documents the use of rehabilitation staff in assisting with the EMA training. This study, by Van Hulle and Hux (2006), was based in a transitional living facility and aimed for clients to achieve independence in self-administering medication. Within this setting staff members were on-hand to assist clients with their daily activities, which included administering medication as required. These individuals assisted the client and researchers in the EMA training by placing the assistive device being trialled in pre-determined locations, for example, the client's shirt pocket, dispensing medications when requested by the client and prompting clients after 15 minutes had passed from the time that medications should have been requested. Staff members also assisted with the recording of outcomes on a daily basis. It was also shown how staff working

with the clients on a day-to-day basis could assist the researchers in explaining variations in clients' performance, for instance, reporting a client's emotional distress on days when there were drops in performance in EMA use.

The systematic reviews of cognitive rehabilitation interventions (Cicerone et al., 2005) and EMA use (Sohlberg et al., 2007) make no reference to including others, such as family, into EMA training. This is unsurprising due to the absence of these details in the previous research descriptions and discussions. They also, however, neglect to mention this as a need for further investigation despite growing evidence in other general rehabilitation literature to the advantages of including families in TBI rehabilitation planning and therapeutic interventions.

The process of **getting others on-board** involved one main inter/action by participants, which was labelled *recruiting*; this inter/action was comprised of a number of sub-categories including *educating*, *joining* and *relationship building*. *Educating* was the most commonly discussed strategy for *recruiting* both staff members and families and involved discussing the use of the aid, the goals it aimed to achieve and the level of support required. One participant who regularly worked with clients during their return to work programs discussed the same actions when *educating* employers and colleagues.

Education to families was often blended with more practical involvement in training where they got involved in using the aids themselves and *joining* the client in training activities. This was felt to be important by the participants as it provided the client with someone to offer ongoing support and share in the rehabilitation journey.

Relationship building between therapists and family members was thought to be important outside of the EMA training so families had a general understanding of the rehabilitation process and realistic expectations. This *relationship building* was seen as a role that the whole rehabilitation team should be involved in as it presented to the client a cohesive rehabilitation team of which the family were a part.

Although none of these strategies are discussed in the literature specific to EMA training, support for these strategies is found in the wider brain injury rehabilitation literature investigating the influence that *recruiting* significant

others has on client outcomes. For example, in their qualitative metasynthesis of experience and recovery following TBI, Levack et al. (2010) identified that clients coped and moved on from TBI by drawing on many different resources, both internal and external. External resources included the support provided, not only by rehabilitation services, but also by friends, family, and community members. Levack et al. identified that the "support provided by family and friends was significantly important for people with TBI to reconstruct a place for themselves in the world" (p. 996).

The inter/action of *recruiting* significant others through *educating*, *joining* and *relationship building* mirrors some of the ideas discussed in the growing body of literature relating more positive client outcomes to establishing a "therapeutic alliance" in post-acute brain injury rehabilitation (Evans, Sherer, Nakase-Richardson, Mani & Irby 2008; Kreutzer, Mawitz, Godwin & Arango-Lasprilla, 2010; Prigatano et al., 1994; Sherer et al., 2007).

The concept of the therapeutic alliance is derived from psychotherapy literature and refers to the collaboration between the client and the therapist in their efforts to combat the client's problems. Therapeutic alliance is determined by client and therapist agreement on tasks of therapy, goals of therapy, and their interpersonal bond (Sherer et al., 2007). Increasingly the role of the family has become an additional component to the therapeutic alliance with studies highlighting the importance of family involvement in rehabilitation programs and the destructive impact of family dysfunction on the rehabilitation process (Evans et al., 2008; Prigatano et al., 1994).

With the degree of therapeutic alliance between the client, family and therapy team being "consistently identified as a key element in the success of post-acute brain injury rehabilitation" (Evans et al. 2008, p. 329), strategies to actively involve families in the rehabilitation process have been studied. The recognition has grown that families have a long-term caring role in the lives of many brain injury survivors and that the lives of family members are often dramatically changed after the injury. Researchers have investigated a combination of strategies to build the therapeutic alliance and provide families with combinations of education, skills training and psychological support.

The earlier research into these family interventions was summarised by Boschen, Gargaro, Gerber and Brandys (2007) who published the findings of a systematic review of family interventions after brain injury and other chronic neurological disorders. They conducted an extensive literature search of Cochrane, MEDLINE, PsychInfo and other databases to gather all relevant studies. They remarked on the biased sampling procedures, small sample sizes and use of non-standardised outcomes measures, and came to the conclusion that research on family interventions is in its infancy (p. 35).

Since this review was completed three further studies have taken place looking into the benefits that family interventions bring to the therapeutic alliance between the treating team and the client, and ways that this family/professional relationship can be fostered in order to gain optimum outcomes for the client (Evans et al., 2008; Kreutzer et al., 2010; Sherer et al., 2007). Two of these studies (Evans et al., 2008 and Sherer et al., 2007) were lead by the same research team, the first was a prospective cohort study aiming to determine the factors that influence the strength of the client/therapist therapeutic alliance and examine the association of this alliance with outcome. The findings suggested that family perceptions and family functioning are important determinants of the therapeutic alliance between therapist and client. Poor therapeutic alliance was predictive of poor effort in therapies and rehabilitation program drop out. A high degree of therapeutic alliance was predictive of higher productivity on discharge.

Following the findings of this first study, linking family involvement with the therapeutic alliance and positive client outcomes, the authors then published an evaluation of an interdisciplinary intervention to improve therapeutic alliance. This intervention included formal family interventions such as the provision of written educational material related to brain injury rehabilitation and education sessions with opportunities to ask the treatment team any questions. Although the statistical power of some findings were weak, overall the group receiving the intervention had more favourable functional status at discharge in comparison to the control group and this was felt to warrant further investigation in larger, better designed studies.

Further to the studies above Kreutzer et al. (2010) published an article describing practical approaches to effective family intervention after brain injury. This was aimed at providing guidance for clinical intervention on the basis of a synthesis of literature and clinical experience. Kreutzer et al. outlined seven intervention strategies for establishing therapeutic relationships with families. The inter/actions of *educating*, *joining* and *relationship building* that were described by participants in the current study are incorporated within the seven strategies described by Kreutzer et al. Those strategies outlined by Kreutzer et al., but not mentioned by the occupational therapists in the current study, tended to be the more psychological interventions such as *positive re-framing* which is based on cognitive-behavioural therapy. It is likely that these types of strategies were felt to be out of the scope of practice of these occupational therapists and something that would be addressed by other members of their teams or referrals made for psychological consultation.

One of the consequences to *recruiting* people, such as friends, families, and employers, into the EMA training was *regular reinforcement*. This reinforcement came through added practice and repetition of the steps in memory aid use during the training period. Repetitive training has been shown to be an important part of brain injury rehabilitation for clients with severe memory deficits. Studies of individuals with amnesia have shown their ability to learn new skills through the use of their procedural memory. Procedural memory is implicit, developing through repetition and practice, and studies have demonstrated that people with amnesia can show improvement in performance of leisure tasks without awareness of having completed the task previously. The level of achievement improves with repetition (Grieve, 2008). The more individuals who were on-board and could practice the use of the memory aids, the more repetitions the clients got in using their aids, and the more likely they were to improve their performance in utilising the aid independently.

