

Communication Training for Paid Caregivers of People with Traumatic Brain Injury (TBI)

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Author's Contribution

Communication training for paid caregivers of people with traumatic brain injury (TBI)

I Nicholas Behn, was primarily and principally responsible for the following: development of the research proposal; submission for ethical approval; data collection; data management; data analysis; and interpretation and presentation of the findings.

I acknowledge the assistance of my supervisors, who provided constructive feedback and critique throughout all stages of the research including development of the research questions, research methods, data analysis and interpretation and reviewed initial drafts of the thesis.

Signed

A handwritten signature in black ink, consisting of a long, sweeping horizontal line with several vertical strokes above it, resembling the name 'Nicholas Behn'.

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Date: 15.6.11

Declaration of Originality

Communication training for paid caregivers of people with traumatic brain injury (TBI)

I certify that this thesis and the research reported in it are original. It contains no material which has been submitted for the award of any degree in any other university, and that to the best of my knowledge and belief, this thesis contains no copy or paraphrase of material previously published or written by another person, except where due reference is made in the text of this thesis.

Signed

A handwritten signature in black ink, consisting of a series of overlapping, sweeping strokes that form a cursive-style name.

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Date: 22.7.11

Abstract

Communication impairments are common following traumatic brain injury (TBI) and affect the ability of a person with TBI to have successful conversations. Ylvisaker, Sellers and Edelman (1998) argue that training to improve the communication skills of an everyday support person would impact on the functioning of a person with TBI. Paid caregivers are often involved to support people with TBI, however, little attention has been focused directly on improving their interaction skills. Therefore, this thesis describes a study conducted to investigate the effect of a communication training program on improving the conversational interactions between paid caregivers and people with TBI.

Participants were 10 paid caregivers randomly selected and allocated to either a control or training group. Treatment comprised a 17 hour program (across 6 weeks) that combined collaboration and elaboration conversational strategies (Ylvisaker et al., 1998) with discourse activities (Togher, McDonald, Code, & Grant, 2004). Two conversational interactions (i.e. structured and casual conversations) were videotaped pretraining, posttraining and at 6 months follow-up. The conversations were rated by two independent judges. In addition, focused interviews were conducted pre and posttraining to explore the experiences of trained paid caregivers.

Training for paid caregivers improved their structured conversational interactions with people with TBI. Independent raters perceived these interactions to be more appropriate, more rewarding and more interesting compared to a control group. Trained paid caregivers made greater improvements in their ability

to acknowledge and reveal the competence of a person with TBI. Improvements were maintained for six months. No significant changes were found for the casual conversational interactions. Findings from the focused interviews revealed that trained paid caregivers reported improvements in their knowledge of effective communicative strategies. This perceived improvement led to interactions reported as more enjoyable and successful and less frustrating. Trained paid caregivers also perceived increased confidence and ability to self-regulate their use of strategies when communicating with people with TBI. Aspects of the training program that were felt to promote or hinder learning were also identified.

The findings from this study highlight the importance of training and educating paid caregivers to improve their communication skills. Training can have a significant impact on interactions that involve both paid caregivers and a person with TBI.

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Presentations

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Chapter 1

Introduction

1.1 Context of the Problem

The impact of sustaining a traumatic brain injury (TBI) is often significant and life changing resulting in long-term cognitive, behavioural and emotional changes. Services to address these changes include inpatient rehabilitation, post-acute rehabilitation programs, transitional living units and community based rehabilitation services. Many services employ paid caregivers to support the person with TBI to achieve independence. In the most severe of cases, paid caregivers can be employed within a home to alleviate the stress and burden of caring for a person with TBI for family members. However, few studies have investigated the skills of paid caregivers in managing the cognitive, behavioural and emotional changes in people with TBI.

Of the many changes that occur following a TBI, communication impairments are common post-injury and are known to impact on successful social and community re-integration (Galski, Tompkins, & Johnston, 1998; Knox & Douglas, 2009; Snow, Douglas, & Ponsford, 1998). Communication impairments make it difficult for a person to return to work and maintain social networks which can lead to social isolation, feelings of withdrawal, anxiety and depression. Intervention approaches that aim to remediate the underlying communication impairment involve the use of behavioural techniques to teach appropriate social behaviour (Dahlberg, Cusick, Hawley, Newman, Morey,

Harrison-Felix, & Whiteneck, 2007; Flanagan, McDonald, & Togher, 1995; McDonald, Tate, Togher, Bornhofen, Long, Gertler, & Bowen, 2008; Wiseman-Hakes, Stewart, Wasserman, & Schuller, 1998). However, improvements post intervention in social communication skills have been shown to reduce over time with little impact on measures of quality of life or social integration (Dahlberg et al., 2007; McDonald et al., 2008). Impairment-based interventions are limited by the exclusive focus on development of specific skills for the person with TBI (e.g. turn taking, starting a conversation). These skills are taught predominantly within a clinic-based environment. Moreover, improvements for people with TBI are affected by significant cognitive impairments including an impaired ability to learn. Therefore, this thesis seeks to move beyond the level of the impairment, to consider the broader communicative environment of the person with TBI by focusing on the role of the communication partner.

As communication is both dynamic and collaborative, communication partners of people with TBI have been recognised as an important contextual factor in the rehabilitation process (Ylvisaker, Feeney, & Urbanczyk, 1993). The skills of a communication partner can influence the extent to which an interaction is either hindered or facilitated (Togher, Hand, & Code, 1997a; Togher, Taylor, Aird, & Grant, 2006). The use of positive communication strategies and the creation of a positive communicative environment can improve the functioning of a person with TBI (Bellon & Rees, 2006; Shelton & Shryock, 2007). Therefore, communication partners should be trained and supported in skills that can improve interactions with people with TBI.

Conversational interactions of people with TBI have been shown to improve following training for communication partners. For example, training police officers alone was found to reduce the number of inappropriate and incomplete remarks made by people with TBI who did not receive any training during telephone interactions (Togher et al., 2004). More recently, people with TBI were perceived to have more appropriate, rewarding and less effortful interactions with family members following training (Togher, McDonald, Tate, Power, & Rietdijk, 2010a). Training the person as well as their communication partner was more effective than training the person with TBI alone. Both these studies highlight the integral role of a communication partner for improving the interactions that involve people with TBI. However, there is a paucity of research that has investigated paid caregivers as communication partners for people with TBI. The only study to have focused on paid caregivers reported improved teaching and interaction skills following training of behaviour management rather than communication strategies (Ducharme & Spencer, 2001). Paid caregivers increased their use of skills in a range of simulated scenarios representative of situations encountered in a rehabilitation setting with people with a brain injury. Training was conducted with paid caregivers alone.

Communication partner training for paid caregivers and other non-family members has also been shown to be valuable in improving the interactions involving people with aphasia, developmental disabilities and the elderly. Training has improved the success of interactions (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Legg, Young, & Bryer, 2005) and positively impacted

the well-being and social participation of the person with disability (Lyon, Cariski, Keisler, Rosenbek, Levine, Kumpula, Ryff, Coyne, & Blanc, 1997; McVicker, Parr, Pound, & Duchan, 2009). Communication partners of people with aphasia, developmental disabilities and the elderly have included paid caregivers and other non-family members such as volunteers, students and nursing assistants. However, there is variability in the length and content of existing communication partner training programs (Dobson, Upadhyaya, & Stanley, 2002; Kagan et al., 2001; Kruijver, Kerkstra, Francke, Bensing, & van de Wiel, 2000; Lyon et al., 1997; Rayner & Marshall, 2003; Togher et al., 2010a). The content of a training program for people with TBI would need to be tailored to the type of communication impairments that present post-injury. Ylvisaker et al. (1998) describe conversational strategies for people with TBI that would help to facilitate more equal and successful interactions and encourage caregivers to be non-directive and non-demanding. Moreover, training for paid caregivers needs to be relevant to the working environment and target situations that frequently occur within the workplace (Bloomberg, West, & Iacono, 2003; Ducharme & Spencer, 2001; Purcell, McConkey, & Morris, 2000). This thesis will review the literature to identify an optimal length and content of a program for paid caregivers of people with TBI.

It is desirable for improvements made from training to be sustained long-term for a paid caregiver and a person with TBI. Previous studies have reported mixed results with skills either improving, returning to baseline levels or remaining unchanged in the weeks and months following the completion of

training (Burgio, Allen-Burge, Roth, Bourgeois, Dijkstra, Gerstle, Jackson, & Bankester, 2001; Dobson et al., 2002; Rayner & Marshall, 2003). Long-term cognitive, behavioural and emotional changes occur in the person with TBI post-injury which may restrict their ability to maintain newly learnt skills. Providing training for paid caregivers may assist with the acquisition of communication skills and the maintenance of improvements. Financial pressures and time constraints for health professionals also make regular training and education of a communication partner difficult. Therefore, improved skills need to be measured and sustained for months after training for the program to be effective.

This thesis aims to investigate and present the findings from a study that evaluates communication partner training for paid caregivers of people with TBI. Minimal research has focused on the support needs of paid caregivers who are frequently involved in the lives of people with TBI. The results of the study will therefore be relevant for speech pathologists and other health professionals and will have strong implications for the support and management of behaviour and communication impairments for people with TBI post-injury.

Before outlining the importance of communication partner training programs and describing the methodology of the study, the next section of the thesis will define, classify and outline the characteristics of TBI. The long-term changes that occur following a TBI and the range of available rehabilitation services will be explored. The importance of paid caregivers within existing rehabilitation services will also be discussed.

1.2 Definition of TBI

Traumatic brain injury (TBI) is a global health problem that leads to lifelong disability and affects the provision of health and medical resources (Bruns & Hauser, 2003; Corrigan, Selassie, & Orman, 2010; Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). According to the World Health Organisation, TBI will surpass many diseases as the major cause of death and disability by the year 2020 (Hyder et al., 2007). The National Head Injury Foundation (NHIF): Harrison and Dijkers (1992) define TBI as “an insult to the brain... caused by an external physical force... which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behaviour or emotional functioning. These impairments may... cause partial or total functioning disability or psychosocial maladjustment”. (p.206). Immediate and long-term management of TBI can often be dependent on the severity of injury which can be determined early post-injury.

1.2.1 Classification of TBI.

Severity of injury for people who sustain a TBI can range from those who die prior to a hospital admission, those in a persistent vegetative state (PVS) or minimally conscious state (MCS) to those who do not admit themselves to the hospital emergency department. Severity is assessed with indicators that measure depth and duration of coma and the presence and length of posttraumatic amnesia (PTA). Measurements provide a grade from mild through moderate, severe and very severe depending on the indicator used. For the

purposes of this study, PTA was used as the indicator of severity which is the period following emergence from coma where the person is confused, disorientated and sometimes agitated (Russell & Smith, 1961). PTA can be assessed with a range of measures that determine a person's orientation to time, person, place and memory for recent events. Assessed either retrospectively or prospectively, periods of less than an hour indicate a mild injury, 1 - 24 hours a moderate injury, 1 - 7 days a severe injury and 1 - 4 weeks a very severe injury (Jennett & Teasdale, 1981).

1.2.2 Incidence and prevalence of TBI.

TBI is a major international problem that has a life-long impact and creates a financial burden on a healthcare system. Conservative estimates for the incidence of TBI that require medical attention or result in death have been cited as greater than 9.5 million for 1990 (Corrigan et al., 2010). The incidence of TBI is between 180 and 250 per 100,000 population per year in the United States (Bruns & Hauser, 2003) and 108 per 100,000 in Australia (Australian Institute of Health and Welfare, 2008). The Australian Institute of Health and Welfare (2008) reported 22,710 hospital admissions related to TBI with 26,000 episodes of patient care costing \$184 million in hospital care direct costs in the years 2004-05. Moderate and severe cases of TBI are likely to impact most on the provision of services occurring in 8 - 25% and 4 - 10% of cases respectively (Bruns & Hauser, 2003). There are 3.2 million US civilian residents who are living with a

disability as a result of TBI which highlights the impact and burden TBI can have on a healthcare system.

1.2.3 Characteristics of TBI.

Common causes of TBI include falls, cycling accidents, assaults, sporting and gunshot injuries with motor vehicle accidents the most common accounting for 48% of all injuries (Kraus, Black, Hessol, Ley, Rokaw, Sullivan, Bowers, Knowlton, & Marshall, 1984). Motor vehicle accidents occur most in the 15 - 24 age group with falls a common cause of TBI in adults over 75 years and children in the 0 - 4 age group (Kraus et al., 1984; Tate, McDonald, & Lulham, 1998). The cause and age distribution of TBI has remained relatively unchanged over time (Bruns & Hauser, 2003). Tate et al. (1998) reported that the highest age specific rate was for people aged 15 - 24 accounting for 26.2% of all traumatic injuries which has been similarly shown by the Australian Institute for Health and Welfare (2008). Tate et al. (1998) reported that the incidence rate reduced after the age of 34 before increasing after the age of 75. Males are consistently at a higher risk compared with females by at least 2:1 (Bruns & Hauser, 2003) particularly during adolescence and young adulthood (Kraus et al., 1984; Tate et al., 1998). However, incidence rates for males and females are similar after 70 - 75 years of age (Australian Institute of Health and Welfare, 2008; Kraus et al., 1984).

1.3 Changes following TBI

Substantial cognitive, behavioural and emotional changes can occur following a TBI as a result of damage to the brain, particularly the frontal and

temporal lobes. Damage can result in problems with attention, memory, executive function, new learning, inhibiting responses, regulation of mood and emotions, planning and organisational abilities and problem solving (Levin & Kraus, 1994; Sohlberg & Mateer, 2001). The person with TBI may lack initiation, drive and motivation, be disruptive, restless and perseverative, lack self-control and empathy, be concrete, rigid and egocentric with poor self-monitoring and regulation of behaviours (Wood, 2001). People with TBI require rehabilitation to be able to deal with the impact of these changes years post-injury.

Changes are known to persist long-term despite early inpatient rehabilitation (Fleming, Tooth, Hassell, & Chan, 1999; Knight, Devereux, & Godfrey, 1998; Levin & Kraus, 1994; Lippert-Gruner, Kuchta, Hellmich, & Klug, 2006; Oddy & Humphrey, 1980; Olver, Ponsford, & Curran, 1996; Sohlberg & Mateer, 2001; Wood & McMillan, 2001). Recently, it was estimated that 43.3% of people discharged from hospital with the diagnosis of TBI will develop some long-term disability (Selassie, Zaloshnja, Langlois, Miller, Jones, & Steiner, 2008). In the United States, this equates to almost 125,000 people per year. Lippert-Gruner et al. (2006) found that changes such as agitation, inaccurate insight, emotional withdrawal, disinhibition, depressive mood, memory deficits, decreased initiative and poor planning persisted 6 - 12 months into the future despite early rehabilitation that lasted between 4 and 78 days. Olver et al. (1996) found that at 5 years post-injury 103 people with TBI that had on average 9 months of inpatient rehabilitation felt more irritable, short-tempered or aggressive (66%), forgetful (71%), slower at thinking (69%), had poor concentration (60%),

experienced fatigue more often (73%) and were depressed (56%) compared to pre-injury. Family members have reported similar changes on average 6 years post-injury (Knight et al., 1998). Therefore, long term services directly targeted to the brain injury are required to address ongoing issues for people with TBI (Hodgkinson, Veerabangsa, Drane, & McCluskey, 2000).

1.4 Long-term Support for People with TBI

A wide range of services exist to provide rehabilitation for the person with TBI in the short and long-term post-injury. Services range from acute inpatient rehabilitation, specialist rehabilitation to longer term post-acute rehabilitation programs. Long-term programs include further inpatient rehabilitation, transitional living units and community based services such as vocational retraining and voluntary work. In the mildest of cases the person with TBI may be discharged home after only a few days whilst in the more severe cases people may require long-term care that can take the form of supported living, live in care or respite care. However, irrespective of severity, people with a brain injury will require some level of access to services years post-injury (Hodgkinson et al., 2000).

Post-acute rehabilitation is a cost effective and clinically proven service that can lead to significant functional gains more than a year post-injury (High Jr, 2005). Murrey and Starzinski (2004) demonstrated a 59% reduction in aggressive behaviours for 44 people with TBI that were on average 63 months post-injury at admission. Likewise, functional and social improvement has been demonstrated following post-acute rehabilitation for 133 people who were on average 2 years

post-injury (ranging from 1 week to 27 years post-injury) (Worthington, Matthews, Melia, & Oddy, 2006). Improvements occurred irrespective of time since injury resulting in lifetime savings in care costs of between £0.8 - 1.1 million for those admitted within the first 12 months to £0.36 - 0.5 million for those admitted after 2 years. Rehabilitation can therefore reduce the long-term financial burden of TBI.

1.5 Paid Caregivers for People with TBI

Paid caregivers are often involved within rehabilitation services to deliver a therapy program and support the person with TBI. Services that employ paid caregivers can include supported living, respite care, community based brain injury centres, vocational training (including sheltered employment) or the voluntary sector. In some cases, support and supervision may be provided in the home by a combination of paid caregivers and family members (McMillan & Oddy, 2001). Paid caregivers differ from other partners in that they are paid to care and have little or no familial connection with the person with TBI. Terms to describe this group have included attendant carer (Douglas & Spellacy, 2000), paid attendant carer (McCluskey, 2000) and support staff (McCrea & Sharma, 2009). For the purposes of this thesis, the term paid caregivers will be used hereafter.

Paid caregivers have a diverse range of roles that require complex interpersonal skills to encourage independence for a person with TBI (McCluskey, 2000). The first role, the attendant, involves helping with the daily practical tasks within the home and the community (e.g. banking, organising

schedules). The second role, the protector, involves using strategies to ensure the person with TBI is kept safe from harm whilst encouraging maximum independence. The third role, the friend, is the person who socialises, chats and shares information. The fourth role, the coach, involves motivating and encouraging the person with TBI to achieve as much independence as possible whilst the final role of negotiator is to set limits and rules for the person with TBI. Roles help to define the level of support provided by a paid caregiver and can often vary for different rehabilitation services.

Level of care and support provided by a paid caregiver in the home or community often differs due to the social circumstances and needs of the person with TBI. For example, if the person with TBI is residing at home, paid caregivers can often be involved for anywhere between 3 and 40 hours per week (McCluskey, 2000). Paid caregivers are often employed to provide respite for family members who can experience anxiety, stress, burden or depression as a result of long-term caring for someone with a TBI (Ergh, Hanks, Rapport, & Coleman, 2003; Hanks, Rapport, & Vangel, 2007; Knight et al., 1998; Kreutzer, Gervasio, & Camplair, 1994; Novack, Bergquist, Bennett, & Gouvier, 1991; Oddy, Humphrey, & Uttley, 1978). Alternatively, if a person with TBI is not able to live independently they may reside in a supported living environment or residential facility with people who have a brain injury, developmental disability or mental health disorder. People are then employed to be the main caregivers for the person with TBI (McMillan & Oddy, 2001). Family members report that the “attendant carer is a bit of a lifesaver” and “attendant care has helped

remarkably; we've been able to holiday separately" (p.83) (Douglas & Spellacy, 2000) highlighting the positive effect paid caregivers can have when employed in the home environment. However, there is limited research that has focused on the experiences and skills of paid caregivers for people with TBI and no studies have explored paid caregivers within long-term care facilities.