Normalising was another form of *regular reinforcement* that came from **getting others on-board** with the EMA training. Examples were given by participants of families that had started using the memory aids themselves, for instance a whole family who used a white board at home to record their weekly schedules and therefore it became part of normal life for the individual with the

brain injury to do the same. This brings to mind the *Rose Paradox*. Rose was an epidemiologist who believed that it was far more important to target a whole population in order to achieve a specific health benefit, rather than to target individuals themselves. Rose (1992) stated that 'it makes little sense to expect individuals to behave differently from their peers; it is more appropriate to seek a general change in behavioural norms and in the circumstances which facilitate their adoption' (p. 102).

Implications for clinical practice

Getting others on-board was not a linear process and did not follow on from the other processes of **developing client insight** or **getting client buy-in** but was completed alongside them, sometimes simultaneously.

Although there is a lack of evidence for this process in the literature relating to EMA use, there has been growing research in brain injury rehabilitation as to the role of the family in promoting positive outcomes for clients. Families are seen as **long-term** care givers for many clients after their injury. They are likely to be present long after the therapy teams have completed their rehabilitation programs. Employers and colleagues are also likely to be working with the client after the formal therapy has ceased in a return to work program. Occupational therapists should be increasingly aware of the need to recruit these individuals into the client's EMA training through building a therapeutic alliance, providing education, actively encouraging others to join in with their formal therapy sessions, and teaching the necessary skills for encouraging repetitive training outside of formal therapy sessions.

Without these other individuals on-board to continue to reinforce the use of a memory aid through repetition and creating an environment where memory aid use can be supported it is unlikely that the use of the aid will be sustained long-term.

Making it real

During data analysis the occurrence of the phrases *'real world'*, *'real life'* and *'everyday life'* in the participant interviews mounted and, as each set of data was compared to the next, the process of **making it real** became

increasingly apparent across all aspects of the participants EMA training. The ubiquitous nature of **making it real** resulted in this becoming the core process, encompassing the previous three processes.

Aspects of **making it real** can be seen throughout each of the other three processes, starting with the *experiencing failure* inter/action in **developing client insight**. The experiences that participants allowed their clients to fail in had to take the form of real life occupations, that is those activities that the clients were engaged in and able to complete prior to the brain injury occurring. Without the use of **making it real** in these situations, clients would not be able to relate their memory errors to their own worlds and would remain lacking in insight.

Making it real is seen again in the *making it meaningful* inter/action of the **getting client buy-in** process. By focusing on the client's functional goals, those related to their real life at home or work, the participants found the clients more willing to participate in EMA training.

When **getting others on-board** participants were hoping to achieve the consequence of *feedback relating to real life*, that is the family or employers were able to provide the therapists with information about the client's performance in real life and how the EMA training was progressing in assisting the clients to manage their everyday activities. **Getting others on-board** also assisted in bringing the clients real world to the rehabilitation units as family and friends could provide the information required to establish what the client's normal routine was and this could be used to create meaningful training activities during the EMA program.

This process of **making it real** seems to be absent from any previous memory aid literature. The previous literature has tended to select the aids for trial and issue them to the client with the purpose of achieving particular goals. Often it is unclear if these goals have been set by the researchers or the client themselves. There is little mention of the role of family or any significant others in the training programs described by previous authors. This lack of real world focus could perhaps be the reason why these authors repeatedly state the concern for the sustainability of the memory aids they have put in place. Without a focus on the client's everyday activities, and the aid supporting the client in achieving these activities, how can sustainable use of an aid be expected?

The commonality of **making it real** across all the participant interviews and the natural assumption that the occupational therapists took that **making it real** should be a part of EMA training begs the question, why this has not been highlighted in previous studies? In view of the fact that all the participants in this study were occupational therapists it made me consider that perhaps the shared perceptions of these individuals was due to their shared theoretical frameworks.

Despite the occupational therapists in this study being trained at different times and different tertiary education institutions there are a limited number of theoretical frameworks on which occupational therapy clinical practice is based. Ashby and Chandler (2010) conducted an exploratory study of the occupation-focused models included in occupational therapy professional education programs in Australia, Canada, the United Kingdom and the United States. They found that the Model of Human Occupation (MOHO) and Canadian Model of Occupational Performance and Engagement (CMOP-E) were the two occupation-focused models most likely to be included in curriculum. From experience as a fieldwork supervisor for undergraduate students in New Zealand CMOP-E is also a particular focus of the New Zealand occupational therapy schools.

The Model of Human Occupation (MOHO; Kielhofner, 2008) was first published in 1980 and was the product of three occupational therapy practitioners attempting to articulate concepts that guided their practice. Since MOHO was first formulated numerous contributions from researchers over the last three decades have enhanced its development. Kielhofner (2008) defined human occupation as follows: "the concept, human occupation, refers to the doing of work, play or activities of daily living within a temporal, physical, and sociocultural context that characterises much of human life" (p. 5). In this definition, work refers to activities that provide services or commodities to others such as ideas, knowledge, entertainment and help; play refers to activities undertaken for their own sake and activities of daily living refer to the tasks required for self-care and self-maintenance.

The Canadian Model of Occupational Performance and Engagement (CMOP-E) is an extension of the 1997/2002 conceptual framework (CMOP) that

describes occupational therapy's view of the dynamic, interwoven relationship between persons, environments and occupations; the addition of engagement to the model signals occupational therapy interests that extend beyond occupational performance. In this model occupation refers to:

Groups of activities and tasks of everyday life, named, organised, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity). (Townsend & Polatajko, 2007, p. 369)

The need for an extension of the original CMOP came from a desire to extend the model beyond occupational performance. Townsend and Polatajko (2007) identified that occupational therapists were also interested in other modes of occupational interactions. Among these are occupational behaviour, occupational capacity, occupational competence, occupational development and occupational engagement. Occupational engagement captured the broadest of perspectives on occupation and encompassed all that people do to involve themselves or become occupied. CMOP-E as a theoretical model extends occupational therapists' concerns with human occupation beyond the actual performance of an occupation, and on to the level of importance it holds or the degree of satisfaction it brings to the individual, family, group or organization.

These models use a variety of occupation-focused terms that are also seen in the participant interviews when they discussed the conditions, inter/actions and consequences involved in the process **making it real**. These included occupational considerations such as work, self-care, productivity and leisure; contextual considerations such as home-life, social life, society, culture, family, community; and engagement terms such as participation, involvement and working together. **Making it real** is perhaps a culmination of all these considerations into a phrase that occupational therapists can use on a daily basis that makes sense to others around them such as clients, families and other professionals.