To support and manage the changes that occur post-injury, paid caregivers in long-term facilities need to firstly develop an awareness of the consequences and psychosocial impact of TBI.

1.6 Psychosocial Consequences of TBI

Changes that occur following a TBI impact upon the person's ability to socially re-integrate back into the community. The person with TBI experiences significantly smaller social networks (Elsass & Kinsella, 1987), can have difficulty forming new friendships and relationships (Zencius & Wesolowski, 1999) and difficulty returning to work (Brooks, McKinlay, Symington, Beattie, & Campsie, 1987; Tomberg, Toomela, Ennok, & Tikk, 2007). Consequently, people with TBI have increased loneliness, social isolation and low self-esteem (Leith, Phillips, & Sample, 2004; Newton & Johnson, 1985; Oddy, Coughlan, Tyerman, & Jenkins, 1985; Olver et al., 1996). They report poor social integration, reduced life satisfaction (Burleigh, Farber, & Gillard, 1998; Stalnacke, 2007) and can experience high levels of anxiety and depression (Deb, Lyons, Koutzoukis, Ali, & McCarthy, 1999; Douglas & Spellacy, 2000; Fann, Katon, Uomoto, & Esselman,

1995; Kreutzer, Seel, & Gourley, 2001; Leach, Frank, Bouman, & Farmer, 1994; Olver et al., 1996; Whelan-Goodinson, Ponsford, Johnston, & Grant, 2009).

Impaired social communication can contribute to the psychosocial consequences experienced following a TBI. Shorland and Douglas (2010) reported how people with TBI had feelings of rejection or a sense of being forgotten by their friends following their return back into the community years post-injury. Impaired social communication is reported at 2 years (31%) and 5 years post-injury (36%) and could contribute to a loss of friends and increased social isolation which can persist long-term for over 50% of people with TBI (Olver et al., 1996). For example, a person with TBI who is egocentric, self-centred and dominates conversations may experience difficulty forming and maintaining new friendships and widening social networks. The next section of the thesis will explore these changes in social communication in more depth and their impact on the person with TBI.

1.7 Changes in Communication following TBI

Changes in communication are common following TBI. Impairments can include excessive talkativeness, poorly organised speech (Coelho, Liles, & Duffy, 1991b; Galski et al., 1998), inaccurate, inefficient or excessive content (Hartley & Jensen, 1992), difficulty starting, maintaining and extending the conversational topic (Mentis & Prutting, 1991; Snow et al., 1998), difficulty taking turns and being socially appropriate (Snow, Douglas, & Ponsford, 1997; Spence, Godfrey, Knight, & Bishara, 1993) and difficulty being indirect and subtle (McDonald, 1992;

McDonald & Pearce, 1998). As a result, interactions are perceived as less rewarding, less interesting, less appropriate and more effortful (Bond & Godfrey, 1997). People with TBI perceive changes such as reduced ability to express a range of emotions, to be tactful, empathic or be a confident communicator to negatively impact on conversations (Shorland & Douglas, 2010). These changes in communication have been shown to persist years post-injury (Bond & Godfrey, 1997; Douglas, 2010; Oddy et al., 1985; Olver et al., 1996; Snow et al., 1998) consistent with long-term changes in cognition, behavioural and emotional function.

Cognitive changes are associated with communication difficulties in people with TBI. McDonald (1993) explained how cognitive impairments such as impulsivity, reduced self-monitoring and poor planning contributed to ratings of disorganised, confusing and ineffective procedural discourse for a person with TBI compared to a control participant. Impaired executive function has also been shown to be associated with impaired social communication abilities (Douglas, 2010; Snow et al., 1998; Struchen, Clark, Sander, Mills, Evans, & Kurtz, 2008a). Moreover, both executive function and social communication abilities uniquely affect measures of occupational and social integration (Struchen et al., 2008a) thus highlighting the wider impact of cognitive and communication changes.

Impaired communication has a significant impact on reintegration back into the community. Features of discourse on narrative, procedural and conversational tasks have been shown to adversely affect social integration and quality of life (Galski et al., 1998). For example, people with TBI tended to

provide less information for a communication partner during conversation compared to controls. Reduced social integration has also been shown to be significantly associated with increased pragmatic errors during conversation (e.g. providing insufficient and redundant information) (Snow et al., 1998) and difficulty in processing non-verbal cues such as the facial expression of others (Knox & Douglas, 2009). People with TBI who perceive themselves to have poorer social communication skills are more likely to perceive reduced social integration, life satisfaction and productivity (e.g. work, school) (Dahlberg, Hawley, Morey, Newman, Cusick, & Harrison-Felix, 2006). Remediating the underlying communication impairment is therefore important to improve re-integration. The next section will discuss existing treatment approaches available for people with TBI.

1.8 Remediation of Communication Skills

Existing treatment approaches to improve impaired communication skills involve training the person with TBI in social skills. Such training is based on behavioural principles incorporating both didactic (e.g. lectures, discussion) and performance based approaches (e.g. role-play, rehearsal). Training targets specific skills that are impaired such as a person's ability to initiate and maintain conversation, take turns and use strategies to maintain the flow of conversation. Earlier studies of social skills training demonstrated improvement, however, were limited by small sample sizes and the absence of a control group (Flanagan et al., 1995; Wiseman-Hakes et al., 1998). Despite this, a systematic review of

treatment outcomes in TBI indicated that the area of social skills was one of only two areas that proved amenable to treatment (Carney, Chesnut, Maynard, Mann, Patterson, & Helfand, 1999). This finding is further supported by a review of social skills training studies for people with TBI (Struchen, 2005). More recently, two randomised controlled studies have shown improved communication skills following training to people with TBI.

The first involved 52 participants evenly allocated to either a treatment or delayed treatment group (Dahlberg et al., 2007). Training was conducted for 1.5 hours per week for 12 weeks with training including peer feedback and interaction, individual goal setting and generalisation of skills through family involvement. Improvements were perceived by blind raters on the Profile of Functional Impairment of Communication (PFIC) which contained 10 scales of social communication (e.g. logical content, general participation, clarity of expression, social style and subject matter). However, this improvement was not sustained at 6 months posttraining highlighting an issue with the long-term maintenance of skills. There was also no change on broader measures of participation, community and social integration.

The second study similarly found no change on broader measures that included emotional adjustment, social perception abilities and self-perceived change by either the person with TBI or a significant other (McDonald et al., 2008). Group training occurred for 4 hours per week over 12 weeks with 51 participants allocated to either a social skills training program (n = 18), social activity program (n = 17) or waiting list (n = 16). Social skills training consisted of

2 hours on targeted social skills (e.g. listening and starting a conversation), an hour on social perception skills (e.g. the ability to recognise emotion) and an individual session with a clinical psychologist to address self-esteem and social anxiety problems. Improvement was found on a partner directed behaviour scale (e.g. less egocentric and more aware of the other person) but not a personal conversational style scale (e.g. use of humour or amount of self-disclosure) with no follow-up data to demonstrate if skills were maintained. Improvement on the measure of social communication did not have a significant impact on broader measures of change highlighting the need to consider additional factors that can affect improvement from training in social skills.

1.8.1 Factors to consider with existing treatment approaches.

The lack of change on wider measures of emotional well-being and community re-integration may reflect several challenges of working directly with a person with TBI. Severity and time since injury and the extent of cognitive, behavioural and emotional changes post-injury are likely to impact upon a person's ability to learn and retain information. These changes are also likely to affect the long-term maintenance of skills and ability for a person with TBI to generalise newly learnt skills to a range of communicative contexts.

Time since injury may impact upon the success of training with more chronic cases of TBI resulting in less improvement. Certainly, positive changes in the Wiseman-Hakes et al. study (1998) could be attributable to spontaneous recovery as four of the six participants were less than 8-months post-injury. In

subsequent studies people had sustained a severe TBI and been on average 4 years (ranging from 1 – 19 years) (McDonald et al., 2008) to 9 years post-injury (ranging from 2 – 22 years) (Dahlberg et al., 2007). None of these studies investigated time post-injury as a factor of improvement. Therefore, it is difficult to determine if more chronic cases of TBI would result in less improvement from training in social skills.

In severe cases of TBI, the cognitive, behavioural and emotional changes that occur post-injury could play a major part in the amount of change made from social skills training. For example, Flanagan et al. (1995) acknowledged that a lack of improvement during training was most likely due to the presence of neurobehavioural problems and extent of cognitive impairments such as new learning. Researchers have attempted to address this by excluding people with TBI with extensive cognitive impairment (McDonald et al., 2008), behavioural concerns and insufficient new learning (Dahlberg et al., 2007) though the process for determining this is often unclear and subjective. Moreover, a person with TBI with poor awareness and motivation and who is defensive when given feedback is less likely to improve (Sohlberg & Mateer, 2001).

Less emphasis on the maintenance and generalisation of skills may have a crucial impact when working with a person with TBI (Ylvisaker & Feeney, 1998). Struchen (2005) reported that few social skills training studies evaluated generalisation and those that did found mixed results. McDonald et al. (2008) attempted to address generalisation through providing weekly homework tasks for situations outside of the training environment. However, it was unclear

whether all participants had access to a range of social situations in which to practice their newly learnt skills and participant compliance with the completion of homework was not reported. Dahlberg et al. (2007) combined weekly homework with involvement from family and friends though not until the latter stages of the program. The problem is that social skills training assumes that skills can be taught, learnt and generalised explicitly by a person with TBI which is difficult given the extensive cognitive impairments that frequently occur post-injury. For training to be effective it needs to take place in real life settings that are meaningful for the person with TBI for transfer of training to occur (Ylvisaker, Jacobs, & Feeney, 2003). Consequently, interventions that target communication impairments need to move beyond the impairment and look at the broader communicative environment for the person with TBI.

1.9 Remediation of the communicative environment

Many of the problems identified in training the person with TBI may be overcome by targeting the skills of the communication partner. Shifting the focus of the intervention to the communication partner has been argued to influence the functioning of people with TBI (Howe, 2008; Ylvisaker & Feeney, 1998; Ylvisaker et al., 1993; Ylvisaker, Szekeres, & Feeney, 2001). Communication partners have been shown to promote or hinder the conversational interactions that involve people with TBI. Togher et al. (1997a) demonstrated that communication partners including a therapist, bus timetable information service and mother made fewer requests for information from a person with TBI compared to

controls. Police requested more information which resulted in people with TBI providing more and somewhat inappropriate information. Interactions with a therapist resulted in people with TBI clarifying or confirming the meaning of what was said more frequently than matched control participants. Togher et al. (2006) found that the communication skills of a person with TBI altered according to both the communication partner (therapist, peer with TBI, group of people with TBI) and context (unstructured chat, a task that required the person with TBI to request information and a task that asked them to provide information). The person with TBI communicated most collaboratively during an unstructured task with the therapist, found it difficult to communicate with a dominating and egocentric peer and made no attempt to participate in a group social chat.

Altering the context and communication partner can have an impact on the communicative abilities of the person with TBI. Togher, Hand and Code (1997b) showed different communication patterns for five people with TBI when contacting a bus timetable service and police officers. People with TBI made more enquiries that obtained information of the bus timetable service compared to the police, however, spent more time introducing themselves and giving personal information to the police. Altering the context to place a person with TBI in an information-giving role resulted in similar discourse abilities to controls who had sustained a spinal cord injury (Togher, 2000). People with TBI were asked to speak with two schoolboys enrolled in a community awareness driver education program about their injury and the long-term impact. Similar amounts of information were exchanged and the meaning was negotiated approximately the

same number of times by people with TBI when compared to the interactions of spinal injury participants. The evidence highlights the potential for influencing the functioning of the person with TBI by training the communication partner to make positive changes to the context.

Involving everyday communication partners is integral to the creation of a positive communication culture and, consequently, to improved communicative competence and participation for people with TBI (Ylvisaker et al., 1993; Ylvisaker et al., 1998). Bellon and Rees (2006) reported that a group of four people with TBI were more positive, appropriate and successful in their communication and improved their participation when supported within a positive social network. The network comprised of volunteer mentors who either had daily contact with the person with TBI in their home or as part of a 3 day camp. Reducing support to 1 - 2 hours per week led to more confused, inappropriate and often negative language by the person with TBI. Shelton and Shryock (2007) also argued that training the use of positive communication strategies would improve interactions and create a positive communicative environment. The use of positive communication strategies such as the “use of short, simple direct sentences and questions”, “facing the patient and making eye contact” and “allow the patient time to respond to questions or directives” improved interactions between a health professional and a person with a brain injury. The more strategies used, the more successful the interaction was perceived to be when rated by both health professionals and speech pathologists. Both studies

highlight the potential impact of training for communication partners of people with TBI.

Training can improve a communication partner's awareness for interacting with a person with TBI. Goldblum and Alant (2009) trained a group of 31 sales assistants during a 4 hour training session that involved viewing and discussing videotaped vignettes of people with cognitive-communication difficulties following TBI. Trained sales assistants had improved confidence and knowledge in identifying barriers and facilitators to successful communication compared to a control group (n = 33). Although the conversational interactions of trained sales assistants were not measured with people with TBI, the study highlights that training can improve knowledge associated with more successful communication.

Recent research has shown improved conversational interactions from training for communication partners of people with TBI. However, no studies have specifically focused on training communication skills for paid caregivers of people with TBI. Several studies have evaluated the impact of training for paid caregivers and volunteers of people with aphasia, dementia and developmental disabilities. The following sections will examine in detail the range of research that evaluates communication partner training.

1.10 Communication Partner Training for those Dealing with People with TBI

Communication partner training programs for people with TBI have focused on two approaches; behaviour management and the use of

communication strategies. The majority have focused on teaching behaviour management rather than communication strategies (Backhaus, Ibarra, Klyce, Trexler, & Malec, 2010; Ducharme & Spencer, 2001; Sander, 2005; Uomoto & Brockway, 1992). Both training approaches incorporate some element of behavioural change in the communication partner in order to effectively promote positive social interactions. Ducharme and Spencer (2001) demonstrated positive changes from training behaviour management strategies (e.g. providing clear task instruction, timing prompts correctly and using reinforcement correctly) to 13 paid caregivers of people with brain injury. Group training was conducted in two separate workshops each lasting 150 minutes. Interactions were videotaped and independently rated for correct use of teaching and interaction skills before and after training. Improved skills occurred for eight posttraining simulated situations (including untrained situations) involving activities of daily living (e.g. setting a table or preparing a sandwich for lunch). Despite being a small sample size with absence of a control group, it provided initial evidence as to the effectiveness of training paid caregivers who are rarely the focus of research in TBI.

More recently, studies have investigated the effectiveness of communication partner training for two groups of people who often deal with people with TBI, police officers and family members. The first study was a randomised controlled trial that demonstrated improved interactions from training only the communication partner of a person with TBI (Togher et al., 2004). Telephone interaction skills of 10 trained police officers were measured and compared to a control group following training in communication that lasted 6

weeks. Trained police officers were found to spend more time establishing the nature of a query, more time giving the answer to a query and increased the number of closing remarks. Changes resulted in fewer inappropriate and incomplete remarks by the person with TBI. Furthermore, there was a reduction in the length of the interaction and an increase in the length of closing remarks for people with TBI interacting with trained police officers. Results highlight the positive impact of training a communication partner alone on the interaction skills of people with TBI.

The second study was a non-randomised controlled trial that showed training the communication partner and the person with TBI together can have a significant impact on the success of interactions (Togher et al., 2010a). A group of 44 people with TBI and their caregivers (including family members, significant others and paid caregivers) were allocated to one of three groups; communication training involving the person with TBI only, communication training involving both the person with TBI and their caregiver and a delayed treatment control condition. Training involved a 2.5 hour group training session and a one hour individual session conducted weekly for 10 weeks. Casual conversations were found by blind raters to be significantly more appropriate, rewarding and less effortful for caregivers trained with the person with TBI compared to training the person with TBI alone or not at all. Inclusion of the communication partner in training had a major impact on the success of conversational interactions.

Both studies demonstrate that interactions involving people with TBI can be improved by training communication partners alone or with the person with TBI. Improvements were shown for micro-behaviours such as the number of opening or closing remarks and more global measures of communicative ability such as how appropriate or interesting an interaction was. Limited research exists to evaluate the effect of communication partner training for paid caregivers of people with TBI. However, research that has shown improvements from training for paid caregivers and non family members in other clinical areas can help to identify differences in training this distinct group of people.

1.11 Paid Caregiver Communication Partner Training in other Clinical Areas

Evidence for the effectiveness of communication partner training of paid caregivers exists for other clinical populations that include developmental disabilities (Bloomberg et al., 2003; Dobson et al., 2002; Money, 1997; Purcell et al., 2000) and dementia (Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001; Burgio et al., 2001). In addition, communication partner training has been shown to be effective for volunteers and students working with people with aphasia (Hickey, Bourgeois, & Olswang, 2004; Kagan et al., 2001; Legg et al., 2005; Lyon et al., 1997; McVicker et al., 2009; Rayner & Marshall, 2003; Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010; Turner & Whitworth, 2006; Worrall & Yiu, 2000). Similar to paid caregivers, volunteers and students do not have a familial connection to the person with whom they interact. The results of

these studies highlight several points that should be considered when training paid caregivers of people with TBI.

First, training can have a significant impact when paid caregivers, volunteers or students are trained independently of the people they support (Bourgeois et al., 2001; Burgio et al., 2001; Dobson et al., 2002; Hickey et al., 2004; Kagan et al., 2001; Legg et al., 2005; Money, 1997; Rayner & Marshall, 2003). Improved communication skills for a person with aphasia and their communication partner was found in a randomised controlled trial where a group of 20 volunteers attended a one day group training workshop (Kagan et al., 2001). People with aphasia had not attended the training. Bourgeois et al. (2001) found that nursing assistants that were trained independently of nursing home residents contributed to more balanced and significantly more informative conversations. Assistants increased their use of facilitative remarks and comments to extend conversations and reduced the number of prompts and requests for information. Training communication partners in isolation can result in significant improvement for both participants involved in an interaction.

Second, effective training for paid caregivers of people with TBI needs to be practical and relevant to the workplace. Inherent difficulties of focusing on paid caregivers from residential and day services include not all paid caregivers being committed to the training, some having little experience in the completion of formal training and a difficulty caregivers may have in the dissemination of information in a supportive manner to colleagues (Bloomberg et al., 2003). To address such difficulties, Purcell et al. (2000) have identified essential

components for training paid caregivers. Training should be based in the workplace around frequently occurring situations. It should focus on the type of people that paid caregivers interact with most and be led by an experienced colleague who understands the needs of the client and has an opportunity to work alongside the paid caregiver in their daily work. Paid caregivers should also be encouraged to improve their skills through an open and facilitative discussion of strategies and active participation on real-life examples. For improvement to occur, many of these factors should be considered when training paid caregivers within the workplace.

Finally, training programs can have a major psychosocial impact on the well-being of the person a caregiver supports. In a qualitative study, McVicker et al. (2009) found that people with aphasia reported feeling more confident, appreciated the opportunity for social contact and were more able to participate in new activities as a result of a trained volunteer visiting them each week for 6 months. Equally, the trained volunteer reported feelings of satisfaction and enjoyment and achieved a greater understanding and insight into the communication difficulties that present following aphasia. Lyon et al. (1997) found a significant difference on a measure of well-being and perceived communicative ability following training for 10 triads of a person with aphasia, their caregiver and a volunteer. Improvements in psychosocial functioning occurred independent of an improvement in impairment. A recent systematic review reported that there was insufficient evidence to conclude that training programs have a significant impact on quality of life (Simmons-Mackie et al., 2010). However, the review also

highlighted that quality of life and psychosocial adjustment are complex and multidimensional and that future training studies should continue to use these measures to better understand the wider impact of communication partner training.

1.12 Sustainability of Change

A limitation of many communication partner training studies is that they fail to follow-up the results of training months after completion. This is important as the aim of any intervention should be for the positive gains to be sustained over time. Maintaining improvements reduces the need for additional input especially within an environment where financial pressures and cost-savings are a reality. Only five studies made mention of follow-up (Burgio et al., 2001; Dobson et al., 2002; Hickey et al., 2004; Lyon et al., 1997; Rayner & Marshall, 2003) that ranged in the length of time posttraining from 3 weeks (Hickey et al., 2004) to 6 months (Dobson et al., 2002). Of these, only three undertook assessments intended to and referred to as follow-up (Burgio et al., 2001; Dobson et al., 2002; Rayner & Marshall, 2003).

Follow-up assessments have demonstrated that improvements can be sustained for months after the completion of training. Burgio et al. (2001) reported that nursing assistants were able to maintain the use of positive statements and a higher rate of speech during care routines with residents 2 months after training. Dobson et al. (2002) followed up eight of the nine paid caregivers of people with developmental disabilities 6 months after training. Non-

significant results between posttraining and follow-up assessments indicated that gains in verbal and non-verbal interaction skills were maintained. Likewise, Rayner and Marshall (2003) found that improved communication skills of a person with aphasia and their communication partner were maintained 9 weeks after the training. Inclusion of follow-up measures months after the completion of training should be integral to any research evaluating the impact of communication partner training.

1.13 Design of Communication Partner Training Programs

Training programs varied in both the length and content of the program. This variability makes it difficult to design a package for paid caregivers of people with TBI when it is unclear what is most effective. Therefore, this section will explore the wide range of communication partner training programs to obtain insight into elements that would be necessary in designing an effective program.

1.13.1 Length of training programs.

There is considerable variability in the length of communication partner training programs. Lengths of a program have ranged from a one day training workshop to volunteers working with people with aphasia (Kagan et al., 2001), 39 hours over six sessions for paid caregivers of people with developmental disabilities (Dobson et al., 2002) to 2.5 hours per week for 10 weeks combined with a one hour weekly one-to-one session for communication partners of people with TBI (Togher et al., 2010a). A review of communication training programs found that there is wide variability of both the number of hours and days of

programs which makes it difficult to identify the optimum dosage for success to occur (Kruijver et al., 2000; Simmons-Mackie et al., 2010). However, Purcell et al. (2000) argued that more intensive and lengthier programs would result in greater and more significant improvements.

Training would need to occur on more than one occasion to create change within an individual. Hickey et al. (2004) demonstrated that student volunteers made changes to their interaction skills with a person with aphasia after a single training session (of unspecified length), however, changes continued to occur following a further one to two training sessions. Kagan et al. (2001) were able to demonstrate improvement within 2 weeks of completing a 1 day group training program and a 1.5 hour hands-on session with people with aphasia. The hands-on session was supervised by a speech pathologist suggesting that volunteers had a further opportunity to discuss and rehearse effective strategies for communicating with a person with aphasia. Legg et al. (2005) demonstrated improvement after training medical students for 4 hours on how to take a case history with someone who has aphasia. However, the students were primed for posttraining evaluations which also involved taking a case history. . So while a single training session will result in change for a particular interaction, more than one training session has the potential for having a greater impact on conversational interactions. .

1.13.2 Content of training programs.

Wide variability exists for the structure, content and delivery of communication training programs. Some studies have utilised manualised treatment protocols (Bloomberg et al., 2003; Hickey et al., 2004; Kagan et al., 2001; Togher et al., 2004; Togher, McDonald, Tate, Power, & Rietdijk, 2009), taught a range of strategies specific to the individual (Lyon et al., 1997) or taught a range of concepts and strategies dependent on previous sessions and participant discussion (Dobson et al., 2002; Rayner & Marshall, 2003). Purcell et al. (2000) evaluated the difference between training in two whole day workshops compared to individual sessions and found no significant differences in the number of verbal and non-verbal communicative acts by paid caregivers and people with developmental disabilities. Money (1997), however, included a third group that combined a group workshop with additional individual sessions and found this to be more effective than either a group workshop or individual sessions alone. Other factors that may affect the success of a training program may include the training environment, availability of staff to attend training sessions and the qualifications of the trainer. Such variability makes it difficult to identify the most appropriate content and delivery of a program.

A range of elements are common to training programs and considered important for creating change in the skills of communication partners. Elements of successful programs for people with aphasia included general education regarding the disorder and its impact on conversation, opportunities to identify strategies that support successful conversations and time for conversational

practice (Turner & Whitworth, 2006). In addition, training that incorporates didactic as well as performance based approaches creates most change for communication partners (Kruijver et al., 2000; Turner & Whitworth, 2006). Didactic approaches may include lectures, discussion, exchange of experience and information and modelling. Performance approaches are more practical in nature and may include role-play, rehearsal, video-taping, feedback and practical work-based exercises. Moreover, a majority of studies that have demonstrated improvement have tended to use group training (Bloomberg et al., 2003; Dobson et al., 2002; Kagan et al., 2001; Rayner & Marshall, 2003; Togher et al., 2004; Togher et al., 2010a). Therefore, a successful training program may include education, opportunities for practice and training for communication partners in a group environment using a range of didactic and performance based approaches.

The content of a training program needs to be relevant and appropriate for working with people with TBI. Previous studies have focused on people with aphasia or developmental disabilities whom often present quite differently to people with TBI. This variability makes it difficult to teach and apply the same strategies and techniques. Fortunately, Ylvisaker and Feeney (1998) propose a set of collaborative and elaborative conversational strategies that can contribute to the creation of a positive communicative environment for people with TBI. These strategies provide opportunities for people with TBI to take a more active and equal part in the conversation, to think and organise their thoughts more logically and to enjoy their part in the conversation. While the use of these

strategies have not been empirically tested, they have been shown to improve the conversations of people with TBI and their family members when combined with discourse type activities in a training program (Togher et al., 2010a).

Discourse activities focus on frequently occurring interactions (small talk or chat) and identify the structure and point of breakdown for communication partners in order to establish where repair needs to occur. Repair can then take the form of the conversational strategies proposed by Ylvisaker and Feeney (1998).

Therefore, these strategies and activities provide a framework for a training program for paid caregivers of people with TBI.

Sections 1.10 to 1.13 identified elements from previous communication partner training studies that would guide the design of a program for paid caregivers of people with TBI. Information regarding the length and content of the program, the training environment and follow-up measures were identified. The following section outlines the research aims, questions and hypotheses for the current study undertaken as part of the thesis.

1.14 Aims, Research Questions and Hypotheses

Paid caregivers comprise a group of people whom are frequently involved in the lives of people with TBI, however, they receive little education, training and support. Communication partner training is an approach that can improve the interaction skills between a communication partner and the person with TBI.

Although studies have targeted communication partners that include police officers, parents and spouses, no study to date has specifically focused on paid

caregivers within a work-based environment and compared the effects of training to a control group.

1.14.1 Aims.

This thesis describes a study conducted with a group of paid caregivers for people with TBI with the following aims;

1. To evaluate the effects of a communication partner training program within a residential rehabilitation centre for a group of paid caregivers compared to a control group exposed daily to people with TBI.
2. To assess the impact of a communication partner training program on the interaction skills of people with TBI who did not participate in the training.
3. To identify and describe the experiences of paid caregivers involved in the training program.

These aims were examined and evaluated in a randomised controlled trial using a mixed methods approach (quantitative and qualitative study). The thesis addresses; (1) the communication skills of the paid caregiver and the person with TBI separately; (2) the global impression of the interaction between the paid caregiver and the person with TBI and; (3) the ability to sustain skills over a period of 6 months. Effects were measured by independent blind judges and subsequent statistical analyses of the data. In addition, the thesis addresses; (4) perceived communicative ability of the person with TBI by the paid caregiver, the

person with TBI and a family member; (5) feelings of burden and stress by the paid caregiver and; (6) daily experiences of paid caregivers working with people with TBI and the impact of training on their interaction skills.

1.14.2 Research questions.

1. Can paid caregivers for people with TBI be trained to improve their communication skills?
2. Can a change in skill for the paid caregivers have an impact on the communication of the person with TBI who was not trained?
3. Is a change of paid caregiver's skills sustainable at a 6 month follow-up assessment posttraining?
4. Does training of paid caregivers impact the communicative ability of the person with TBI as perceived by a paid caregiver, person with TBI and family member?
5. Do changes in communication skills impact on a paid caregiver's experience of burden and stress?
6. What categories emerge regarding a paid caregiver's experience of communicating with a person with TBI and can training in communication alter the paid caregiver's self-reports of their own interaction skills.

1.14.3 Hypotheses.

1. Communication partner training for paid caregivers will improve their interactions skills and consequently lead to reduced feelings of stress and burden.

2. Training will improve the interaction skills for the person with TBI who was not involved in the training.
3. Communication partner training has a positive impact on the global impression ratings of the interaction between a paid caregiver and a person with TBI.
4. Improved interaction skills as a result of training are sustainable for a period of 6 months.
5. Ratings of communicative ability of the person with TBI as perceived by the paid caregiver, person with TBI and their family member will improve as a result of communication training and be maintained for 6 months.
6. Paid caregivers who are trained in communication strategies will describe positive experiences and changes in their communicative ability as a result of the training.

1.15 An Overview of Thesis Plan

Chapter 1 presented the background knowledge of the problem regarding people with TBI and the paucity of research that focuses on paid caregivers. Section 1.13 outlined the aims, research questions and hypotheses for the current study.

To evaluate the effectiveness of the program a single blinded randomised controlled trial incorporating both quantitative and qualitative analyses was designed (Chapter 2). Quantitative methods were used to enable statistical comparison between two groups (training and control) and qualitative analysis

would enable identification of barriers and facilitators to training and complement the quantitative findings.

The results of the study are presented in the next three chapters (Chapters 3, 4 and 5). Chapter 3 focuses on the quantitative results which compare the training and control groups on a range of blinded communication outcome results. Chapter 4 focuses on the qualitative results and the perspectives of paid caregivers who had participated in the communication training program. Three case examples that illustrate the impact of training are shown in Chapter 5. The results report the first randomised controlled trial investigating the impact of communication partner training for paid caregivers of people with TBI.

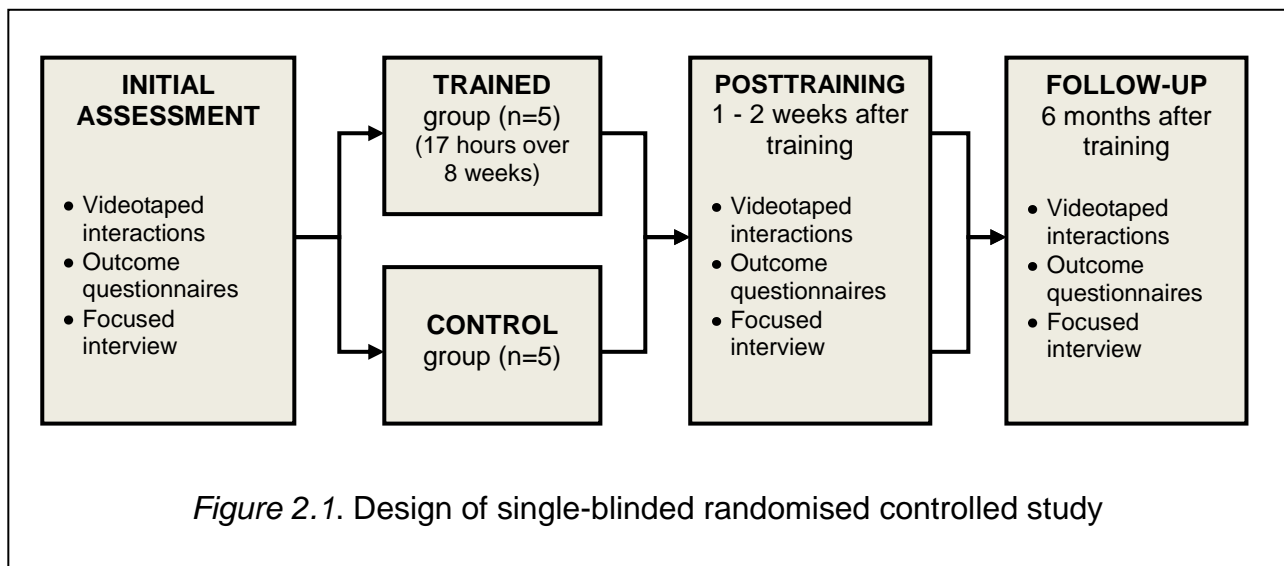
Chapter 6 discusses the results and identifies the key findings from the preceding chapters. The impact of the training program for both the paid caregiver and the person with TBI are discussed. Significant and non-significant results are explored with reference to comments and categories that arose from the qualitative analysis. This chapter highlights the limitations of the current study and suggestions for future research. Finally, clinical implications and critical features for future training programs are identified with a final remark of the importance of the study for rehabilitation services worldwide.

Chapter 2

Methodology

2.1 Design of Study

This thesis describes a single-blinded randomised controlled trial incorporating mixed methods (quantitative and qualitative) to investigate the effect of communication partner training for paid caregivers of people with TBI. The study was conducted over a period of approximately 9 months at a long-term residential rehabilitation centre in the United Kingdom. Data was collected at three intervals for both the paid caregiver and person with TBI in the control and training group: (1) one to two weeks prior to the commencement of training; (2) one to two weeks following the end of training and; (3) six months after the completion of training. Figure 2.1 provides a visual representation of the study design.



2.2 Ethics

The study was approved by The University of Sydney Human Research Ethics Committee on the 14 August 2008 (Ref. No. 10676). The study was approved by the Brain Injury Rehabilitation Trust's Ethics Committee on the 25 April 2008 (see Appendix A).

2.3 Participants

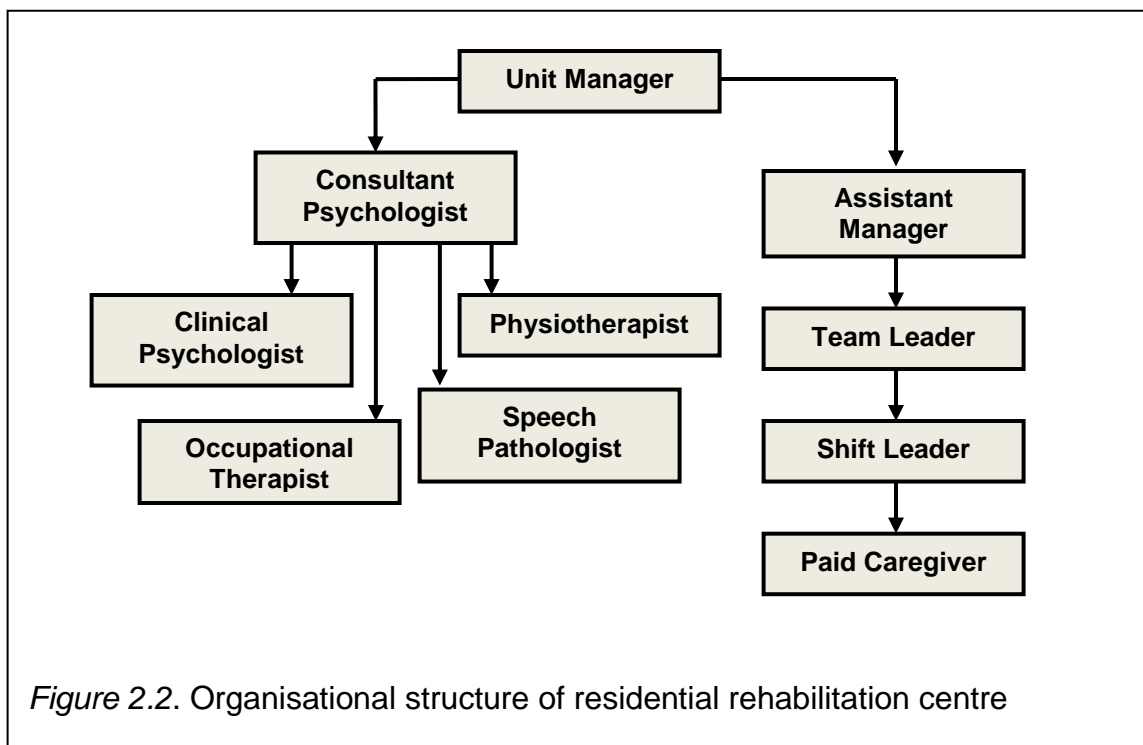
2.3.1 Paid caregivers.

Paid caregivers were recruited from a residential rehabilitation centre in the UK. The centre was part of a larger not-for-profit organisation that delivers rehabilitation services for people who have sustained an acquired brain injury (ABI)¹. People within these centres have been reported to be on average 2 years post-injury (range 1 - 1409 weeks) (Worthington et al., 2006). The centre where the study was conducted uses a neurobehavioural approach to manage up to 25 people with an ABI (including TBI). People are supported by paid caregivers. The role of the paid caregiver is to support people with ABI to complete tasks both within the centre and whilst out in the community as independently as possible on a daily basis. All paid caregivers have initial training in the neurobehavioural

¹ ABI is defined as an "injury to the brain which results in deterioration in cognitive, physical, emotional or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological diseases or stroke..." (p xii) (Australian Institute of Health and Welfare, 1999).

approach and how best to support people with ABI within the residential rehabilitation centre (McCrea & Sharma, 2009).

The duties of a paid caregiver are fulfilled as part of a clinical team that include other paid caregivers, managers and clinical professionals (i.e. physiotherapist, occupational therapist, psychologist and a speech pathologist). The paid caregivers are hierarchically organised with team leaders managing the duties of caregivers during a shift lasting approximately 7 hours. The structure of the centre is shown below (Figure 2.2).



Paid caregivers were selected by two managers who were independent of and blind to the purpose of the study. Inclusion criteria were;

1. No known previous history of significant alcohol/substance abuse or psychiatric problems. At the time of the study, several paid caregivers were known to have mental health disorders that would have impacted on experiences of burden and stress for the duration of the study. The author of the thesis was also not sufficiently experienced to be able to deal with and treat issues that may have arisen over the course of the study.
2. A proficiency in spoken English to be able to engage and participate in the videotaped interactions and communication partner training. This proficiency was assessed by the author of the thesis who was a qualified Speech Pathologist in collaboration with a manager.
3. Not attended or obtained university qualifications which would be consistent with previous studies where paid caregivers are less likely to have professional qualifications (Hatton & Emerson, 1993).
4. Employed full-time, as it was a requirement for paid caregiver's to be available to attend assessment and communication training sessions.