During my final interviews and as a result of theoretical questioning, I was exploring with one participant what the phrase **making it real** meant to her, as it had become a central category to my analysis. Her response was as follows:

I like making it real; I mean that is a good title. That to me embodies what we do more than all our OT words that to me just conjure up pictures of cooking in the kitchen with pots and pansí how are we going to make it real for this person, like in their own home, with the family around? It is good, I like it. (Participant 8, 12:8)

This statement demonstrates, similar to the CMOP-E, that for this therapist the process **making it real** moves beyond merely considering an occupational performance, in this case preparing a meal, and also takes into account the wider contexts of the client's real world such as family and home-life.

Making it real, encompassing the ideas of client impairment, activity performance, environmental contexts and client participation in their real world, can be seen in another model of rehabilitation, The International Classification of Functioning Disability and Health (ICF; WHO, 2001). The ICF incorporates components of functioning and disability, including the client's activities and participation and environmental factors that make up the physical, social and attitudinal contexts in which the client lives. Although the ICF identifies that personal factors such as gender, race, age, fitness and lifestyle may also have an impact on the outcome of various interventions, they are not classified within the ICF because of the large social and cultural variance associated with them. The ICF, therefore identifies and addresses the condition of *environment* in the process **making it real** but makes clear that it does not address the second condition identified in the process **making it real**, that of *client characteristics*.

Making it real is the core process that the occupational therapists engaged in when carrying out EMA training with their clients after TBI. This process took account of conditions such as the *environment* and *client characteristics* that are considered as impacting on the success of rehabilitation interventions in models of health care such as the ICF. **Making it real** inter/actions include *creating real life* opportunities in which clients can carry out their EMA training. These inter/actions are likely to stem from shared occupation-focused theoretical models like MOHO and CMOP-E, however, the language from these models is not the everyday language that the participants used to explain concepts of human occupation, perhaps as these are no longer part of their daily language when explaining terms to clients, families and other professionals. The consequence of **making it real** was *sustained use* of the memory aids. The concerns stated in regard to a lack of sustained use of aids in

previous EMA training literature may be accounted for by the fact that very little attention was paid to the process of **making it real** and therefore aids were not a good fit with the individuals' activities in their home, work and social lives.

Implications for clinical practice

The process **making it real** was found to have an impact on all the other processes previously described. This process has not been explored in any of the previous EMA literature and this could be a reason why previous authors were concerned for sustainable use of their EMAs once clients left their studies.

Making it real may have been a focus for participants in the current study as all the participants were occupational therapists and shared a common theoretical perspective and used occupation-focused models of practice. The interactions involved in **making it real**, such as *creating real life*, focus EMA training on meaningful activities that fit the clients' real world and are important to them. This has an impact on experiencing meaningful, pre-injury activities and building insight into the difference in pre and post-injury performance. It also has an impact on client motivation for EMA training, as the training is directly relevant to their lives outside of rehabilitation. There is also an element of family, friends, employers and colleagues becoming involved in **making it real** and giving clients feedback on their progress in the EMA training.

Making it real is the most important process for occupational therapists to engage their clients in when carrying out EMA training as it ensures that the training fits with the clients' real life outside of rehabilitation. **Making it real** will add to the likely sustainability of the aid following completion of the rehabilitation program.

The four sections above relate the findings of this Masters study to previous literature and have discussed how these findings have bridged gaps in the EMA training literature or addressed barriers that have been highlighted by previous authors. The clinical implications of these findings have also been emphasised. This discussion chapter will now move on to exploring the strengths and limitations of this study and provide suggestions for future research in this area.

Strengths and limitations of this study

In chapter three my strategies for ensuring the rigour of this study were described and these will be revisited here and provide a structure for considering the strengths and limitations of the study.

Constant comparative method

It is proposed that the detailed process involved in gathering and analysing the data within a grounded theory study provides the foundation for rigour (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The constant comparative method outlined by Strauss and Corbin (1998) is meant to ensure a constant interplay between data collection, analysis and sampling and assist the researcher in staying truthful to the data. Initially it took time for me to come to grips with the procedures involved in the constant comparative method. After my first three interviews I took three to four months to analyse the data collected and compare back-and-forth between the interviews. I found coding each interview relatively simple but then building these codes into more abstract categories and checking these with each interview felt like a huge undertaking with the number of codes that I had. I required assistance from my supervisors to group these codes and make data more manageable.

Once I had established this skill of analysing the codes from one interview with the previous interviews I was able to group these together and build codes into more abstract categories. This then informed my sampling and questioning for the next interview. In this way I ensured that the theory evolved from the data itself and not from pre-conceived ideas of my own. This system also ensured that negative cases, for instance data from interviews that did not fit with the developing concepts, was considered. When interview data was grouped into the emerging concepts I could go back and look at the codes that were left and ask myself why they were there and how did they fit into the bigger picture of the data analysis. Any questions that emerged from these left-over codes could be integrated into the next interview questions to ensure that concepts became fully developed.

Reflexivity

Reflexivity refers to the way in which the researcher and the research process have shaped the data collected, including prior assumptions and experience (Mays & Pope, 2006). I have been clear throughout this research that I am an occupational therapist working in TBI rehabilitation and as such I engage in cognitive rehabilitation with clients on a regular basis, this includes training clients in the use of EMAs. I have first hand experience of processes and barriers that influence my EMA training and also of evidence that informs my own clinical practice. In preparation for this research study and in order to meet the needs of the university's application and ethics processes I had to review literature specific to the topic of memory rehabilitation and EMAs. During my research process I have remained aware of this clinical experience and its potential impact on the data. I have openly acknowledged this and shared my position with readers.

I have employed a number of ways in which to monitor my personal views and insights regarding emerging themes in the data, including the use of memo-writing and diagramming. I regularly met with my two supervisors to discuss the research process. I took examples of my coding to demonstrate my analysis and to explore the concepts that were emerging from the data. My supervisors provided a third party analysis of the data and were able to bring their own interpretations to raw data and the creation of concepts. These interpretations could then be examined in relation to my own analysis, for example, when discussing the inter/actions involved in process **making it real** one supervisor asked "are the participants really *creating real life* or are they maintaining it for their clients?" This forced me to go back and examine the data to ensure that I had considered this view and ensured clarity of the conditions, inter/actions and consequences of each process.

In addition to my supervision sessions, I was also a member of a grounded theory research group that met once a month. I was fortunate that the members of this group were predominantly people who had already completed their Masters studies using grounded theory methodology and therefore were able to provide me with a wealth of practical experience. I found discussions in this group useful in terms of challenging and reflecting on my use of grounded

theory methodology, which deepened my understanding of analytical procedures. This group also helped to broaden my understanding of the theoretical basis for grounded theory and the variety of perspectives that informed the different approaches to grounded theory. I was asked to reflect on my preferred perspective of symbolic interactionism and examine how this influenced my approach to analysing data.

On the recommendation of my supervisors I took part in a pre-suppositions interview prior to starting my own research interviews. This further assisted in ensuring reflexivity by drawing my attention to my own opinions and potential biases and enabling me to recognise these when they appeared. I am aware that this pre-suppositions interview exposed my own ideas of addressing client insight and engaging families in the EMA training. Although these became two of the final processes that emerged from the data I was cognisant of my biases towards these two issues and made an effort to ensure that, when my participants initially raised them, it was not through my influence.

Transferability

Transferability is described by Chiovitti and Piran (2003) as, 'the probability that the research findings have meaning to others in similar situations' (p. 433). Through my study I aimed to generate a substantive theory of the process of EMA training based within a neuro-rehabilitation context and preformed by occupational therapists.

As my employer has supplied the majority of funding for undertaking this Masters, I have been asked to provide updates to my therapy team at regular intervals about my experiences of the research process and the findings from my study. The feedback from these presentations has assisted me in establishing if findings are transferable to the setting in which I work. People have commented on their association with the processes that have emerged, particularly with **making it real** and **getting others on-board** and have related well to these, recognising them as actions that they carry out themselves in clinical practice.

I have also had the opportunity to present my preliminary findings at a national rehabilitation conference. The feedback that I received from occupational therapists that attended this conference was positive. These therapists described being referred clients in the community with TBI and

memory difficulties, and being asked to provide intervention to address the impact of memory deficits. They felt there was no guidance to help them with this and were tending to just 'throw everything at it'. Therapists were keen to hear more about my work and understand how they could implement aspects of it into their client interventions.

The fact that I have had positive feedback in relation to the study findings so far strengthens the sense that findings may be transferable to occupational therapists working in TBI rehabilitation. Where transferability is unclear is whether these findings could be applied to other areas of rehabilitation where memory issues have an impact on the individuals, for example the management of dementia. It is also unclear as to whether the findings can be related to other professions who undertake memory rehabilitation such as psychologists and speech language therapists. These professions are likely to have a different set of theoretical models underpinning their clinical practice and therefore may take a different approach to EMA training. Their approach may not place such a great emphasis on processes that could be considered more occupational therapy specific such as **making it real**. Further study would be required with therapists working in different client populations and therapists outside of the occupational therapy profession in order to establish if the processes found here apply elsewhere.

A further limitation of this study, which has an impact on the transferability of the findings, is that the experiences of clients with TBI and their family/whanau have not been examined. This is an area of further study that is discussed further in the following section.

Saturation

My concern partway through this research process was that I would not reach a saturation point within the time constraints applied to Masters research. However, using the grounded theory approach to analysing my interview data, the coding and comparative analysis of the emerging processes did lead to a saturation point where no new information was being collected. By my seventh and eighth interviews I was able to discuss some of the emerging concepts from the previous interviews and get the participants opinions on these. This added to the richness of the data by examining the findings through the lens of others and

adding these opinions to the data analysis. A possible explanation for why saturation occurred in fewer interviews than expected could be that some of the participants were familiar with the literature relating to EMA use after TBI. As mentioned in the introductory chapter of this thesis my colleagues and I had become aware of the need to improve our evidence based practice in this area and had sought out relevant articles to review. As this is a common intervention for occupational therapists working in all areas of TBI rehabilitation there is every chance that others I interviewed had done the same. In fact certain models of memory and authors of EMA literature were mentioned during the interviewing, for example in a quote on page 77 participant 7 mentions "Sohlberg" who is one such author. My interviewing did not examine this interaction between the study participants and the background literature.

Areas for further study

This study has explored the process of EMA training by occupational therapists by interviewing the therapists about their interventions with clients following a brain injury. This method of data collection seemed appropriate for a novice researcher, such as myself, as it was thought to be less complex than fieldwork or observations. These latter techniques were seen as intrusive, time consuming and requiring the need for more advanced analysis than I was capable of at the outset of this research. However, observations have a lot to offer, as it is not unusual for people to say they are doing one thing but in reality be doing something very different. The only way to know is through observation of the person interacting within their environment. Also people may not be consciously aware of, or be able to articulate, the subtleties of what goes on in interactions between themselves and others (Corbin & Strauss, 2008). An ethnographic study or another grounded theory study incorporating participant observations as a data gathering technique might yield further interesting findings relating to the EMA training that is completed with clients. By observing occupational therapists completing a range of EMA training sessions, from initial assessments, to final reviews it could be seen if what they have said they are doing is actually what happens.

It would also be interesting to include other professions who use similar memory rehabilitation techniques with their clients in a further study and see if an alternative professional perspective adds to the processes that have been discovered from occupational therapists. Psychologists and speech language therapists also play a role in addressing memory impairments with clients after TBI. Their theories and models of practice may be different to those used by occupational therapists and therefore have an influence on the processes they complete with clients. The processes described here could then be further refined into a more interdisciplinary approach to EMA training.

Now this theory of EMA training has been established it would be interesting to interview clients and their families/whanau about the process and their thoughts on how it fits with their first hand experience of EMA training and their likelihood of sustaining EMA use in the long-term.

There are obviously other client groups who experience memory difficulties and further study could explore whether the processes used by the participants in this study are the same as those used by therapists working in other clinical areas. This would assist in establishing if the theory of the four interacting processes: **developing client insight, getting client buy-in, getting others on board** and **making it real**, can be extended beyond EMA training with clients after a TBI and into other clinical areas.

My supervisors made an interesting observation when the development of the four above processes was taking shape. They noted that these four processes might be applied to other aspects of rehabilitation and not just to EMA training. It would, therefore, be interesting to compare these processes to those that occur in other common rehabilitation interventions that aim to manage specific impairments such as fatigue management programs. Such programs have a number of similarities to EMA training such as relying on the client having some insight into the issue being addressed, the need for active client participation in the program, the possibility of support from family/whanau and the need to relate the strategies learnt into real life scenarios.

Conclusion

When commencing this study I wanted to answer the question ‘how do occupational therapists train clients to use EMAs following a TBI?’ Through the research process I aimed to achieve the following:

- Explore occupational therapists’ experiences of external memory aid training
- Identify a process to external memory aid training
- Inform future clinical practice and research by generating a process for external memory aid training
- Provide support for clinicians/service managers in justifying this type of cognitive rehabilitation to funders

The experiences of eight occupational therapists working with clients after TBI contributed to the emergence of four processes to EMA training: **developing client insight, getting client buy-in, getting others on board and making it real**. These processes did not stand-alone and each interacted in some way with the others. **Making it real** was the core process that surrounded the other three.

This study has added to the evidence for EMA training and helped to inform clinical practice by bridging a number of gaps identified in the previous literature relating to the use of EMA training with clients after TBI. One particular barrier to successful EMA training that has been addressed is that of **developing client insight**. This study has identified useful theoretical models that occupational therapists can integrate into their practice to address this barrier and practical ways to assist clients with limited insight into their memory impairments.

Doing the groundwork was highlighted as an important aspect of EMA training in terms of **getting client buy-in**, this involved therapists finding out what aids had been used by the client previously, normalising the use of EMAs, and setting the client up with practice scenarios. *Doing the groundwork* addressed some of the barriers to EMA training previously identified in literature such as clients feeling like they are cheating in some way or identifying themselves as different from other people because they use a memory aid.

Identifying previous use of aids also had a positive impact when clients were learning to use the aid as they could rely on prospective memory, therefore making training less laborious.