Ten female paid caregivers were identified. An initial interview and a questionnaire were initially completed (see Appendix B). Each paid caregiver was assessed on the Wechsler Test of Adult Reading (WTAR) (2001) which is able to predict a full-scale IQ on the Wechsler Adult Intelligence Scale – 3rd Edition (WAIS-III) (Wechsler, 1997). One paid caregiver was not assessed on the WTAR as she did not learn to read English as a child despite being a proficient speaker of English. Characteristics of paid caregivers are shown in Table 2.1. Means,

standard deviations and the range of demographic characteristics are shown in Table 2.2 and Figures 2.3 and 2.4.

Table 2.1

Characteristics of Paid Caregivers

Carer	Age (y)	Ed (y)	Caring exp (y)	Caring in ABI (y)	WTAR ^a	Description of previous experience
1	46	14	23	3.5	96.0	Dementia care, DD, mental health
2	49	14	12	1	87.0	Commtly care; dementia, spinal, degen
3	19	12	4	3	-	Dementia care
4	58	11	13.5	1	98.0	Commtly care ; dementia, degen, CVA
5	21	12	4	3	88.0	Nursery for children
6	29	13	2	2	92.0	No previous experience
7	27	11	11	3	93.0	Dementia care and the elderly
8	21	14	3.5	3.5	94.0	No previous experience
9	24	11	3	3	86.0	No previous experience
10	20	14	0.16	0.16	94.0	No previous experience

Note. y = years; ed = education; exp = experience; ABI = acquired brain injury; DD = developmental disability; commtly = community; degen = degenerative; CVA = cerebral vascular accident; WTAR = Wechsler Test of Adult Reading.

^aPredicted full-scale IQ for the Wechsler Adult Intelligence Scale – 3rd Edition (WAIS-III)

After consenting to participate, paid caregivers were assigned a number from 1 - 10. The numbers were then randomised using a list randomiser (Haahr, 1998) with the first five numbers comprising one group and the next five numbers comprising the second. These were then labelled as either control group or

training group by a person blind to the purpose of the study. Allocation was known to the investigator prior to training, however, was concealed from the paid caregivers until after pretraining measures were collected.

Table 2.2

Demographic Characteristics of Paid Caregivers

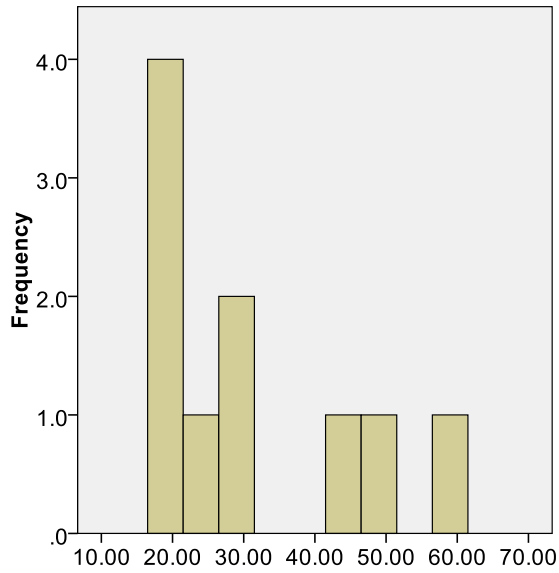
Variable	Minimum	Maximum	Mean	SD
Age	19.0	58.0	31.4	14.2
Education (y)	11.0	14.0	12.6	1.3
Working in care (y)	0.2	23.0	7.6	7,1
Working in ABI (y)	0.2	3.5	2.1	1.2
WTAR ^a	86.0	98.0	92.0	4.2

Note. SD = standard deviation; y = years; ABI = acquired brain injury; WTAR = Wechsler Test of Adult Reading

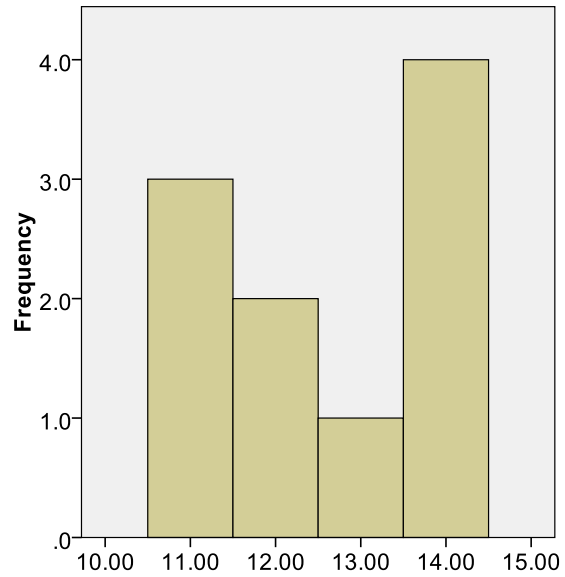
^aPredicted full-scale IQ for the Wechsler Adult Intelligence Scale – 3rd Edition (WAIS-III)

In addition to these 10 paid caregivers, an eleventh member of staff who did not meet criteria (the caregiver worked part-time) heard about the research and approached the investigator to be included (C11). This paid caregiver was willing to participate voluntarily and whilst the data obtained from the interactions were not included in the final quantitative data analysis, the focused interviews were included in the qualitative results of the study. This paid caregiver was female, 36 years of age, 11 years of education, 15 years of working in care with two of those years for people with acquired brain injury (ABI). Although the

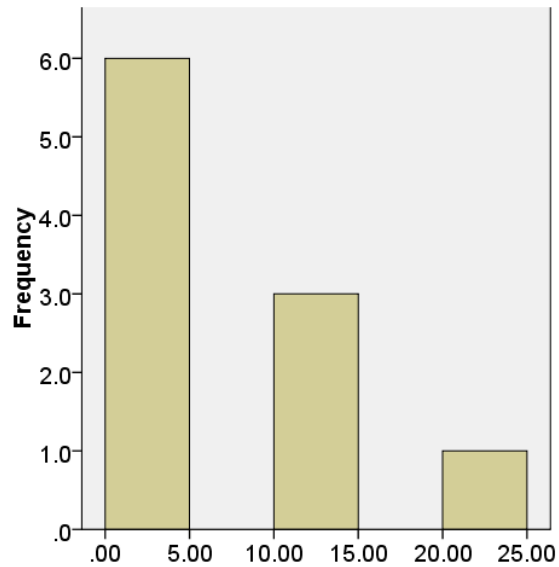
caregiver was not included in the group communication partner training package, the paid caregiver was trained on an individual basis.



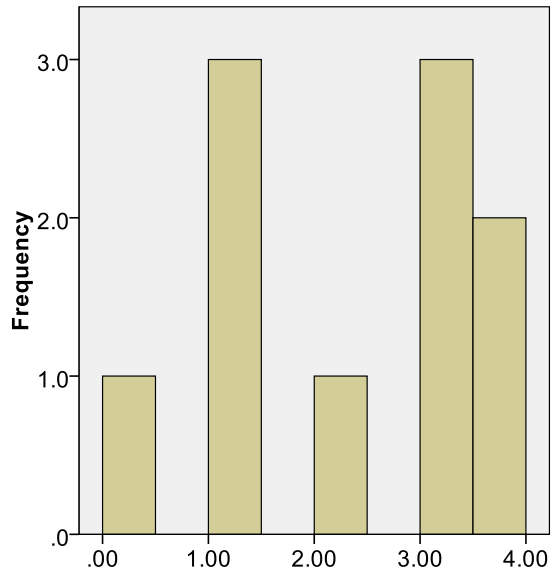
a) age of paid caregivers



b) years education of paid caregivers



c) no. of years working in caring



d) years caring for people with ABI

Figure 2.3. Distribution of demographic characteristics

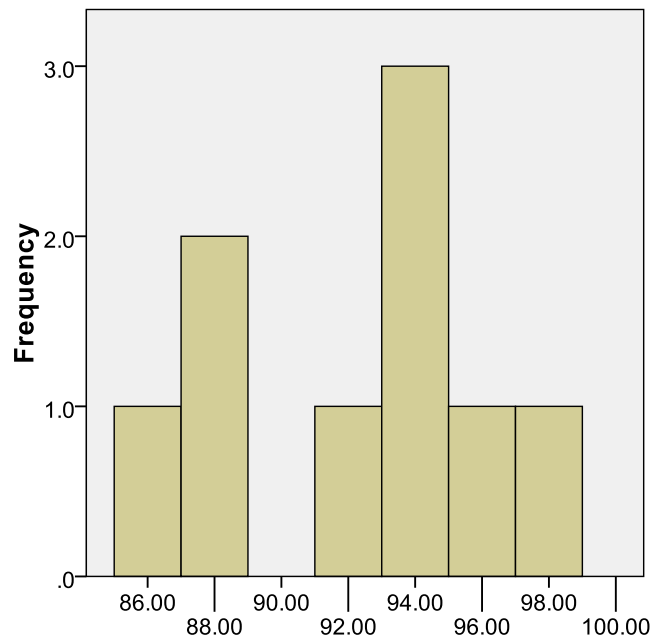


Figure 2.4. Distribution of predicted full-scale IQ for the Wechsler Adult Intelligence Scale – 3rd Edition (WAIS-III)

2.3.2 People with TBI.

People with TBI were recruited from 28 consecutive admissions from the residential rehabilitation centre during the period January 2005 - November 2007. Inclusion criteria for the study were; (1) a diagnosis of TBI; (2) a minimum estimated period of posttraumatic amnesia (PTA) of 14 days (Snow et al., 1998) as determined by a qualified clinical psychologist/neuropsychologist; (3) occurrence of injury at least 6 months earlier; (4) discharged from the residential rehabilitation centre for a minimum of 6 months and living in the community and; (5) evidence of a pragmatic communication disorder as diagnosed by a speech pathologist. Exclusion criteria included; (1) the presence of a motor speech

impairment or moderate-severe aphasia as diagnosed by a speech pathologist; (2) previous diagnosis of other ABI; (3) people receiving speech pathology intervention for the duration of the study and; (4) English as a second language.

From the sample of 28 people with TBI, 11 met the inclusion criteria. Of these, one person declined to participate, one person was sectioned within a mental health unit and therefore unable to be released for the purpose of the study, three people lived out of area and unable to fulfil the obligations of the study and one person was unable to be contacted. Five people with TBI were left to participate in the study which involved attending the residential rehabilitation centre to take part in interactions with paid caregivers.

Demographic and clinical characteristics of the five people with TBI are reported in Table 2.3 and pseudonyms were used in place of their names. Owing to the limited number of people with TBI, attempts were made to match each of them to both a trained and control caregiver at each time (pretraining, posttraining, 6 month follow-up). Allocation was not randomised but was dependent on the availability of people with TBI and staffing schedules. As a result, matching was not completely successful for two out of the five dyads (see Table 2.3).

Table 2.3

Demographic and Clinical Characteristics of TBI Participants

Person	Sex	Age (y)	PTA estimate (m)	Time post TBI (y)	Time postdischarge (m)	Nature of injury	CT scan
Paul ^a	M	30	Several	11	6	MVA	DAI with (R) frontal and temporal contusion and SAH
Simon ^b	M	48	4	5	16	Assault	Bilateral haematomas
Adam ^a	M	29	1	4	12	MVA	Small thalamic bleed, shearing
Sally ^a	F	19	4	2	12	MVA	(L) SDH, SAH and DAI
Lisa ^c	F	20	Unknown	12	6	MVA	Large extradural haematoma, small acute SDH
Mean		29.2	3	6.8	10.4		

Note. y = years; m = months; PTA = posttraumatic amnesia; TBI = traumatic brain injury; MVA = motor vehicle accident; DAI = diffuse axonal injury; SAH = sub-arachnoid haemorrhage; SDH = sub-dural haemorrhage; L = left; R = right.

^a Person with TBI who interacted with 1 control and 1 trained paid caregiver. ^b Person with TBI who interacted with 1 trained paid caregiver. ^c Person with TBI who interacted with 1 control and 2 trained paid caregivers

2.4 Development

2.4.1 Communication partner training program.

This section of the thesis describes the design and development of the communication training program for the study. To address the needs of paid caregivers the program needed to be work-based, reflecting the daily needs of people with TBI and the type of interactions that frequently occur in that environment. Moreover, the program was designed to assist the paid caregiver to create a positive communicative environment for themselves and the person with TBI. The program was modified from a previous communication partner training program shown to be effective for family members of people with TBI (Togher, McDonald, Tate, Power, Ylvisaker, & Rietdijk, 2011).

Positive communication was taught using a range of collaboration and elaboration conversational strategies (Ylvisaker et al., 1998). These strategies encouraged non-directive, non-demanding and non-patronising communication. Collaborative strategies aimed to encourage a person with TBI to take a more active, equal and balanced part in conversations. Elaboration strategies encouraged positive interaction where a communication partner would introduce topics of interest, maintain the topic and invite additional comments from the person with TBI.

The 10 week program was trialled by Togher et al. (2009, 2010a) with family members and friends and then modified to reflect the needs of the paid caregivers for the current study. Sessions that contained information on the causes and consequences of TBI were removed as paid caregivers had already

received training on these areas (McCrea & Sharma, 2009). Sessions that summarised and rehearsed strategies were reduced compared to the original program by Togher et al. (2011) owing to time demands and the manager's ability to release staff for training. The final program contained a 2 hour introductory session followed by five 3 hour sessions (17 hours in total). Training was conducted in small groups of two to three paid caregivers where possible. A range of didactic and performance based approaches that have been shown to be effective for other communication partner training programs were used (Kruijver et al., 2000; Turner & Whitworth, 2006). These approaches included group discussion, modelling, role-play, feedback, rehearsal, positive reinforcement, observing videotapes of people with ABI interacting with others and written exercises.

Each session targeted a range of formal and informal interaction types that frequently occur for paid caregivers within the workplace. Examples included;

- a) Planning and organisation of tasks (e.g. community visit, meal).
- b) Interaction with members of the community (e.g. coffee shop, restaurant).
- c) Discussion of a program watched on television.
- d) Ability to problem solve situations that commonly occur within the centre.
- e) Chat following an aggressive incident with another person with ABI or paid caregiver.
- f) Ability to conduct a group discussion with people with ABI.

The structure of each interaction type was identified with reference to how it differed according to the context (e.g. residential rehabilitation centre vs. community) and communication partner (e.g. family member vs. paid caregiver). Interaction types were often presented as videotaped role-plays, commercial television vignettes or situations that would be rehearsed and role-played between group members. There was an opportunity to discuss the differences between different interactions and the type of communicative behaviours and strategies that may facilitate or hinder a successful exchange of information.

Homework exercises were provided to enable paid caregivers the opportunity to rehearse particular strategies and generalise skills outside of the training environment. Paid caregivers were provided with a tape recorder to audiotape conversational interactions with people with an ABI. Recorded conversations were reviewed within the group at the beginning of each session. Discussion focused on how to adapt communication strategies which would improve interactions within a range of contexts and people with ABI to aid generalisation of skills.

Each session involved discussion of a toolbox of communication strategies (Togher et al., 2011) that was individualised for each paid caregiver to self-monitor their use of strategies (see Appendix C). Caregivers had to identify strategies that were successfully used and those that required improvement. At the end of training, the toolbox was reviewed in detail to make suggestions that would assist the maintenance, consolidation and further development of skills.

2.4.1.1 Materials.

To ensure that training was kept consistent across all sessions, a trainer's manual and caregivers guide was adapted from the initial program designed by Togher et al. (2011). The manual and guide were divided into six sections to reflect each individual session. Appendix D provides examples of the training session exercises. The following items were included in each manual/guide;

Trainer's Manual: This manual contained all of the program information provided to the paid caregivers and also included;

- a) Questions to be asked to stimulate discussion and to assist a paid caregivers understanding of strategies during training.
- b) Role-play activities designed to simulate everyday communication problems in the workplace.
- c) Resources and scripts to conduct communication based activities.

Caregiver's Guide: In developing this manual, materials needed to be accessible for paid caregivers with little or no professional training. Therefore, all materials were designed to be user-friendly and written in plain English. Materials included:

- a) A series of handouts and information sheets utilised over the course of the training program.
- b) A range of worksheets and written exercises intended to be completed within training sessions.

- c) A toolbox of communication strategies that assisted the identification of strategies to improve.
- d) Homework tasks to complete at the end of each training session.

Videotaped Vignettes: These were developed to illustrate various styles of communication that caregivers may have with people with TBI.

Commercial videotapes: Segments from The Catherine Tate Show, Little Britain, Dragon's Den, Scrapheap Challenge and The Office were used to facilitate discussion and to illustrate the range of interaction types. For example, vignettes from Scrapheap Challenge were used to stimulate conversation between participants. This TV show required two teams to build a vehicle from scrap metal and compete against one another. Participants would watch part of the show and then use it to ask positive, open-ended questions of one another (e.g. "what do you think they are trying to do?", "what things do you think they will need?" and "what do you think will happen next?"). Other TV shows such as The Catherine Tate Show and Dragon's Den were used to illustrate the different types of interactions (e.g. service encounter, recount, persuasion/argument). These vignettes (some of which were humorous) did not always contain the required elements for a particular interaction so there were opportunities for discussion about what was required and what was missing.

2.4.1.2 Training modules.

The training program contains a 2 hour session and five 3 hour sessions described as follows;

1. *Introduction.* This session included four main areas; (1) Discussion of difficult conversational situations within the workplace; (2) The range of cognitive, behavioural and social communication changes following a TBI; (3) Understanding how to observe and compare interactions of people with TBI to those who have not sustained a TBI; and (3) Introduction of the use of tape recorders for homework tasks.
2. *Brain Injury and Communication.* This session included five main areas; (1) Understanding the importance and purpose of communication; (2) Describing the use of language within different communicative contexts and understanding the role of the communication partner in affecting the outcome; (3) Examining the structure of interaction types that are found to be most problematic within the workplace; (4) Discussing a range of communication strategies that can facilitate good interactions and; (5) Identifying barriers to successful conversations within the workplace.
3. *Collaboration.* This session introduced the five components of a collaborative style of communication based on Ylvisaker and Feeney (1998); (1) Collaborative intent; (2) Cognitive support; (3) Emotional support; (4) Questions: positive style; and (5) Collaborative turn taking.

The session subsequently put all the strategies together to identify how best to speak and receive a message from a person with TBI.