Getting others on-board emerged as an important process for achieving sustainability of the memory aid. This process has been poorly reported in other EMA studies and authors have expressed concerns regarding the long-term sustainability of the memory aid use. By **getting others on-board** with the EMA training, therapists interviewed in this study felt their clients were more likely to continue the use of the aid beyond formal therapy sessions, as family or employers were aware of the positive impact of the aid and could continue to reinforce its use.

The core process **making it real** may be specific to occupational therapists due to the theoretical frameworks that underpin their clinical practice. However, more generic models that are used in rehabilitation such as the ICF also support this process. The process components of **making it real** are missing from much of the literature regarding EMA use and it has been argued here that, without the EMA training being related to the client's real life and the activities that they find important and meaningful, the client is unlikely to recognise the full potential of the aid in assisting them with their daily living. Therefore, again, sustainability is unlikely to occur. In this study the data gathered from the participant interviews suggests that **making it real** is the most important of the four processes and the most likely to lead to durable and sustained use of an EMA for a client following TBI.

References

- Aadal, L., & Kirkevold, M. (2011). A model for neurorehabilitation after severe traumatic brain injury: Facilitating patient participation and learning. *Advances in Nursing Science*, 34(1), 1-17.
- ABI Rehabilitation Management Limited (Sept, 2010). *IRS-TBI Database Quarterly Report Two*. Auckland, New Zealand: ABIRM.
- Accident Compensation Corporation. (2010). *Concussion service - Operational guidelines*. Retrieved April 2011. URL <http://www.acc.co.nz/for-providers/contracts-and-performance/operational-guidelines/index/.htm>
- Accident Compensation Corporation. (2010). *Integrated rehabilitation services for traumatic brain injury – Operational Guidelines*. Retrieved April 2011. URL <http://www.acc.co.nz/for-providers/contracts-and-performance/operational-guidelines/index/IRS-TBI.htm>
- Accident Compensation Corporation. (2009). *Training for independence – Operational Guidelines*. Retrieved April 2011. URL <http://www.acc.co.nz/for-providers/contracts-and-performance/operational-guidelines/index/trainingforindependence.htm>
- Ashby, S., & Chandler, B. (2010). An exploratory study of the occupation-focused models included in occupational therapy professional education programmes. *The British Journal of Occupational Therapy*, 73(12), 616-624.
- AUT Ethics Knowledge Base (2008). *AUTEC Ethical Principles*. Retrieved May 2008. URL <http://www.aut.ac.nz/about/ethics/default.htm>
- Boschen, K., Gargaro, J., Gan, C., Gerber, G., & Brandys, C. (2007). Family interventions after acquired brain injury and other chronic conditions: A critical appraisal of the quality of evidence. *Neurorehabilitation*, 22(1), 19-41.
- Bradbury-Jones, C. (2007). Enhancing rigour in qualitative health research: Exploring subjectivity through Peshkin's I's. *Journal of Advanced Nursing*, 59(3), 290-298.
- Brown, D., Lyons, E., & Rose, D. (2006). Recovery from brain injury: Finding the missing bits of the puzzle. *Brain Injury*, 20(9), 937-946.

- Buckner, R. L., Koutstaal, W., Schacter, D. L., Wagner, A. D., & Rosen, B. R. (1998). Functional-anatomic study of episodic retrieval using fMRI. *Neuroimage*, 7, 151-162.
- Cabeza, R., Kapur, S., Craik F. I. M., & McIntosh, A. R. (1997). Functional neuroanatomy of recall and recognition: A PET study of episodic memory. *Journal of Cognitive Neuroscience*, 9(2), 254-265.
- Cernich, A. N., Kurtz S. M., Mordecai K. L., & Ryan, P. B. (2010). Cognitive rehabilitation in traumatic brain injury. *Current Opinions in Neurology*, 12, 412-423.
- Chiovitti, R. F., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing*, 44, 427-435.
- Cicerone, K. D., Dahlberg, C., & Malec, J. F. (2005). Evidence-based cognitive rehabilitation: updated review of the literature from 1998 through 2002. *Archives of Physical Medical Rehabilitation*, 86, 1681-1692.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). CA: Sage Publications
- Crotty, M. (1998). *The foundations of social research; Meaning and perspective in the research process*. St. Leonards, NSW: Allen & Unwin Ltd.
- Dirette, D. K. (2002). The development of awareness and the use of compensatory strategies for cognitive deficits. *Brain Injury*, 16(10), 861-871.
- Dirette, D., & Plaisier, B. R. (2007). The development of self-awareness of deficits from 1 week to 1 year after traumatic brain injury: Preliminary findings. *Brain Injury*, 21(11), 1131-1136
- Dirette, D. (2010). Self-awareness enhancement through learning and function (SELF): a theoretically based guideline for practice. *British Journal of Occupational Therapy*, 73(7), 309-317.
- Donabedian, A. (1997). The quality of health care: How can it be assessed? *Archives of pathology and Laboratory Medicine*, 121 (11), 1145-1150.
- Donaghy, S., & Williams, W. (1998). A new protocol for training severely impaired patients in the usage of memory journals. *Brain Injury*, 12, 1061-1076.

- Evans, C. C., Sherer, M., Nakase-Richardson, R., Mani, T., & Irby, J. W. (2008). Evaluation of an interdisciplinary team intervention to improve therapeutic alliance in post-acute brain injury rehabilitation. *Journal of Head Trauma Rehabilitation*, 23(5), 329-338.
- Evans, J. J., Wilson, B. A., Schuri, U., Andrade, J., Baddeley, A., Brunea, O., Canavan, T., Sala, S. D., Green, R., Laakonen, R., Lorenzi, L. & Taussik, I. (2000). A comparison of errorless and trial and error learning methods for teaching individuals with acquired memory deficits. *Neuropsychological Rehabilitation*, 10(1), 67-101.
- Fleming, J. M., Shum, D., Strong, J., & Lightbody, S. (2005). Prospective memory rehabilitation for adults with traumatic brain injury: A compensatory training programme. *Brain Injury*, 19, 1-10.
- Gamboa, A. M., Holland, G. H., Tierney, J. P., & Gibson D. S. (2006). American Community Survey: Earnings and employment for persons with traumatic brain injury. *Neurorehabilitation*, 21(4), 327-333.
- Gentry, T., Wallace, J., Kvarfordt, C., & Lynch, K. B. (2008). Personal digital assistants as cognitive aids for individuals with severe traumatic brain injury: A community-based trial. *Brain Injury*, 22(1), 19-24.
- Giddings, L. S., & Wood, P.J. (2000). The methodological journey of a grounded theorist: an interview with Denise Dignam. *Nursing praxis in New Zealand*, 16(2), 4-16.
- Glaser, B. G. (1992). *Emergence vs forcing: Basics of grounded theory analysis*. Mill Valley CA: Sociology Press.
- Glaser, B.,G. (1998). *Doing grounded theory: issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Adeline De Gruyter.
- Grieve, J., & Gnanasekaran, L. (2008). *Neuropsychology for occupational therapists* (3rd ed.). Oxford: Blackwell.
- Hagedorn, R. (1997). *Foundations for practice in occupational therapy* (2nd ed.). London: Churchill Livingstone.

- Halligan, P. W. (2006). Awareness and knowing: Implications for rehabilitation. *Neuropsychological Rehabilitation, 16*(4), 456-473.
- Hart, T., Seignourel, P. J., & Sherer, M. (2009). A longitudinal study of awareness of deficit after moderate to severe traumatic brain injury. *Neuropsychological Rehabilitation, 19*(2), 161-176.
- Health Research Council of New Zealand (1998). *Guidelines for researchers on health research involving Maori*. Auckland: Health Research Council of New Zealand.
- Kapur, N. (1988). *Memory disorders in clinical practice*. London: Butterworth & Co. Ltd.
- Kennedy, M. (2006). Managing memory and metamemory impairment in individuals with traumatic brain injury. *The ASHA Leader, 11*(14), 34-36.
- Kielhofner, G. (2008). *Model of Human Occupation: theory and application* (4th ed.). Philadelphia, PA: Lippincott, Williams & Wilkins.
- Kreutzer, J. S., Marwitz, J. H., Godwin, E. E., & Arango-Lasprilla, J. C. (2010). Practical approaches to effective family intervention after brain injury. *Journal of Head Trauma Rehabilitation, 25*(2), 113-120.
- Lannin, N. A., Carr, B., Allaous, J., MacKenzie, B., Tate, R., & Falcon, A. (2010). Using a handheld computer (PDA) improves the functional ability of people with memory and planning difficulties after brain injury. *RSU News, 12*(2), 3.
- Lee, A. C. H., Robbins, T., Smith, S., Calvert, G. A., Tracey, I., Mathews, P., & Owen, A. M. (2002). Evidence for asymmetric frontal-lobe involvement in episodic memory from functional magnetic resonance imaging and patients with unilateral frontal-lobe excisions. *Neuropsychologia, 40*, 2420-2437.
- Levack, W. M. M., Kayes, N. M., & Fadyl, J. K. (2010). Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disability and Rehabilitation, 32*(12), 986-999.
- Levack, W. M. M., Taylor, K., Siegert, R. J., Dean, S. G., McPherson, K. M., & Weatherall, M. (2006). Is goal planning in rehabilitation effective? A systematic review. *Clinical Rehabilitation, 20*, 739-755.

- Lloyd, J., Riley, G. A., & Powell, T. E. (2009). Errorless learning of novel routes through a virtual town in people with acquired brain injury. *Neuropsychological Rehabilitation*, 19(1), 98-110.
- Mays, N., & Pope, C. (2006). Quality in qualitative health research. In C. Pope & N. Mays (Eds.), *Qualitative research in health care* (pp.82-101). Oxford: Blackwell publishing Ltd.
- McCallin, A. (2003). Grappling with the literature in a grounded theory study. *Contemporary Nurse*, 15(2), 61-69.
- McColl, M.A., Law, M., Stewart D., Doubt, L., Pollock, N., & Krupa, T. (2003). *Theoretical Basis of Occupational Therapy* (2nd ed.). Thorafare, New Jersey: Slack Inc.
- McGhee, G., Marland, G. R., & Atkinson, J. (2007). Grounded theory research: Literature reviewing and reflexivity. *Journal of Advanced Nursing*, 60(3), 334-342.
- McKerracher, G., Powell, T., & Oyeboode, J. (2005). A single case experimental design comparing two memory notebook formats for a man with memory problems caused by traumatic brain injury. *Neuropsychological Rehabilitation*, 15(2), 115-128.
- McNamara, P., Durso, R., & Harris, E. (2006). Life goals of patients with Parkinson's disease: A pilot study on correlations with mood and cognitive functions. *Clinical Rehabilitation*, 20, 818-826.
- Morse, J. M., Stern, P. N., Corbin, J., Bowers, B., Charmaz, K., & Clarke A. E. (2009). *Developing grounded theory: The second generation*. Walnut Creek, CA: Left Coast Press.
- New Zealand Association of Occupational Therapy. (2009). *Te Umanga Whakaora Accelerated Maori Occupational Therapy Workforce Development*. Wellington: NZAOT.
- New Zealand Guidelines Group. (2006). *Traumatic brain injury: diagnosis, acute management and rehabilitation. Evidence-based best practice guideline produced for ACC*. Wellington, New Zealand: ACC.
- Occupational Therapy Board of New Zealand (2004). *Code of ethics for occupational therapists*. Wellington: OTBNZ

- Owensworth, T. L., McFarland, K., & Young, R. M. (2000). Development and standardisation of the self-regulation skills interview (SRSI): A new clinical assessment tool for acquired brain injury. *The Clinical Neuropsychologist*, 14(1), 76-92.
- Port, A., Willmott, C., & Charlton, J. (2002). Self-awareness following traumatic brain injury and implications for rehabilitation. *Brain Injury*, 16(4), 277-289.
- Powell, T. (2007). *Head Injury: A practical guide (3rd ed.)*. Brackley: Speechmark Publishing Limited.
- Powell, T., & Malia, K. (2006). *Brain Injury Workbook: Exercises for cognitive rehabilitation*. Bicester: Speechmark Publishing Limited
- Prigatano, G. P., Klonoff, P. S., O'Brien, K. P., Altman, I. M., Amin, K., Chiapello, D. A., Shepherd, J., Cunningham, M., & Moram, M. (1994). Productivity after neuropsychologically oriented milieu rehabilitation. *Journal of Head Trauma Rehabilitation*, 9(2), 91-102.
- Prigatano, G. P. (2005). Disturbances of self-awareness and rehabilitation of patients with traumatic brain injury: A 20-year perspective. *Journal of Head Trauma Rehabilitation*, 20(1), 19-29.
- Prigatano, G. P. (2009). Anosognosia: clinical and ethical considerations. *Current Opinion in Neurology*, 22, 606-611.
- Relyea-Chew, A., Hollingworth, W., Chan, L., Comstock, B. A., Overstreet, K. A., & Jarvik, J. G. (2009). Personal bankruptcy after traumatic brain injury or spinal cord injury: The role of medical debt. *Archives of Physical Medicine & Rehabilitation*, 90(3), 413-419.
- Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53(3), 304-310.
- Rose, G. (1992). *The strategy of preventative medicine*. Oxford: Oxford University Press.
- Schmitter-Edgecombe, M., Fahy, J. F., Whelan, J. P., & Long, C. J. (1995). Memory remediation after severe closed head injury: Notebook training versus supportive therapy. *Journal of Consulting and Clinical Psychology*, 63, 484-489.