4. *Elaboration.* This session introduced the two components of an elaborative style of communication based on Ylvisaker and Feeney (1998); (1) Elaboration of topics including maintenance of topic and; (2) Elaborative organisation during a topic, between topics and over time including the review of information during a conversation. The session subsequently put all the strategies together to assist people with TBI to extend and elaborate their conversations.
5. *Asking Questions* (see Appendix D for sample exercises). This session focused on the variety of question types that may contribute to the effectiveness of a conversation. These included (1) Open and closed questions; (2) Simple and complex questions; (3) Primary and follow-up questions; (4) Dynamic questions; (5) Loaded and neutral questions and; (6) Testing and true questions. The session involved teaching a more positive style of questioning.
6. *Putting It All Together.* This session focused on consolidating information from the previous sessions and incorporating them into genres that are specific to the paid caregiver's and the workplace. This session focused on five genres in particular: (1) Planning and negotiating what activities to participate in during a one-to-one session; (2) Discussion about something on TV or in the newspaper; (3) Problem solving difficult situations that could occur within the residential rehabilitation centre; (4) Planning a shopping list and; (5) Casual conversation. The session

involved the rehearsal and role-play of the various interaction types using both a collaborative and elaborative style of communication.

2.5 Procedure

Paid caregivers attended sessions to provide assessment data at three intervals as outlined in Figure 2.1; (1) One to two weeks prior to the commencement of training; (2) One to two weeks following the end of training and; (3) Six months after the completion of training. On each occasion, paid caregivers participated in two videotaped interactions with a person with TBI (structured and casual conversation), completed two questionnaires (La Trobe Communication Questionnaire and modified burden questionnaire) and participated in a focused interview. Data collected contained a combination of both quantitative and qualitative information. Outlined below are further details about the videotaped conversations, the focused interview and the training procedure. The questionnaires will be explained later in this chapter.

2.5.1 Videotaped conversations.

Previous communication partner training programs have used conversational discourse to measure the effects of training (Bloomberg et al., 2003; Dobson et al., 2002; Hickey et al., 2004; Kagan et al., 2001; Legg et al., 2005; Rayner & Marshall, 2003; Togher et al., 2010a). However, obtaining an accurate and reliable sample can be problematic with varied elicitation procedures (Correll, van Steenbrugge, & Scholten, 2009; Turner & Whitworth, 2006). These have ranged from consisting of five sentences or more in length

(Coelho, 1999), 15 minutes of conversation (Prutting & Kirchner, 1987), 5 minutes of conversation about an area of interest with guideline questions and prompts to be used if required (Galski et al., 1998), an 18 minute conversation with a structured list of prompt questions (Turkstra, Brehm, & Montgomery Jr, 2006) to the use of a list of questions surrounding three main topic areas (Snow, Douglas, & Ponsford, 1995; Snow et al., 1997, 1998). Elicitation methods and the type of conversational sample used to measure the effects of training needs to reflect the interactions that occur for paid caregivers of people with TBI.

For the purpose of this study, two conversational samples were conducted; (1) Structured conversation and; (2) Casual conversation. These conversational samples reflect the type of interactions that occur between a paid caregiver and a person with TBI. For example, a structured conversation occurs when a paid caregiver is doing personal care or when completing a shopping task. Casual conversation occurs when watching TV, reading the newspaper or going to the cinema. In many instances, there are a range of structured and casual conversations that occur within the workplace on a daily basis.

Conversational samples were taken at three points during the course of the study; pretraining, posttraining and at follow-up (see Figure 2.1). All participants were seen by the author of the thesis in a quiet room at the residential rehabilitation centre. Assessment sessions were videotaped with a Hitachi DZ-GX5060E DVD video camera/recorder mounted on a tripod. Sessions were audio-taped using a Sony IC Recorder ICD SX46 as a backup in case of technical problems with videotaping. All conversations were then edited to delete inadvertant references to training or times of the year that would have alluded to

the time of videotaping. The next section will describe in further detail the two conversation types and elicitation methods.

2.5.1.1 Structured conversation.

The structured conversational sample was based upon a set of probing questions proposed by Snow et al. (1995, 1997, 1998). In these studies the conversation consisted of questions that constituted a warm-up period and then a further list of questions. No time frame was indicated for the length of this conversation. Questions were given to the paid caregiver in written form prior to the commencement of the interaction (see Appendix F). Questions used by Snow et al. (1995, 1997, 1998) in the warm-up period needed to be adapted to suit the workplace environment. Initial questions were;

1. How did you get here today?
2. Where did you come from? (Seek clarification re: where they live and who with)
3. How do you feel about being at the long-term residential rehabilitation centre? (Seek clarification re: what they did when they were a resident, who they were friends with).

The following questions asked were identical to those used by Snow et al. (1997, 1998) to engage both people in conversation about three main topic areas (work/study, use of leisure time, TV viewing habits).

4. Can you tell me about the sort of work/study you do/did previously? (Seek clarification re: time with current employer, previous types of work, preferred aspects of the job, future plans).
5. What sort of things do you normally do on the weekends? (Seek clarification re: sport, special interests, time spent with family).
6. Do you have any particular favourite TV programs? (Seek clarification re: reasons for preferences, together with questions re: recent films/movies seen, and preferences re: videos/cinema).

2.5.1.2 *Casual conversation.*

The second conversational sample was a casual conversational sample based on previous studies (Coelho et al., 1991b; Galski et al., 1998) where the author of the thesis (N.B.) said “I am going to leave you. If you could have a chat about an area of interest for 15 minutes and then I will come back into the room”. The author of the thesis then left the room and returned after that time. No further support or guidance was provided.

2.5.1.3 *Length of conversational sample.*

Appropriate length of time for conversational samples involving a person with TBI is currently unclear. Videotaped interactions lasting have been reported to last from 5 minutes (Galski et al., 1998) to 18 minutes (Turkstra et al., 2006). In fact, most research had tended to utilise longer interaction samples (Coelho, Liles, & Duffy, 1991a; Prutting & Kirchner, 1987; Turkstra et al., 2006), however, Togher, Power, McDonald, Tate and Rietdijk (2010b) were able to demonstrate

that 5 minutes of conversation was sufficient for the purposes of rating. More recently, a 3 - 5 minute segment of a longer conversation was considered sufficient between a person with aphasia and their communication partner though communication changes following TBI are quite different to aphasia (Correll et al., 2009). Moreover, both Correll et al. (2009) and Togher et al. (2010a) described interactions occurring between a family member and a person with a TBI or aphasia. In these cases there can often be a level of familiarity between the two people that will not be present for the paid caregiver and person with TBI in the current study. Although 5 minute samples may be considered sufficient to measure the outcome of an interaction, Boles and Bombard (1998) reported that 10 minute conversational samples “rarely missed the mark” (p.557). Given that the paid caregivers were unfamiliar communication partners and the people with TBI presented with subtle cognitive-communication changes, the first 10 minutes of the 15 minute conversation was used for evaluation and analysis. Focused Interview.

The use of a mixed-methods approach to this research enabled interpretation of both quantitative and qualitative data to answer the research questions. Creswell (2012) highlighted that use of both methods in combination provides a “better understanding of the research problem and question than either method by itself” (p. 535). Moreover, Kovarsky and Curran (2007) highlight the need for a client’s voice to become part of the evidence when evaluating treatment effectiveness and that qualitative information will help to “provide deeper insight into the meaning and quality of the evidence being generated” (p.

60). Focused interviews were conducted with paid caregivers to explore their experience of being involved in a communication training program.

Given that there are few studies that have investigated paid caregivers of people with TBI, it was important to gather as much information about the effects of training for paid caregivers. Focused interviews provide qualitative information that explores the experiences of paid caregivers. Interviews have previously been utilised as part of a qualitative study that examined the experiences of team members involved in a communication training program for people with aphasia (Simmons-Mackie, Kagan, Christie, Huijbregts, McEwen, & Willems, 2007). Increased participation, improved communicative access for people with aphasia and changes within the organisation were identified by team members as a result of inclusion in the program. Team members also reported factors that facilitated or hindered their learning that would not have been identified through quantitative measures alone. Therefore, use of interviews with paid caregivers of people with TBI can provide information not easily captured by quantitative data alone.

Combining quantitative and qualitative data can often be difficult and there exists several different forms of mixed-methods designs to achieve this. Choosing the correct design depends on how the data is collected and the priority given to each form of data. For the purposes of this study, an embedded design was used where both forms of data are collected simultaneously but the qualitative data supports the quantitative data (Creswell, 2012). In other words, the qualitative information gained from focused interviews was used to complement and explain the quantitative results as well as providing additional sources of information not provided by the quantitative data.

The focused interview was semi-structured and conducted with the paid caregivers in a quiet room at each time interval. Each interview was audio and videotaped and lasted from between 5 - 20 minutes. An interview protocol was used to ask a set of open-ended questions to ensure consistency across the interviews (Creswell, 2007). The protocol contained the opening probe question “tell me about your experiences of talking and communicating with people with a brain injury” with further questions and sub-questions that probed a paid caregivers thoughts and feelings further without unnecessarily influencing their opinions. The protocol is outlined in Appendix G. A further question was included posttraining to obtain information of the paid caregiver’s experiences of the training program. Further questions were included to identify what improvements and changes that would be necessary for future training programs.

The interviews were facilitated by the author of the thesis (N.B.) who was also responsible for delivering the communication training program. NB was a male speech pathologist with 10 years of clinical experience in adult neurogenic communication disorders. He had also worked as a senior speech pathologist within the residential rehabilitation centre for 3 years. Being in the role of senior clinician may have led to a power imbalance with paid caregivers where they may have refrained from providing particular information and responded in a socially desirable way. However, Johnson, Avenarius and Weatherford (2006) highlight that being in the role of participant observer can have certain benefits when collecting qualitative information and may be a “prerequisite to the ultimate success of the study” (p. 132). The role of participant-observer involves shared knowledge and experience which can lead to obtaining more meaningful data. In

this study, mutual respect and understanding between interviewer and paid caregivers had already been developed in the 3 years prior to this research being conducted. The interviewer had a thorough knowledge of the working and treating environment, factors that would affect the outcome of training and had a shared knowledge of the type of people with ABI that paid caregivers interacted with on a daily basis. This shared knowledge contributed to the information collected during interviews. While being a senior clinician in the centre and trainer may have affected the degree of objectivity during analysis of the interview transcripts, steps were undertaken to validate the accuracy of the findings including independent verification of the data and member checking.

2.5.2 Communication partner training process.

Paid caregivers randomised to the trained group (n = 5) received communication partner training within one to two weeks of the initial videotaped interaction being conducted. Paid caregivers randomised to the control group (n = 5) did not receive the training, however, remained employed in the same residential rehabilitation centre as the trained paid caregivers. Each paid caregiver in the trained group attended an initial 2 hour introductory session that was followed by five 3 hour sessions. Training sessions were conducted over a period of eight weeks in small groups of two to three paid caregivers due to changes in staffing schedules. Participants in the training group were asked not to discuss the content of the training sessions with other staff in the centre until after the completion of the study. The manualised treatment program described

in section 2.4.1 was used to structure the program and ensure consistency across sessions.

2.6 Primary Outcome Measures

2.6.1 Adapted Measure of Participation in Conversation (MPC) and Measure of Support in Conversation (MSC).

The Measure of Participation in Conversation (MPC) and Measure of Support in Conversation (MSC) are two measures that were recently adapted to rate the conversational interactions between a person with TBI and their communication partner (Togher et al., 2010b). The initial measures were developed to rate the interactions between a volunteer and a person with aphasia (Kagan et al., 2001; Kagan, Winckel, Black, Duchan, Simmons-Mackie, & Square, 2004). The first measure, the Adapted MPC (see Appendix H), refers to the level of participation of the person of TBI within a conversation. It consists of two scales, interaction (social connection) and transaction (content). Interaction refers to how the person with TBI is able to engage and share the conversation, whilst transaction refers to how the person with TBI is able to provide information that indicates an understanding of the conversation. The second measure, the Adapted MSC (see Appendix I), is used to rate the skill of the communication partner and the support provided to the person with TBI. It consists of two scales, acknowledging competence (AC) and revealing competence (RC) of the person with TBI. Revealing competence is further divided into 3 subscales; ensuring the adult understands, ensuring the adult has a means of responding and verification. Measures are scored on a 9-point Likert

scale ranging from 0 to 4 with 0.5 intervals. The MPC scale ranges from 0 (no participation) through 2 (some participation) to 4 (full participation). The MSC scale ranges from 0 (not supportive) through 2 (basic skill in support) to 4 (highly skilled support). The three subscales of the RC scale for the MSC are rated separately and then averaged to give a total RC score. Psychometric information has been reported to establish the inter-rater reliability and construct validity for the original measures (Kagan et al., 2004) and the inter-rater and intra-rater reliability for the adapted measures (Togher et al., 2010b).

2.6.2 Global Impression Scales.

The Global Impression Scales are a measure of global communicative ability for a social interaction (Bond & Godfrey, 1997) (see Appendix J). Rather than separately rating the communicative behaviours of the person with TBI and their communication partner, these scales rate the overall interaction. The rater is required to rate their first impression of interactions on scales of how appropriate, effortful, interesting and rewarding they perceived the interactions to be. Scoring is conducted on a 9-point Likert scale ranging from 0 (not present) to 4 (present throughout) with 0.5 intervals. Reverse scoring is applied to the effort scale where a high score reflects less effort. The Global Impression Scales have been utilised to evaluate the effects of communication partner training for people with TBI (Togher et al., 2010a) and have been shown to have high inter-rater reliability ($r = 0.89 - 0.92$) (Bond & Godfrey, 1997).

2.6.3 Establishing inter-rater reliability.

Two judges (female) were recruited from the University of Essex, UK to establish inter-rater reliability on the primary outcome measures. The primary judge was a recently graduated speech pathologist and the secondary judge was a final year speech pathology student. Both judges were trained in the use of the MPC, MSC (Adapted) and Global Impression Scales. Training involved judges familiarising themselves with the scales, rating videotaped conversational interactions and discussing scoring and any discrepancies. Judges were trained until scoring was within 0.5 for 80% of the measures for 12 consecutive videotaped interactions. Training lasted 35 hours over 6 weeks. Study samples were then randomised with the first 27% (8/30) of the structured conversations presented to both judges. Judges were blind to group assignment and the time at which the videotaped conversation occurred but not to the purpose of the study. Inter-rater reliability was established for two scales of the Adapted MPC (interaction and transaction) and MSC (AC and RC) and the four Global Impression Scales (appropriate, effortful, interesting, rewarding). The primary judge then proceeded to rate the remainder of the structured conversations independently. Further training was conducted for 6 hours to both judges before the first 27% (8/30) of the casual conversations were presented to establish inter-rater reliability for the Adapted MPC, MSC and Global Impression Scales. The primary judge then proceeded to rate the remainder of the casual conversations independently.

2.7 Secondary Outcome Measures

2.7.1 La Trobe Communication Questionnaire (LCQ).

The La Trobe Communication Questionnaire (LCQ) is a questionnaire that measures perceived communicative ability for a person with TBI (Douglas, O'Flaherty, & Snow, 2000). The questionnaire measured the perception of the person with TBI, a relative and the paid caregiver. The LCQ consists of 30 questions rated on a modified Likert scale: (1) Never or rarely; (2) Sometimes; (3) Often; (4) Usually or always with reverse scoring for six out of 30 items to prevent response bias. Twenty of the items are based upon normal communicative behaviours with the remaining 10 based upon commonly reported cognitive-communication deficits following TBI. The questionnaire gives a total score that ranges from 30 to 120 where a higher score reflects poorer communication skills. The questionnaire has been shown to have high test-retest reliability (Douglas, Bracy, & Snow, 2007a) and is able to discriminate between people with TBI and their close others with similar trends for both groups (Bracy & Douglas, 2005; Douglas et al., 2007a; Struchen, Pappadis, Mazzei, Clark, Davis, & Sander, 2008b; Watts & Douglas, 2006). The internal consistency of the questionnaire is considered acceptable despite ranging from fair (Struchen et al., 2008b) to high (Douglas et al., 2007a). The construct validity of the questionnaire has been demonstrated with a factor analysis of items demonstrating the interaction of cognitive and language function on communication (Douglas, Bracy, & Snow, 2007b; Struchen et al., 2008b).

2.7.2 Modified Burden Questionnaire.

To examine the broader issue of a caregiver's experiences an evaluation of their experiences of burden and stress were examined. Previous research has identified burden and stress for paid caregivers of people with developmental disabilities (Hatton, Brown, Caine, & Emerson, 1995; Hatton, Emerson, Rivers, Mason, Mason, Swarbrick, Kiernan, Reeves, & Alborz, 1999; Jenkins, Rose, & Lovell, 1997; Rose, Jones, & Fletcher, 1998). Therefore, a questionnaire was modified to measure the emotional experiences of paid caregivers participating in this study.

The questionnaire used contained 22 items that were adapted from the modified Burden Questionnaire which contained 30 items describing the care-giving experience (Machamer, Temkin, & Dikmen, 2002). The original measure had been intended for family members or people who care for a person with TBI within their home environment. Therefore, many of the items were not relevant to paid caregivers in this study. Of the 30 items, only 12 items could be applied to paid caregivers. For the 12 items included in the final questionnaire, eight referred to negative care-giving experiences and four referred to positive care-giving experiences. An additional 10 items were added to capture the experiences and effects of training in this study. These included items such as "do you feel nervous about talking with the clients?", "do you feel in control when running a session or task with a client?" and "do you feel that the client is demanding when they communicate?". Of these 10 items, four of them

concerned negative communication experiences and six of them concerned positive communication experiences.

The final modified burden questionnaire contained 22 items with 10 items addressing positive care-giving experiences and 12 items addressing negative care-giving experiences of paid caregivers for people with TBI (see Appendix E). Each item was rated on a Likert scale scored from 1 to 5 to represent frequency of occurrence, ranging from “never feel that way”, “rarely”, “sometimes”, “quite frequently” and “nearly always”. Items that described the positive experiences of care-giving utilised reverse scoring. A total score ranged from 22 to 110 with a lower score indicative of less burden or stress and more positive experiences of care-giving. No reliability or validity information is available for this questionnaire and as such, this is considered an exploratory investigation of these issues.

2.8 Data Analysis: Quantitative Measures

2.8.1 Preliminary analyses.

Three sets of preliminary analyses assessed the comparability of the groups at baseline, and the inter-rater reliability of the outcome measures: (1) between groups t tests to compare the two groups of paid caregivers on the demographic characteristics of age, years of education, years working as a caregiver, years working in ABI and scores on the WTAR (2001); (2) between groups t tests were used to compare the two groups for their primary and secondary outcome measure pretraining scores and; (3) inter-rater reliability of individual item scores was assessed by sampling 27% of the measures from both judges.

2.8.1.1 Independent samples *t* tests.

These tests were used to compare the scores of the control and training group on demographic variables and primary and secondary outcome measures at baseline (between-groups factors). Independent samples *t* tests rely on the fact that the distribution of scores is approximately normal and that the variances of the two groups (related to the standard deviation) are approximately equal. Normal distribution was determined by values of skewness (lack of symmetry) and kurtosis (pointyness). If the *z* scores of skewness and kurtosis are between minus 2.58 and positive 2.58 then this indicates that 99% of the data lay within this range and that scores are normally distributed. An independent samples *t* test also assumes that the variances are equal (homogeneity of variance). This was tested with Levene's test for equality of variances. If this test was significant and the test of equal variances has been violated, then the *p* value from the "equal variances not assumed" was used.

2.8.1.2 Intra-class correlation coefficients (ICC's).

The reliability of the primary outcome measures is integral to determining the effectiveness of the intervention. Inter-rater reliability needs to be established to examine the amount of variability between the judge's ratings on the primary outcome measures. One way to do this would be to calculate the percentage of agreement for the two judges, however, this could result in high levels of chance agreement if one or two categories predominate (e.g. several cases of dyads scoring at the low or high end of the spectrum). The method therefore taken to establish inter-rater reliability was to calculate the ICC's, which take judges'

differences into account. Such coefficients can take many different forms though for the purposes of this study the ICC (3,1) procedure was the most appropriate (Shrout & Fleiss, 1979). This procedure was chosen as each target (i.e. videotaped interaction) was rated by the same two judges whose ratings were the only ones of interest. Reliability was established for the primary outcome measures on 27% of videotaped interactions (structured and casual) with the primary judge rating the remainder of all interactions.

2.8.2 Procedures used to test hypotheses.

To test all hypotheses, pretraining, posttraining and follow-up scores were examined using repeated-measures ANOVA with helmert contrasts (Field, 2009; Tabachnick & Fidell, 2001). These contrasts examined the differences between the two groups (training and control) in the amount of change they demonstrated over time (interaction effects). Structured and casual conversation scores were analysed separately as the inclusion of conversation type as a third factor would have taken enough degrees of freedom away from the error term to reduce power substantially given the small n. The two group by time interaction contrasts provided the most direct test of the research predictions. The first interaction tests if any change from pretraining to posttraining and follow-up is the same in both groups. The second interaction tests if any change from posttraining to follow-up is the same in both groups. An alpha level of 0.05 was used to determine statistical significance. Main effects and effect sizes were obtained for all measures to provide further evidence as to the effectiveness of training. All analyses were computed using SPSS, Version 17.0 (2008).

2.8.2.1 Repeated measures ANOVA with helmert contrasts.

Repeated measures ANOVA is most suited for this study as the same people (i.e. paid caregivers and people with TBI) are repeatedly assessed at more than two points in time (i.e. pre, post and follow-up). It therefore avoids the problems associated with conducting multiple paired t tests such as inflation of type I errors. There are a number of assumptions that need to be satisfied when conducting repeated measures ANOVA. Firstly, scores need to be normally distributed (see section 2.8.1.1). Secondly, the rule of homogeneity of variances cannot be violated. Thirdly, participants should be independent of one another and finally, only people with scores present at all time points are included in the analysis (Howell, 1997; Marston, 2010)

The use of contrasts enables a researcher to locate where the differences between groups lie and whether the means of the groups follow a particular pattern. Essentially, a contrast is a comparison between two means (or groups of data). Contrasts can be divided into orthogonal and non-orthogonal. Whilst non-orthogonal contrasts are a follow-up analysis to ANOVA, orthogonal contrasts are an alternative way of conducting an ANOVA. In that sense, it takes the data further than repeated measures ANOVA and is a powerful contrast type when testing specific hypotheses or comparisons between means. Helmert contrasts compare the mean (of a group of data) and compare it to the mean effect of all subsequent categories which occurs for all groups of data except the last as there is no data to compare it against. In general, with k treatment means, sets of only $(k-1)$ contrasts are possible. In the current study, there are three categories

of data (pre, post and follow-up) which will result in two rows of coefficients or two contrasts. The helmert contrasts will test whether any interaction between means is the same for both groups (i.e. control and training). The contrasts are constructed as follows:

1. We compare the mean of the pretraining scores with the average of the other two means (i.e. posttraining and follow-up).
2. We drop the first mean and compare the second mean (i.e. posttraining) with the third (i.e. follow-up). The second interaction tests if any change from posttraining to follow-up is the same in both groups.

The set of helmert contrasts can be represented by two rows of coefficients as shown in Table 2.4 (Field, 2009). A set of contrasts has the property that each is independent of the other. In other words, the first contrast does not affect the second, because the first mean is not involved in the second contrast. Taken together these helmert contrasts make up a set of orthogonal contrasts. To ensure their independence (or orthogonality) the sum of the products in any two rows is zero.

Table 2.4

Rows of Coefficients for Helmert Contrasts

Group	Contrast 1	Contrast 2	Product (Contrast 1 x 2)
Pre	-2	0	0
Post	+1	+1	1
Follow-up	+1	-1	-1
Total	0	0	0

Use of orthogonal contrasts reduces the number of multiple comparisons conducted (from three comparisons of pre, posttraining and follow-up scores to two). Dealing with type I and II errors is difficult with such a small sample size. A Bonferroni adjustment (i.e. using a stricter p value based on the number of planned comparisons) would have protected against type I errors, however, it may have led to the increased likelihood of a type II error (acceptance of the null hypothesis when it is false). When there is an issue with multiple comparisons, Siegl (1990) suggests that a good compromise to the situation would be to include the results of interactions and the individual estimates (i.e. means and standard deviations) to assist the reader to understand the results being discussed. A researcher should also refrain from examining non-significant results (which was not done in this study) and examine the significant results for individual differences as this is likely to increase the chance of a type I error (Siegl, 1990).

2.8.2.2 Main effects.

In two-way experiments main effects can be reported which examine the effect of one variable and ignore the effect of the other. Main effects can be a useful approach to understanding your results when you do not have interaction effects. For this study, main effects will be evaluated for group and time (independent variables) for each dependent variable. In other words, were there improvements in interaction on particular dependent variables irrespective of group and did differences exist between the two groups irrespective of time for particular dependent variables?

2.8.2.3 Effect sizes.

Effect sizes were also calculated which quantify the size of the difference between two groups and refers to the magnitude of treatment and practical significance of the findings. Effect size attempts to explain the total variance within the data. One measure of effect size is partial eta squared which provides the proportion of variance in a dependent variable that is not explained by other variables in the study. Each of these measures provides a value from 0 to 1. A partial eta-squared of less than 0.01 represents a small relationship, less than 0.06 a medium relationship and greater than 0.14 a large relationship between variables (Sink & Stroh, 2006). However, caution must be taken when interpreting the results of the current study as a small sample size and unusual scores in the sample can easily distort estimates (Strube, 1988). For example, estimates of eta squared can be inflated with small sample sizes.

2.9 Data Analysis: Qualitative Measures

2.9.1 Transcription of data.

After all focused interviews had been conducted, an administration assistant transcribed the audiotapes verbatim. All identifying information was removed from the transcript. Interviews were then checked and corrections made by the author of the thesis using both the audio and videotaped version of the interview.

2.9.2 Analysis and verification.

Pre and posttraining transcripts from the trained paid caregivers were analysed for categories using a generic 6-step analysis procedure described by Creswell (2009). Each transcript was initially read by the author of the thesis. A conscious effort was made to read the transcripts without pre-existing expectations and to obtain a sense of what the paid caregivers were attempting to say. The interviews were then re-read with precoding and preliminary jottings (Saldana, 2009). Each paid caregiver's transcript was read one at a time during the coding process which meant that successive transcripts would often influence and result in recoding of previous paid caregivers transcripts.

Saldana (2009) summarised a list of questions that were considered when coding (p.18):

- a) What are the people doing? What are they trying to accomplish?

- b) How, exactly, do they do this? What specific means and/or strategies do they use?
- c) How do members talk about, characterise, and understand what is going on?
- d) What assumptions are they making?
- e) What do I see going on here? What did I learn from these notes?
- f) What strikes you?

As the transcripts were analysed, similarities in the codes led to categories of data being developed with the emergence of new ones. Consequently, data was rearranged, recoded and re-categorised into different and even new categories and sub-categories following analysis of all transcripts. During this process, transcripts were reviewed with a comparison of occurrence rates of categories and sub-categories across pre and posttraining transcripts. Trends and patterns in the data were identified before the major categories arose.

Steps were undertaken to validate the accuracy of the findings (Creswell, 2009). Further validation of the data was important as the interviewer was both the researcher and senior clinician within the residential rehabilitation centre. Verification of the data was completed by the author's primary supervisor (LT) to examine the transcripts, review and confirm the codes and verify the categories created. Member checking was also completed to ensure accuracy of the qualitative findings. Attempts were made to have a telephone conversation with all trained paid caregivers to summarise the categories and to discuss the interpretation of the data. Only four of the six paid caregivers remained employed

by the residential rehabilitation centre when the analysis was completed.

Telephone conversations with the four paid caregivers verified the findings and emergent categories.

2.10 Summary

This chapter described the methodology for a single blinded randomised controlled trial conducted for paid caregivers of people with TBI. The study aims to demonstrate that communication partner training for paid caregivers is effective in improving the conversations that involve people with TBI and that positive gains are maintained for 6 months following training. The initial steps of the study were described including the development of a communication partner training program. Participants were then chosen from a residential rehabilitation centre within the UK with two videotaped conversations (i.e. structured and casual) conducted with people with TBI pre, posttraining and at 6 months follow-up.

The methodology of the study involved a mixed methods approach incorporating both quantitative and qualitative analysis. Primary and secondary outcome measures were described and include a combination of scales to rate the videotaped interactions of paid caregivers with people with TBI and self-report questionnaires. The quantitative analysis involved a range of statistical tests that show the inter-rater reliability of the scales, interaction and main effects and effect sizes. In addition, the qualitative analysis compared the pre and posttraining focused interviews for the trained paid caregivers to complement the quantitative data. The following 3 chapters will outline the results of the study.

Chapter 3

Quantitative Results

This chapter presents the quantitative results from the study in four parts; (1) Attendance and compliance; (2) Preliminary analyses; (3) Analysis of treatment effects and; (4) A brief description of the issue of type I and II errors based on the significant and non-significant findings from the study.

3.1 Attendance and compliance.

All paid caregivers received the entire training program with no drop-outs. Training was conducted by the author of the thesis. The 2 hour introductory session was initially attended by four out of the five paid caregivers. The fifth paid caregiver received the introductory session on an individual basis. Whilst training was intended to be conducted in small groups of two to three, sudden changes in the staffing schedules resulted in three of the five caregivers attending one training session on an individual basis.

Data on the paid caregiver's compliance with the completion of homework tasks was variable for the last five training sessions. This data is important as homework tasks enable an opportunity for caregivers to practice and rehearse skills outside of the training environment. Each homework task involved obtaining three audio-taped conversations each week. Overall, tasks were attempted 56% of the time and compliance varied from 20 - 80% for the completion of tasks. Paid caregivers would attempt their homework but no paid caregivers were compliant with obtaining all conversations.

3.2 Preliminary Analyses

3.2.1 Demographic variables.

Table 3.1 reports the means and standard deviations of the demographic data for the two groups of paid caregivers. As the variable of age violated the assumption of homogeneity of variances a non-parametric test was applied to the data. Mann-Whitney U revealed no significant difference between groups, $U = 8.50$, $z = -0.84$, $p = 0.4$, $r = 0.26$.

Table 3.1

Basic Demographic Data for Paid Caregivers as Randomised

	Training (n=5)	Control (n=5)	F	df	p
Age (y)	24.20 ± 3.83	38.60 ± 17.56	1.79	1,8	0.14 ^a
Education (y)	12.60 ± 1.51	12.60 ± 1.34	<0.001	1,8	1.00
Work caregiver (y)	3.93 ± 4.15	11.30 ± 7.89	1.85	1,8	0.10
Work ABI (y)	2.33 ± 1.33	1.90 ± 1.24	-0.53	1,8	0.61
WTAR	91.80 ± 3.35	92.25 ± 5.56	0.15	1,7	0.88

Note. Values are mean ± SD. ABI = acquired brain injury; WTAR = Wechsler Test of Adult Reading

^aLevene's test of equality of variances significant at 0.002 so "equal variances not assumed" p value reported

3.2.2 Baseline comparisons.

One of the assumptions for conducting an independent t test is that the distribution of scores is approximately normal. Skewness and kurtosis of data is

used to assess normal distribution and was conducted for all demographic, primary and secondary outcome variables of the study at each time (pre, post and follow-up). The only variable to have both skewed and kurtotic data was the appropriateness data from the pretraining structured conversations (see Figure 3.1). The skewness z score was -2.82 and the kurtosis z score was 3.69 meaning that the data was negatively skewed with a heavy-tailed distribution (also known as a leptokurtic distribution). No significant difference between groups was revealed on parametric tests, $t(8) = -0.930$, $p = 0.38$ or the non-parametric equivalent Mann Whitney U ($U = 10.0$, $z = -0.57$, $p = 0.57$, $r = 0.18$).

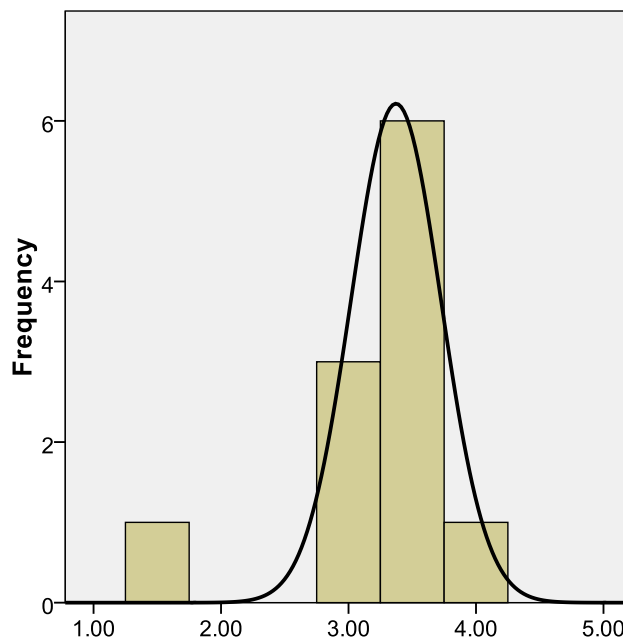


Figure 3.1. Pretraining scores for appropriateness in the structured conversation

The modified burden measure was the only variable to reveal a significant difference between groups at baseline, $t(8) = 2.51$, $p = 0.036$. Caregivers in the training group identified greater burden at baseline compared to caregivers in the

control group. This was further confirmed with the Mann Whitney U ($U = 3.0$, $z = -1.98$, $p = 0.047$, $r = 0.63$).

3.2.3 Inter-rater reliability.

The trained judges rated identical videotapes for 27% of the structured and casual conversation. Two-way mixed effects ICC's with absolute agreement were used to measure inter-rater reliability. Table 3.2 reports the ICC's for the primary outcome measures. Reliability coefficients below 0.4 are considered to have poor clinical significance, 0.40 - 0.59 fair clinical significance, 0.60 - 0.74 good clinical significance and 0.75 - 1.0 excellent clinical significance (Cicchetti, 1994). The majority of measures had excellent inter-rater reliability (0.78 - 0.97).

Table 3.2

Intra-class correlations and 95% confidence intervals on primary outcome measures

Outcome	Structured Conversation			Casual Conversation		
	ICC	95% CI	<i>p</i>	ICC	95% CI	<i>p</i>
MPC						
Interaction	0.53	[-0.11, 0.88]	0.02	0.86	[0.39, 0.97]	0.001
Transaction	0.66	[0.07, 0.92]	0.02	0.85	[0.37, 0.97]	0.001
MSC						
AC	0.86	[0.44, 0.97]	0.002	0.94	[0.56, 0.99]	<0.001
RC	0.78	[0.26, 0.95]	0.007	0.97	[0.82, 1.00]	<0.001
Impression Scales						
Appropriate	0.80	[0.29, 0.96]	0.006	0.86	[0.45, 0.97]	0.002
Effortful	0.86	[0.44, 0.97]	0.002	0.79	[0.27, 0.95]	0.003
Interesting	0.86	[0.48, 0.97]	0.001	0.79	[-0.07, 0.96]	<0.001
Rewarding	0.94	[0.73, 0.99]	<0.001	0.74	[0.10, 0.94]	0.004

Note. ICC = intra-class correlations; CI = confidence interval; MPC = Measure of Participation in Conversation; MSC = Measure of Support in Conversation; AC = acknowledge competence; RC = reveal competence

3.3 Analysis of Treatment Effects

3.3.1 Primary outcome variables.

Means and standard deviations for the structured and casual conversation for the Adapted Measure of Participation in Conversation (MPC), Adapted Measure of Support in Conversation (MSC) and Bond and Godfrey (1997) Global Impression Scales are shown in Tables 3.3 and 3.4 respectively (see Tables K1 and K2 in Appendix K for raw scores). Interaction effects for the structured and casual conversations are shown in Tables 3.5 and 3.6. For the sixteen interactions, five in the structured conversation condition were significant (see Figure 3.2). Three of these measures were highly significant, MSC (acknowledging competence) ($F_{1,8} = 36.54, p < 0.001$), MSC (revealing competence) ($F_{1,8} = 21.51, p = 0.002$) and rewardingness subscale of the Global Impression Scales ($F_{1,8} = 20.1, p = 0.002$). Two scales just reached significance, appropriateness ($F_{1,8} = 5.20, p = 0.05$) and interestingness subscales of the Global Impression Scales ($F_{1,8} = 7.11, p = 0.03$). Non-significant results are shown in Figures L1, L2 and L3 of Appendix L.

Table 3.3

Scores (mean and standard deviation) at pretraining, posttraining and at follow-up on the primary outcome measures for structured conversation

Outcome (0-4)	Pretraining		Posttraining		Follow-Up	
	Train	Control	Train	Control	Train	Control
MPC						
Interaction	2.6 ± 0.65	3.0 ± 0.87	2.9 ± 0.82	3.0 ± 0.50	2.7 ± 0.76	2.7 ± 0.76
Transaction	2.9 ± 0.82	3.2 ± 0.67	3.0 ± 0.87	3.0 ± 0.50	3.0 ± 0.87	3.0 ± 0.61
MSC						
AC	2.5 ± 0.61	3.3 ± 0.76	3.1 ± 0.65	2.4 ± 0.65	2.9 ± 1.14	2.6 ± 0.65
RC	2.4 ± 0.74	3.2 ± 0.67	3.1 ± 0.53	2.4 ± 0.66	2.9 ± 0.95	2.6 ± 0.71
Impression scales						
Appropriateness	3.0 ± 0.87	3.4 ± 0.42	3.3 ± 0.57	3.1 ± 0.42	3.4 ± 0.65	3.1 ± 0.22
Effortful	2.7 ± 0.91	3.1 ± 0.74	2.8 ± 1.03	2.6 ± 0.74	2.9 ± 0.96	2.7 ± 0.67
Interesting	2.7 ± 0.57	3.2 ± 0.76	2.9 ± 0.74	2.7 ± 0.76	3.1 ± 0.89	2.7 ± 0.84
Rewarding	2.2 ± 0.84	3.0 ± 0.71	2.8 ± 0.76	2.4 ± 0.82	2.8 ± 0.91	2.6 ± 0.65

Note. MPC = Measure of Participation in Conversation; MSC = Measure of Support in Conversation; AC = acknowledge competence; RC = reveal competence.