- Sherer, M., Evans, C. C., Leverenz, J., Stouter, J., Irby, J. W., Lee, J. E., & Yablon, S. A. (2007). Therapeutic alliance in post-acute brain injury rehabilitation: Predictors of strength of alliance and impact of alliance on outcome. *Brain Injury*, 21(7), 663-672.
- Sherer, M., Hart, T., Nick, T. G., Whyte, J., Thompson, R. N., & Yablon, S. A. (2003). Early impaired self awareness after traumatic brain injury. *Archives of Physical Medicine Rehabilitation*, 84, 168-176.
- Shores, E. A., Marossezeky, J. E., Sandanam, J., & Batchelor, J. (1986). Preliminary validation of a scale for measuring the duration of post-traumatic amnesia. *Medical Journal of Australia*, 144(11), 569-572.
- Sivaramen Nair, K. P. (2003). Life goals: The concept and its relevance to rehabilitation. *Clinical Rehabilitation*, 17, 192-202.
- Sivaraman Nair, K. P., & Wade, D. T. (2003). Life goals of people with disabilities due to neurological disorders. *Clinical Rehabilitation*, 17, 521-527.
- Sohlberg M. M., Kennedy, M., Avery, J., Coelho, C., Turkstra, L., Ylvisaker, M., & Yorkston, K., (2007). Evidence based practice for the use of external aids as a memory compensation technique. *Journal of Medical Speech-Language Pathology*, 15 (1), 15-24.
- Sohlberg, M. M., & Mateer, C. A. (1989). Training use of compensatory memory books: A three stage behavioural approach. *Journal of Clinical and Experimental Neuropsychology*, 11, 871-891.
- Stalnacke, B., Elgh, E., & Sojka, P. (2007). One year follow-up of mild traumatic brain injury: Cognition, disability and life satisfaction of patients seeking consultation. *Journal of Rehabilitation Medicine*, 39(5), 405-411.
- Stanley, M. (2006). A grounded theory of the wellbeing of older people. In L. Findlay & C. Ballinger (Eds.), *Qualitative research for allied health professionals: Challenging choices* (pp. 63-78). Chichester: John Wiley & Sons.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. California: Sage Publications.

- Strauss, A., L., & Corbin, J., (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory* (2nd ed). Thousand Oaks, CA: Sage Publications.
- Stroud, A. (2009). Understanding and adapting after head injury: Impact of awareness on rehabilitation. *British Journal of Neuroscience Nursing*, 5(5), 200-204.
- Stuss, D. T., & Anderson, V. (2004). The frontal lobes and theory of mind: developmental concepts from adult focal lesion research. *Brain and Cognition*, 55(1), 69-83.
- Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness: A practical scale. *Lancet*, 2, 81-84.
- The Brain Injury Association of New Zealand Inc. (2007). *Brain Injury New Zealand*. Retrieved Feb 17, 2010, from www.brain-injury.org.nz/braininjury_what.html.
- Thickpenney-Davis, K. L., & Barker-Collo, S. L. (2007). Evaluation of a structured group format memory rehabilitation program for adults following brain injury. *Journal of Head Trauma Rehabilitation*, 22(5), 303 - 313.
- Tobin, G., A., & Begley, C., M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, 48(4), 388-396.
- Townsend, E.A., & Polatajko, H. J. (2007). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation*. Ottawa, ON: CAOT Publications ACE.
- Van den Broek, M. D., Downes, J., Johnson, Z., Dayus, B., & Hilton, N. (2000). Evaluation of an electronic memory aid in the neuropsychological rehabilitation of prospective memory deficits. *Brain Injury*, 14, 455-462.
- Van Hulle, A., & Hux, K. (2006). Improvement patterns among survivors of brain injury: Three case examples documenting the effectiveness of memory compensation strategies. *Brain Injury*, 20, 101-109.
- Wilson, B., Cockburn, J., & Baddeley, A. (1991). *The Rivermead Behavioural Memory Test* (2nd ed.). Bury St. Edmunds: Thames Valley Test Company.

- Wilson, B., Emslie, H., Quirk, K., Evans, J., & Watson, P. (2005). A randomized control trial to evaluate a paging system for people with traumatic brain injury. *Brain Injury*, 19 (11), 891-894.
- World Health Organization (2001). *International Classification of Functioning, Disability and Health*. Geneva: WHO
- Wright, P., Rogers, N., Hall, C., Wilson, B., Evans, J., Emslie, H., & Bartram, C. (2001). Comparison of pocket-computer memory aids for people with brain injury. *Brain Injury*, 15, 787-800.

Appendix A – Participant Information Sheet



Participant Information Sheet

Date Information Sheet Produced: 20th November 2009

Project Title: *A qualitative exploration of external memory aid training by occupational therapists*

An Invitation

You are invited to take part in this research project exploring the processes in which occupational therapists engage when training clients in the use of external memory aids following traumatic brain injury (TBI). Your participation in this project is entirely voluntary. You can choose to withdraw at any time without consequence.

What is the purpose of this research?

To explore occupational therapists' experiences of external memory aid training which have led to efficient and durable use of a memory aid by their clients

To identify a process to external memory aid training

To inform future clinical practice and research by generating a process for external memory aid training

To provide support for clinicians/service managers in justifying this type of cognitive rehabilitation to funders

This project will contribute towards my Masters in Health Science. I also plan to submit the study findings for publication in relevant journals or for conferences.

How was I chosen for this invitation?

You are invited to take part in this study as you are a member of the Auckland Regional Neurological Special Interest Group and it is likely that you either currently provide rehabilitation for clients after a TBI or have done so in the recent past (e.g. as part of a rotation scheme). If this is the case, then you have relevant experience that could inform this project. If you choose to participate in this study please reply via my email address or telephone number below.

What will happen in this research?

The study involves interviews with occupational therapists that work in the area of TBI rehabilitation. If you choose to take part you will be asked to spend approximately 1 hour being interviewed about your experience of external memory aid training. The interview will be audio taped and will be conducted at a venue suitable to you. During my analysis of the data collected, the occasion may arise where I need to return to you to clarify any emerging concepts. In this instance I will contact you and arrange a convenient time to make these clarifications.

What are the discomforts and risks?

In the interviews we will be discussing your experiences of training clients to use external memory aids. As an occupational therapist you will be used to reflecting on your clinical practice and therefore the discomfort to you will be minimal. At this time there is no recognised 'best practice' for this type of intervention and therefore there are no 'right-or-wrong' answers, I am only interested in hearing your experience.

How will these discomforts and risks be alleviated?

You will be given the opportunity to review the transcript of your interview once it has been typed and confirm that the transcript is a realistic reflection of your interview. You may withdraw from the interview and/or study at any time if you are feeling uncomfortable. Should any unforeseen discomfort arise through the interview process there is an option of debriefing sessions with AUT Health, Counselling and Wellbeing Services. These contact details are given below.

What are the benefits?

You may find that being interviewed about your experiences is an enjoyable way to reflect on your current practice. It is hoped that the outcomes of the study will benefit occupational therapists by adding to the body of knowledge around external memory aid training and inform future clinical practice. Ultimately, the study will help occupational therapists to provide evidence-based services to their clients.

How will my privacy be protected?

Interview recordings and transcripts will only be available to me, as the researcher, and my supervisors (named below). The interview data will be coded so as to ensure anonymity and data will be kept in a locked cabinet or password accessible computer file. In the written material, all participants will be given a pseudonym instead of their real name and work place descriptions will be kept generic so as to reduce the risk of identification.

What are the costs of participating in this research?

The only cost to you as a participant in this research is your time. If you choose to take part, you will be involved in an interview with me, lasting approximately 1 hour. I can meet you at your place of work or somewhere convenient to you.