Table 3.4

Scores (mean and standard deviation) at pretraining, posttraining and at follow-up on the primary outcome measures for casual conversation

Outcome (0-4)	Pretraining		Posttraining		Follow-Up	
	Train	Control	Train	Control	Train	Control
MPC						
Interaction	2.5 ± 1.00	2.8 ± 0.57	2.6 ± 0.82	2.9 ± 0.42	2.8 ± 0.97	2.9 ± 0.65
Transaction	2.8 ± 1.04	2.8 ± 0.57	2.8 ± 0.97	3.0 ± 0.35	2.9 ± 1.08	2.8 ± 0.57
MSC						
AC	2.3 ± 1.35	2.5 ± 1.06	2.3 ± 1.04	2.8 ± 0.84	3.1 ± 0.89	2.8 ± 1.04
RC	2.2 ± 1.10	2.4 ± 0.99	2.2 ± 1.06	2.7 ± 0.70	2.9 ± 0.99	2.7 ± 1.06
Impression scales						
Appropriateness	2.7 ± 1.04	2.9 ± 0.74	3.0 ± 0.71	3.1 ± 0.65	3.2 ± 0.76	3.0 ± 0.61
Effortful	2.2 ± 1.04	2.4 ± 0.65	2.5 ± 0.71	3.0 ± 0.50	3.0 ± 0.79	2.9 ± 0.82
Interesting	2.2 ± 1.04	2.8 ± 0.76	2.7 ± 0.76	3.0 ± 0.61	2.9 ± 0.89	3.0 ± 0.79
Rewarding	2.2 ± 1.03	2.6 ± 0.82	2.4 ± 0.82	2.7 ± 0.44	2.9 ± 0.96	2.8 ± 0.83

Note. MPC = Measure of Participation in Conversation; MSC = Measure of Support in Conversation; AC = acknowledge competence; RC = reveal competence.

Table 3.5

Interaction effects for scores at pretraining, posttraining and at follow-up on the primary outcome measures for structured conversation

Outcome	Training ^a			Maintenance ^b		
	F (1,8)	<i>p</i>	ES	F (1,8)	<i>p</i>	ES
MPC						
Interaction	3.27	0.11	0.29	0.08	0.79	0.01
Transaction	2.05	0.19	0.21	<0.001	1.00	<0.001
MSC						
AC	36.54	<0.001	0.82	0.78	0.40	0.09
RC	21.51	0.002	0.53	0.43	0.53	0.05
Impression Scales						
Appropriate	5.20	0.05	0.39	0.07	0.79	0.01
Effortful	2.40	0.16	0.23	<0.001	1.00	<0.001
Interesting	7.11	0.03	0.47	0.17	0.69	0.02
Rewarding	20.1	0.002	0.72	0.17	0.69	0.02

Note. Effect sizes are expressed as partial η^2 . ES = effect size; MPC = Measure of Participation in Conversation; MSC = Measure of Support in Conversation; AC = acknowledge competence; RC = reveal competence

^aInteractions indicating training effects (pre vs post/follow-up interactions)

^bInteractions indicating maintenance effects (post vs follow-up interactions)

Table 3.6

Interaction effects for scores at pretraining, posttraining and at follow-up on the primary outcome measures for casual conversation

Outcome	Training ^a			Maintenance ^b		
	F (1,8)	<i>p</i>	ES	F (1,8)	<i>p</i>	ES
MPC						
Interaction	0.04	0.85	0.005	0.29	0.61	0.03
Transaction	0.02	0.90	0.002	0.51	0.49	0.06
MSC						
AC	0.02	0.88	0.003	3.37	0.10	0.30
RC	0.02	0.91	0.002	1.71	0.23	0.18
Impression Scales						
Appropriate	0.18	0.68	0.02	0.45	0.52	0.05
Effortful	<0.001	1.00	<0.001	3.27	0.11	0.29
Interesting	0.55	0.48	0.06	0.24	0.64	0.03
Rewarding	0.53	0.49	0.06	0.56	0.48	0.07

Note. Effect sizes are expressed as partial η^2 . ES = effect size; MPC = Measure of Participation in Conversation; MSC = Measure of Support in Conversation; AC = acknowledge competence; RC = reveal competence

^aInteractions indicating training effects (pre vs post/follow-up interactions)

^bInteractions indicating maintenance effects (post vs follow-up interactions)

Main effects for group and time were measured with the effortfulness subscale of the Global Impression Scales for the casual conversation condition the only primary outcome variable to yield a significant main effect for time ($F_{2,16} = 4.43, p = 0.03$). Figure 3.3 shows the mean scores for the primary outcome measure of effortfulness in the casual conversation.

No significant interaction effects were found for the primary outcome measures for either conversation type that compared posttraining with follow-up scores (see Tables 3.5 and 3.6). Therefore, the significant improvements on outcome measures in the structured conversation condition were maintained at follow-up.

Large effect sizes were found for all primary outcome measures in the structured conversation, however, caution must be taken as a small sample size can easily distort estimates (Strube, 1988). Similarly, large effect sizes were obtained for non-significant results in the structured and casual conversations. Whilst these effect sizes were smaller than those obtained for significant results, it indicates that the sample is not large enough to reject the null hypothesis.

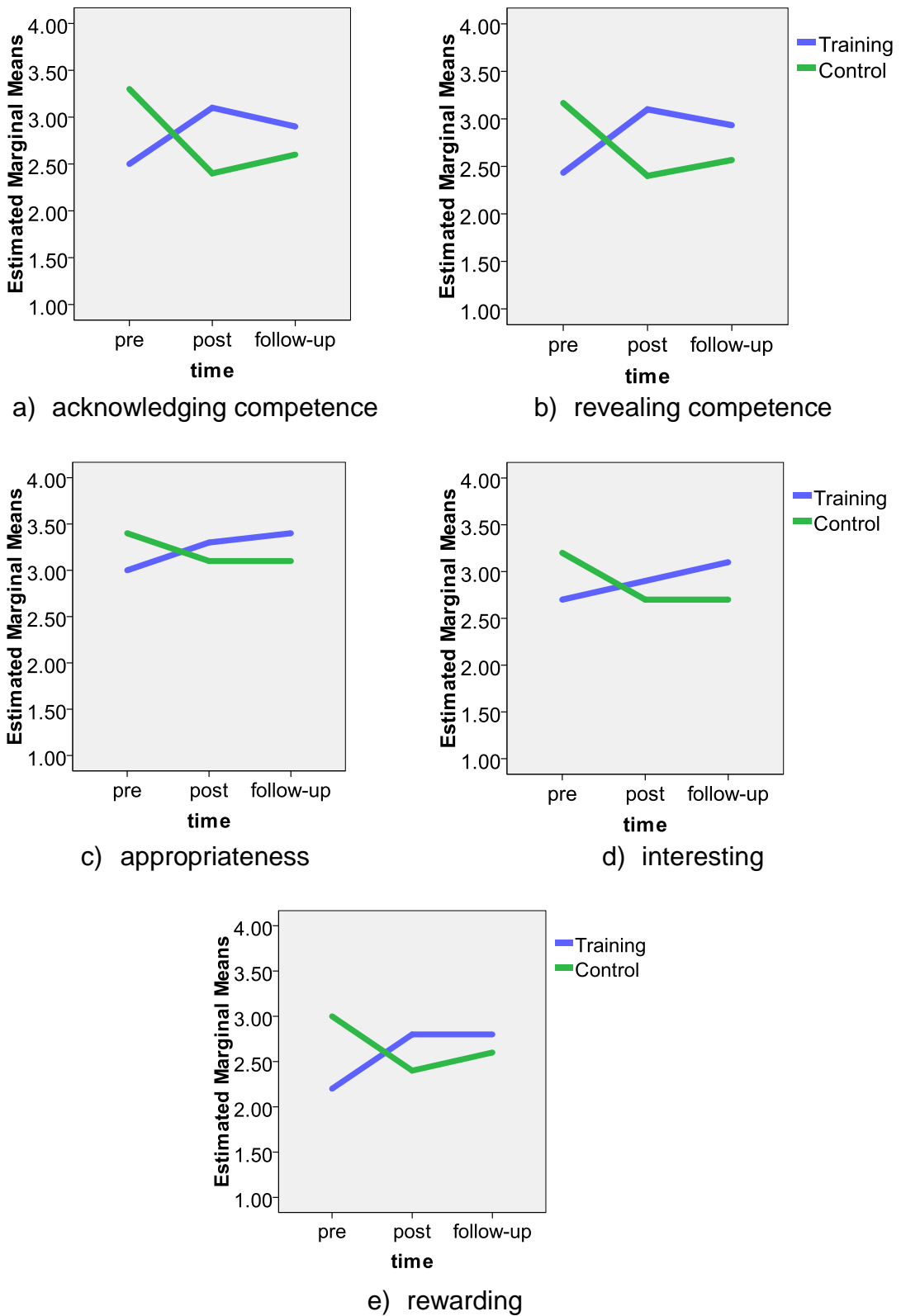


Figure 3.2. Mean scores for significant pretraining, posttraining and follow-up primary outcome measures in the structured conversation

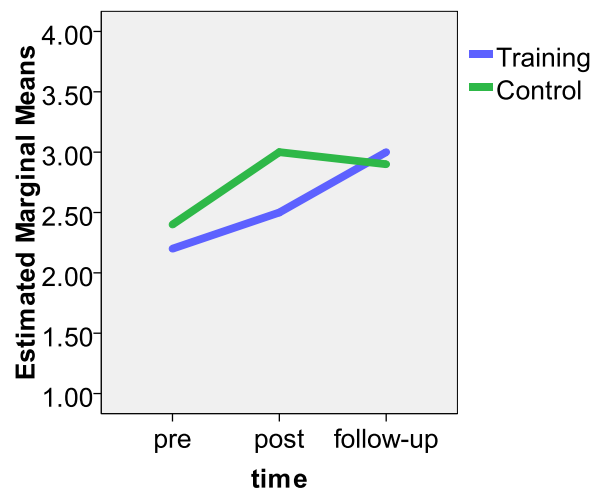


Figure 3.3. Mean scores for effort at pretraining, posttraining and follow-up for casual conversation

3.3.2 Secondary outcome variables.

No significant interaction effects were found for the secondary outcome measures as shown in Tables 3.7 and 3.8. The interaction effects are further shown in Figure M1 of Appendix M. A main effect for group was found for the Modified Burden Scale ($F_{1,7} = 9.38, p = 0.018$) and there was a main effect for time for the La Trobe Communication Questionnaire (LCQ) (relative report) ($F_{1,8} = 8.57, p = 0.003$) (see Figure 3.4). No other main effects were found. As the Modified Burden Scale contained items describing positive and negative aspects of care-giving, these were analysed further. A main effect for group was found for those items describing the negative aspects ($F_{1,7} = 6.57, p = 0.037$) rather than positive aspects of care-giving ($F_{1,7} = 1.53, p = 0.26$) (see Figure 3.5). In other words, those paid caregivers in the training group reported more negative experiences of caring compared with the control group irrespective of time.

Table 3.7

Mean scores (mean and standard deviation) at pretraining, posttraining and at follow-up on secondary outcome measures for the two groups

Outcome	Pretraining		Posttraining		Follow-up	
	Train	Control	Train	Control	Train	Control
LCQ (Caregiver)	54.8 ± 12.32	56.8 ± 6.98	56.2 ± 5.54	67.2 ± 12.70	55.2 ± 6.02	64.8 ± 8.31
LCQ (self-report)	58.2 ± 6.10	61.0 ± 5.74	58.0 ± 13.17	63.0 ± 15.76	56.2 ± 10.62	61.8 ± 11.26
LCQ (relative)	80.0 ± 8.92	83.6 ± 4.28	76.4 ± 8.62	77.8 ± 7.63	75.8 ± 7.19	76.8 ± 5.89
Burden Scale	46.8 ± 3.86	38.6 ± 5.03 ^a	44.8 ± 7.89	35.0 ± 5.24	44.3 ± 3.86	35.8 ± 3.96

Note. LCQ = La Trobe Communication Questionnaire

^aSignificant difference between scores at baseline on independent samples t-test

Table 3.8

Interaction effects for scores at pretraining, posttraining and at follow-up on the secondary outcome measures

Outcome	Training Effect				Maintenance Effect			
	F	df	p	ES	F	df	p	ES
LCQ (Paid Caregiver)	1.25	1,8	0.30	0.14	0.26	1,8	0.63	0.03
LCQ (Self-report)	0.23	1,8	0.65	0.03	0.02	1,8	0.89	0.002
LCQ (Relative)	0.86	1,8	0.38	0.10	0.02	1,8	0.89	0.003
Burden Scale	0.09	1,7	0.77	0.01	0.21	1,7	0.66	0.03

Note. Effect sizes are expressed as partial η^2 . ES = effect size.

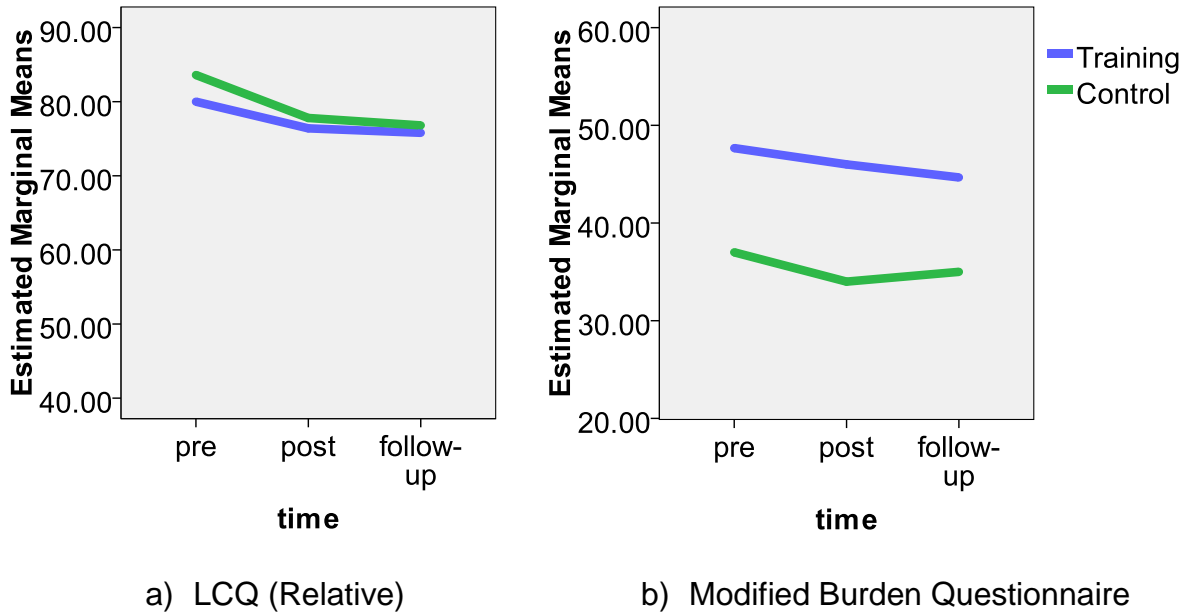


Figure 3.4. Mean scores for significant pretraining, posttraining and follow-up secondary outcome measures.

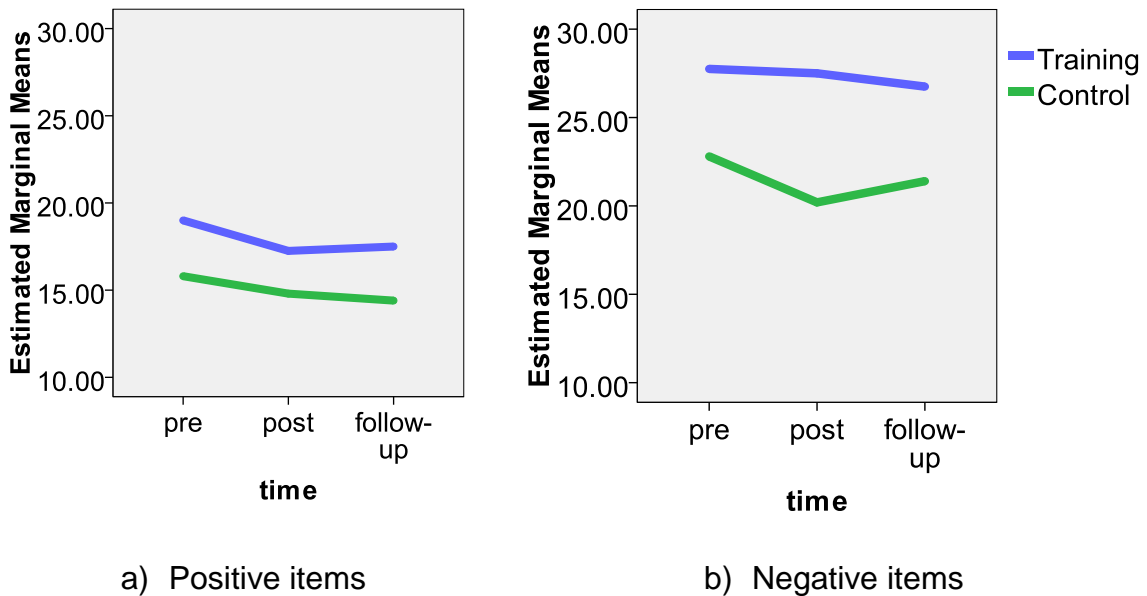


Figure 3.5. Mean scores for items of the burden scale describing positive and negative aspects of care-giving at pretraining, posttraining and follow-up.

3.4 Type I and II Errors

3.4.1 Preliminary analyses.

Conducting multiple independent t tests can create a problem where the results can lose their effectiveness if too many comparisons are undertaken at once. This study involved 25 t tests on variables at baseline (i.e. 5 demographic variables, 16 primary outcome variables, 5 secondary outcome variables). In such cases excessive t tests can inflate the chance of a type I error (where you reject the null hypothesis when it is true), however, a significant result was found for only one variable (i.e. modified burden questionnaire). A non-parametric test confirmed this finding which raises the possibility of the result being a type I error especially since the non-parametric p value was only marginally significant (i.e. $p = 0.047$). For the one variable where there was not a normal distribution of scores (i.e. structured conversation; appropriateness) a non-parametric test confirmed the non-significant result of the parametric t test. The lack of a significant finding suggests that there was no evidence of an effect most likely due to a lack of power resulting from a small sample size. Also, a lack of an effect could be the result of little change in the appropriateness subscale as the pretraining ratings were already high at baseline.

3.4.2 Analysis of treatment effects.

Findings were mixed with both significant and non-significant results. Three of the interaction effects are unlikely to represent a type I error as the results were highly significant (i.e. acknowledging and revealing competence and

rewarding subscale of the Global Impression Scales for structured conversation) as indicated by a p value close to 0.001 (Siegl, 1990). However, marginally significant results (i.e. appropriateness and the interestingness subscale of the Global Impression Scales for structured conversation) would need to be confirmed with a larger sample size.

3.5 Summary

The chapter outlined the quantitative results from the study. A range of significant and non significant results were found particularly for the primary outcome measures in the structured conversation condition. Trained paid caregivers were perceived to have higher scores for acknowledging and revealing the competence of people with TBI and higher scores that showed their interactions were perceived to be more rewarding following the training. Marginally significant findings were found for trained paid caregivers on scales that measured how appropriate and interesting a conversation was perceived by blind raters. Gains were shown to be maintained at 6 month follow-up. A range of main effects were found and identified for both primary and secondary outcome measures. The next two chapters will present the results of the qualitative analyses before interpreting the results in their entirety in Chapter 6.