What opportunity do I have to consider this invitation?

Please contact me via the email or telephone contacts provided below to express your interest within 1 week of receiving this information sheet.

How do I agree to participate in this research?

Once you have indicated your interest to participate in the research, you will need to complete a simple consent form and demographic form, which will be sent to you either via email or post. Once you have completed these forms and returned them, I will contact you to arrange an interview date and venue.

Will I receive feedback on the results of this research?

You will receive a copy of the interview transcript, which you are invited to review and comment on. You can choose to receive a summary of the findings of the research once the project has been completed. Please keep in mind that this may be up to 12 months after your interview. This summary can be posted to an address of your choice.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the researcher, Jonathan Armstrong, or the Principle Project Supervisor, Kathryn McPherson, via the contact details below. Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTECH, Madeline Banda, madeline.banda@aut.ac.nz , 921 9999 ext 8044.

Whom do I contact for further information about this research?

Researcher Contact Details:

Occupational Therapist. Email: jnx7020@aut.ac.nz, Phone: 021 022 34106

Project Supervisors Contact Details:

Kathryn McPherson, Professor of Rehabilitation, Division of Rehabilitation and Occupation Studies, AUT University. Email: kathryn.mcpherson@aut.ac.nz, Phone: 09 921-9999 ext 7110

Shoba Nayar, Occupational Therapy Lecturer, Division of Rehabilitation and Occupation Studies, AUT University. Email: shoba.nayar@aut.ac.nz, Phone: 09 921 9999 ext 7304.

AUT Health, Counselling and Wellbeing Services:

City Campus: 09 921 9992 or North Shore Campus: 09 921 9998

Approved by the Auckland University of Technology Ethics Committee on 12th January 2010 ethics, Reference number 09/300.

Appendix B – Consent Form



Consent Form

Project title:

A qualitative exploration of external memory aid training by occupational therapists

Project Supervisors: Kathryn McPherson and Shoba Nayar

Researcher: Jonathan Armstrong

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 20th November 2009
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes may be taken during the interviews and that they will also be audiotaped and transcribed.
- ☐ I am aware that I may be contacted following my interview should there be a need to clarify any points that have emerged during the data analysis
- ☐ I understand that I may withdraw myself, or any information that I have provided, from this project at any time prior, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one):
Yes ☐ No ☐

Participant's signature:.....í í í í í í í í í í

Participant's name:.....í í í í í í í í í í í ..

Participant's Contact Details:

í
 í
 í
 Date: í í í í .

AUTEC Reference number 09/300.

Appendix C – Demographic Data Form



Demographic Data Form

Your answers to the following questions will assist me in establishing your work history and current working environment. This will enable me to select participants to interview who provide variation in the information being collected.

Name

In which year did you qualify as an occupational therapist?

How many years experience do you have in working with clients who have had brain injury?

What type of health service do you work in? (tick those which apply)

- ☐ ACC Provider
- ☐ DHB
- ☐ Private Practice
- ☐ Residential Rehabilitation Service
- ☐ Community Rehabilitation Service

At which stages of clients' rehabilitation do you mostly work? (tick those which apply)

- ☐ Acute (< 1 month)
- ☐ Post-Acute Rehabilitation (1 to 6 months)
- ☐ Longer-term rehabilitation (6 months to 2 years)
- ☐ Later stage (2+ years)

Signed

Date

Appendix D – Participant Demographics

Participant	Year of OT registration	Years of TBI experience	Type of service	Stage of rehabilitation
1	2005	3	Residential Rehab	Post-acute (1 to 6 mths)
2	1990	3.5	Residential & Community Rehab	Post-acute to later stage (1 mth to 2 yrs)
3	2007	2.5	Community Rehab	Post-acute to long-term (1 mth to 2 yrs)
4	2002	5.5	Community Rehab	Post-acute to long-term (1 mth to 2 yrs)
5	2005	2	District Health Board ó in-patient	Post-acute (1 to 6 mths)
6	2004	3	ACC Provider, long-term residential	Longer term and later stage (6mths - 2yrs+)
7	1999	8	ACC Provider, community rehab	Post-acute and longer term (1mth ó 2 yrs)
8	2006	2	Residential Rehab	Post-acute (1 ó 6 mths)

Appendix E – Interview Question Examples

Tell me about a time when you have implemented an external memory aid with a client.

How did you go about selecting the aid for your client?

Can you identify any specific stages in your training process?

What was it about the process that made it work/or not work for both you and the client?

What was it that made the external memory aid successful/ or unsuccessful?

Tell me about any barriers you have come across when training someone in the use of an external memory aid?

Appendix F – Interview Question Grid, August 2010

Talk me through the area that you work in and the sort of clients that you see.

Tell me about your experience of external memory aid training with previous clients, what did you do and how did you do it?

Ultimately what were you hoping to achieve?

<p>Getting family/friends/employers etc “on-board” ó when, how and why?</p> <p>Reasons so far:</p> <ul style="list-style-type: none"> • öReinforceö • Durability • öRepetitionö • Create örealö context <p>Does the quality of these relationships have an impact on the intervention?</p>	<p>Client participation ó How and why?</p> <p>öWorking togetherö</p> <p>Participation</p> <p>Engagement</p> <p>öBuy-inö</p>
<p>Importance of creating the öreal worldö</p> <p>öReal worldö</p> <p>öReal lifeö</p> <p>öMeaningfulö</p> <p>öGoalsö</p>	<p>Groups as a medium</p> <p>Peer support?</p> <p>Improving insight?</p>
<p>What barriers do you see in this kind of intervention? What makes it difficult?</p> <p>Structural ó contracts, management, resources, staffing</p> <p>Client ó sensory, physical impairments</p> <p>Self??? ó lack of knowledge</p> <p>How do you decide what/what not to address?</p>	<p>What support structures are there in place to help you with implementing an EMA?</p> <p>No mention of supervision as yet</p>
<p>Addressing client insight</p> <p>Assessing insight</p> <p>Building insight through education, reality testing (öfailureö) and explanation of failure, client öself-reflectionö</p> <p>Emotional for OT and client?</p>	<p>How do you evaluate what you have done?</p> <p>Achievement of goals</p> <p>Integration of EMA in öreal lifeö</p> <p>Outcome measure?</p>

Appendix G – Ethics Approval



MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Kathryn McPherson
 From: **Madeline Banda** Executive Secretary, AUTEC
 Date: 12 January 2010
 Subject: Ethics Application Number 09/300 **A qualitative exploration into the process of external memory aid training by occupational therapists.**

Dear Kathryn

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 14 December 2009 and that I have approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 8 February 2010.

Your ethics application is approved for a period of three years until 12 January 2013.

I advise that as part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/research/research-ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 12 January 2013;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/research-ethics>. This report is to be submitted either when the approval expires on 12 January 2013 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at ethics@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the AUTECH and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

A handwritten signature in black ink, appearing to read 'M. Banda', with a stylized flourish at the end.

Madeline Banda

Executive Secretary

Auckland University of Technology Ethics Committee