Chapter 4

Qualitative Results

Chapter 4 describes the qualitative analysis that emerged from the focused interviews conducted with trained paid caregivers. The use of a mixed-methods design provided information about the effects of training and experiences of paid caregivers that could be interpreted alongside and in addition to the quantitative results. The qualitative results of the study are based on six focused interviews conducted with trained paid caregivers pre and posttraining. The sixth paid caregiver was described in section 2.3.1. In addition, the term acquired brain injury (ABI) is used in the analysis rather than TBI. Whilst the videotaped interactions involved people with TBI, paid caregivers interacted on a daily basis with people with ABI (including TBI) in the residential rehabilitation centre. Therefore, the results reflect the workplace experiences paid caregivers have for a range of people with ABI.

As a result of the qualitative analysis, four major categories emerged from the data. Categories were formed from a range of codes and sub-codes across and within the pre and posttraining transcripts as shown in Figure 4.1 (Appendix N provides an example of a coded transcript). Categories were: (1) Knowledge of strategies to improve communication; (2) Communicative success; (3) Psychosocial impact of training and; (4) Barriers and facilitators to learning. Categories highlighted that paid caregivers could perceive changes in their own ability to communicate following training. Trained paid caregivers identified an

increased knowledge in how to communicate effectively with a person with ABI. They expressed improved confidence in using positive communication strategies and techniques to facilitate conversations. Caregivers also provided information on workplace and training barriers that would need to be addressed in future training programs to improve learning for paid caregivers.

Placing the author of the thesis in the role of participant observer was felt to be advantageous. The paid caregiver and interviewer held a shared knowledge of particular people with ABI and the daily challenges of working within the residential rehabilitation centre. This shared knowledge enabled paid caregivers to comfortably describe positive and negative experiences of communicating with people with ABI and the impact training had on those interactions. The interviewer was also in a position to probe a paid caregiver about particular experiences they had identified and discussed during training sessions and situations that may have arisen with particular clients between sessions (both positive and negative). The fact that paid caregivers could highlight poor interactions and training barriers suggest that they did not necessarily feel obliged to give socially desirable responses.

Each of the categories that emerged from the transcripts is identified and described below.

Category: Knowledge and Use of Communicative Strategies

- Code: Strategy Use
 - Subcode: Use of collaboration strategies
 - Subcode: Use of elaboration strategies
 - Subcode: Use of other communicative strategies
 - Subcode: Unsuccessful communication attempts with ABI clients
- Code: Understanding of the cognitive impact of communication
- Code: Evidence of self-monitoring/awareness
- Code: Knowledge
 - Subcode: Increased knowledge of skills learnt
 - Subcode: Knowledge of different communication style required

Category: Communicative Success

- Code: Outcome of communication attempts
 - Subcode: Unsuccessful communication attempts that cause frustration for paid caregivers
 - Subcode: Unsuccessful communication attempts of communication that do not cause frustration for paid caregivers
 - Subcode: Workplace factors that cause frustration
- Code: Evidence of paid caregiver perceiving change in skill
- Code: Changes in the communicative abilities of the person with ABI

Category: Psychosocial and Emotional Impact of Training

- Code: Confidence
 - Subcode: Increased confidence in the use of strategies
 - Subcode: Lack of confidence in communicating
- Code: Enjoyment in communicating with people with ABI
- Code: Uncertainty with using strategies and techniques)
- Code: Emotional impact of communicating with people with ABI
- Code: Enjoyment of the communicative interaction for the person with ABI

Category: Barrier and Facilitators of the Training Program

- Code: Language/Content of the program
- Code: Methods of instruction
- Code: Workplace factors affecting performance

Figure 4.1. Categories, codes and subcodes from qualitative transcripts

4.1 Categories

4.1.1 Knowledge of strategies to improve communication.

The first category that emerged from the data described the paid caregiver's experience of communicating with people with ABI. This category was derived from codes and sub-codes that highlighted the importance of paid caregivers knowledge of strategies to facilitate communication both pre and posttraining. Pretraining paid caregivers' reported that their ability to communicate was influenced by previous experiences of caring, mainly for people resident in nursing or residential homes. Paid caregivers also identified that communicating with a person with ABI was different to clients with other etiologies as shown below in the pretraining example:

It's [communicating] something different that I have never done, I have worked in care homes where clients haven't spoken to me back and here all the clients talk to me and then I can actually make a conversation with them... they tend to interact differently (C3).

I probably am a bit nervous when I first came here cause I don't know what to expect but they're not nearly half as what you think they're gonna be... just talk calmly with [person with ABI] explain things to him properly and he's pretty good (C11).

Paid caregivers were aware that they needed to change their way of communicating for people with ABI. However, they had a limited understanding of the cognitive factors that impact upon a person with ABI's ability to communicate. Only one paid caregiver highlighted how poor concentration affects communication and described a strategy to maintain a person's interest.

...he will be in the middle of a conversation and then he is distracted and you cannot get his attention back from him. I always make sure he switches the TV off if we are in his room because otherwise again he is distracted...but I find that's the best way, to get his concentration first, make sure he is comfortable (C4).

Posttraining, paid caregivers were able to demonstrate an improved knowledge of strategies to facilitate and support conversations with a person with ABI. Paid caregivers made regular references to positive questioning styles and creating equal and collaborative conversations through asking open questions. Closed and testing questions that demanded a "yes" or "no" response for information already known was acknowledged to have been used previously by paid caregivers. Moreover, a greater understanding of the impact of cognition on communication was revealed posttraining. Instructions needed to be kept short and simple and the person with ABI needed time to respond to questions and comments made. Examples of these changes posttraining are shown below:

Learning more about different sorts of questions and how to ask questions instead of asking yes/no questions. It helps me to get more out of the clients... elaborate on things. Clients I find hard to communicate with. Got more ideas of how to put like things (C5).

I am more open to listening...we'll negotiate, talk about this [when the person with ABI is frustrated]...I was very channel vision of my conversation in the way that I asked them to do something whereas now I stop and think you know, tell me what we are going to do next, or can you explain it or where are we going to go first. Find different ways of getting them to think about it as opposed to just telling them (C2).

It takes a long time for them to give me an answer, so I have learnt to use a lot of shorter sentences to get my message across (C1).

Earlier studies have highlighted that improved knowledge is not always an indicator of improved interactions (Bloomberg et al., 2003; Foreman, Arthur-Kelly, & Pascoe, 2007). However, paid caregivers were able to provide examples of actual situations where they had successfully or unsuccessfully utilised the strategies taught. These examples illustrated how paid caregivers could translate knowledge into practice. This resulted in the development of the second category.

4.1.2 Communicative success.

Paid caregivers reported pretraining that communicative attempts with people with ABI were not always successful leading to frustration and distress for both people involved. This category emerged from data that coded the paid caregiver's personal daily experiences of communicating with people with ABI including both successful and unsuccessful interactions. Pretraining examples of unsuccessful interactions and the impact on a paid caregiver include:

...you know what he wants to tell you, what's going on but he can't [tell you], that's the really frustrating thing. I want to be able to know what he's trying to say to me (C11).

...I can get a bit frustrated if I am trying to be quite clear with them and explain it in a rational way what they need to do, but then they still don't understand it, it can be a bit frustrating for both of us (C1).

Posttraining, paid caregivers reported fewer unsuccessful attempts of communication. More frequent attempts were made to encourage collaborative discussion and provide opportunities for people with ABI to express their own thoughts and opinions. Paid caregivers would paraphrase information, request clarification and organise the thoughts of a person with ABI. Posttraining examples include:

But now I can ask the question, say “ [person with ABI] do you think you can ask that by me again, I didn’t understand quite what you were saying?”. You know I can talk to them differently and get a little bit more out of them (C4).

[since the training] asking her how she feels about things, ask them to tell me about things more, [be]cause she opened up more... instead of being demanding asking them like in a more non-demanding way (C5).

[talking about groups] I give each of the clients enough time to talk. Know that I can actually say “do you mind waiting a minute because we are talking about this at the moment”, you know, rather than just cut somebody off dead or ignore them or talk over the top of them (C11).

In addition, paid caregivers reported an ability posttraining to self-monitor and regulate their communicative behaviours. They could modify the use of strategies to suit different people and contexts. Paid caregivers were able to self-monitor their abilities during an interaction or reflect afterwards. Examples posttraining include:

if I was struggling to have a conversation with somebody I would now be able to think that’s not working so let’s try this (C11).

I think I am thinking before I answer, so instead of dive bombing into a situation, stopping to think, they are picking up and why are they picking up. What's the reason? (C2).

4.1.3 Psychosocial impact of training.

The third category that emerged from coded data highlighted the psychosocial and emotional impact of communicating with a person with ABI. Paid caregivers reported experiencing frustration and stress from unsuccessful attempts at communication. These negative experiences would make caregivers anxious and apprehensive and lead them to lack confidence in their own communication skills to facilitate positive conversations with people with ABI.

...but the thing is when I am reading I feel the eyes are on me and I need to read properly and I panic. I have made mistakes before where they [people with ABI] have actually corrected me... and I feel like uncomfortable (C3).

Everyone...is totally different from each other it's just, not knowing what to expect, that's what I'm nervous about (C11).

Paid caregivers did report positive experiences of communicating with people with ABI pretraining. However, enjoyable and rewarding experiences emerged from group rather than individual interactions. Paid caregivers enjoyed having the opportunity to learn the likes, dislikes, interests and hobbies of people

with ABI. Paid caregivers were also rewarded by increased participation of people with ABI within group sessions.

...these are people that don't normally want to come [to group sessions] and they are contributing towards the group and that's brilliant (C11).

I love getting them all involved especially the ones that don't normally have anything to do with it, making them interested in what we are talking about. I love that (C11).

Following the training, greater feelings of confidence and enjoyment emerged for all paid caregivers for individual and group interactions. Paid caregivers felt more comfortable communicating and improving the participation of people with ABI. Increased communicative success contributed to reports of more positive conversations.

I like finding out more about them... I feel more confident talking to them like sharing the conversation more (C5).

Feel a little bit more confident about going in there... getting them to join in... I love to see them [people with ABI] communicating with each other (C11).

It's nice to talk about what she [person with ABI] did at weekends and get to find out a bit more about her, away from her in her home environment and that (C1).

Paid caregivers did, however, remain apprehensive and uncertain with conversational interactions with people with ABI. People with ABI with severe cognitive and behavioural problems were a particular challenge. Use of strategies was often unsuccessful and paid caregivers reported not knowing how to create a more positive interaction. Communication training is unable to cater for the needs of all people with ABI and in some circumstances more individualised strategies may be required. Examples of the paid caregivers continued frustrations are provided below:

I find it frustrating when I can't get through to a client when I can sit there for ages, and I can be so patient... I haven't been able to get any conversation, or they are just not interested (C4).

Still sometimes I don't know what to say or when I do say something it's like before (C5).

4.1.4 Barriers and facilitators to learning.

Overall, paid caregivers expressed enjoyment from participating in the training. All of them perceived positive changes that enabled more successful and positive communication with people with ABI. For some paid caregivers

changes occurred despite years of experience caring for people with a range of disabling conditions. Therefore, the following comment highlights the wider impact of training:

It's definitely improved my skills, it's definitely made me see things differently and I look at the clients differently and I speak to them differently (C4).

Paid caregivers could identify factors that affected their ability to learn over the course of the training program. These factors emerged posttraining in response to the question “can you tell me about your experiences with the training”. Paid caregivers offered their opinions and thoughts as to what components or teaching methods were more effective than others. Although no specific comments were made about group training, observations would suggest that it was largely positive. Group training enabled a non-threatening, relaxed and comfortable environment in which feedback could be given in a supportive and facilitative way. Factors reported by trained paid caregivers to promote learning involved practical based approaches such as the participation in role-play exercises and viewing videotapes of people with ABI and their communication partners. Completing audio-taped homework tasks which were reviewed within sessions were also reported to have been of benefit.

when I started talking to the clients and doing the tapes [homework exercises] then it sort of slipped into place (C4).

[about role-play] ... putting us in the clients shoes. I think that helps because we don't actually know...(C3)

Most agreed that the training would be of benefit to other paid caregivers to encourage them to communicate effectively with people with ABI.

But I would say it's a good thing for everyone to do this training... even if you do a refresher course so people have that knowledge (C1).

Paid caregivers were also able to identify terminology and the amount of information as barriers that hindered their ability to learn. One such barrier was the terminology used during the program. Terms such as “collaboration”, “elaboration” and “conversation repair” were difficult terms for paid caregivers to understand. The amount of information that was provided to paid caregivers in their training manuals was also for some, too excessive and seemed to overload and prevent them from being able to comprehend it fully.

maybe some of it could be simplified (C4).

...a lot less print I can read more pictures as opposed to print (C2).

it's just a lot of information (C1)

Identifying barriers enabled paid caregivers to provide suggestions that would improve the training for the future. Paid caregivers expressed an overwhelming desire for more practical activity based approaches rather than lecturing and written exercises during training.

Probably more time to like practice with tape recorders and stuff [be]cause we didn't get a lot of time... some time in our work time that we can practice (C5).

Perhaps we could do it with you as the client, look at yourself. I still wish I could see myself back [on video]... find that useful, with body language, posture, what am I saying to you...(C2)

One barrier to improvement that was identified both pre and posttraining was factors within the workplace. For example, paid caregivers highlighted poor communication with work colleagues as a reason for difficulty in the implementation of change:

I really enjoy doing the groups because I like to... like the flower arranging, I have noticed that, nothing against my work colleagues, they put the

flowers on the table and then they say to the clients “right, get on with it”.

And I think that’s not what it’s about (C4).

I have noticed that when other members of staff don’t do it right, that’s

terrible isn’t it? (C11)

4.2 Summary

Four categories emerged from the qualitative analysis which included: (1) Knowledge of strategies to improve communication; (2) Communicative success; (3) Psychosocial impact of training and; (4) Barriers and facilitators to learning. These categories demonstrated that paid caregivers perceived changes in their knowledge and way of communicating with people with ABI as a result of the training. Paid caregivers could describe and provide examples of how they had improved their interactions with people with ABI and how this impacted upon their level of confidence and enjoyment of conversations. Paid caregivers were also able to provide valuable insight into what promoted and hindered their learning during the training. These insights will help to improve the design of future training programs for paid caregivers of people with TBI. These results will be discussed with implications for clinical practice in Chapter 6.

Chapter 5

Case Illustrations

This chapter depicts the conversations of three pairs of paid caregivers conversing with a person with TBI in order to highlight the gains made from training in individual cases. The first two conversations show the effects of training in individual cases. The first two conversations show the effects of training by comparing the pretraining and posttraining conversations. Both paid caregivers were perceived to have improved in their ability to acknowledge and reveal the competence of people with TBI. Moreover, they were both perceived to have improved on at least two global impression scales. The third conversation shows how improvement can occur in the 6 months from posttraining to follow-up. The person with TBI was perceived to have improved communication skills on the interaction and transaction scales of the MPC and the paid caregiver was perceived to have improved in their ability to acknowledge and reveal the competence of the person with TBI. The conversation was also rated positively higher on all the global impression scales. In other words, the conversation was perceived to be more appropriate, less effortful, more interesting and more rewarding when compared to pretraining raw scores. Table 5.1 gives the raw scores and demonstrates the improvement for each dyad as rated by blind raters on the Measure of Participation of Conversation (MPC), Measure of Support in Conversation (MSC) and Bond and Godfrey (1997) Global Impression Scales. Figure 5.1 provides a summary of the symbols used in the conversational transcripts (www.talkbank.org/AphasiaBank).

?	question
+...	trailing off
+/.	interruption by another speaker
+//.	self-interruption or correction
[links utterance with an overlapping utterance or non-verbal action
(.)	pause between words
(..)	long pause between words
()	shortenings e.g. runnin(g) for running and (be)cause for because
(())	description of some non-verbal aspect of the conversation
[: text]	target/intended words e.g. gonna [:going to]
Word [xN]	word repeated N times
(unin)	unintelligible utterance
"text"	quotation

Figure 5.1. Transcription symbol summary.

5.1 Conversation One

The first conversation occurred between a paid caregiver (C4) (see Table 2.1) who was 58 years of age and had been a caregiver for almost 14 years but only for a year for people with ABI. The person with TBI (S) (see Table 2.3) was 48 years of age and had sustained his TBI as a result of an assault 5 years earlier. He had left the residential rehabilitation centre 16 months earlier and neither the caregiver nor the person with TBI had met before the commencement of the study. The pre and posttraining conversations are shown in Examples 1 and 2 respectively.

Table 5.1

Raw scores for paid caregivers and people with TBI on primary outcome measures in the structured conversation condition

Outcome (0-4)	Conversation One ^a			Conversation Two ^b			Conversation Three ^c		
	Pre	Post	Change	Pre	Post	Change	Post	Follow-Up	Change
MPC									
Interaction	2.5	3	0.5	1.5	1.5	0	3	3.5	0.5
Transaction	3	3.5	0.5	1.5	1.5	0	3	3.5	0.5
MSC									
AC	3	4	1.0	1.5	2.5	1.0	3	3.5	0.5
RC	3	4	1.0	1.3	2.8	1.5	2.7	3.8	1.1
Impression scales									
Appropriateness	3.5	4	0.5	1.5	2.5	1.0	3	4	1.0
Effortful	3.5	3.5	0	1.5	1	1.5	3	4	1.0
Interesting	3.5	4	0.5	2	2	0	3	4	1.0
Rewarding	3	4	1.0	1	2	0	2.5	3.5	1.0

Note. MPC = Measure of Participation in Conversation; MSC = Measure of Support in Conversation; AC = acknowledge competence; RC = reveal competence.

^aConversation between C4 (paid caregiver) and S (person with TBI). ^bConversation between C3 (paid caregiver) and A (person with TBI).

^cConversation between C2 (paid caregiver) and P (person with TBI)

S: check my arm to see where it is ((looking at tattoo to find daughter's birth year))(.) she was born in (.) it's blurry can't read it

C4: but you like the tattoo's then?

S: ((looking at arm)) no but everyone see if something like when birthday has [my daughter on that side and my two boys on that side ((pointing to left and right side of arm))

C4: [yeah

C4: did you get, were you in the services told [to get those?

S: [no

C4: no? [just like +/.

S: [just rebellious me

C4: yeah

S: but they were good um (.) me mum went ape, me mum went absolutely ballistic when [(unin) she went mad

C4: [yeah

S: but they've stood me in good stead (be)cause when I was a soldier left laying on the floor [messed up in a pool of blood it was my criminal record (unin) that they pressed me on

C4: [yeah

S: (be)cause [all I wanted to do are all police files

C4: [oh (.) yeah

S: so when they du +/.. dialled 999 and said we've just found a man covered in blood beaten up in a badly +/.. [bad way

C4: [yeah

S: laying there totally unconscious ((pulling up his sleeves to show his tattoos')) checked these on the files, "oh that's Simon you just found"

C4: oh right that's good then so +/.

S: so I wouldn't have had it done +/.

C4: better than DNA then +/.

S: so if I wouldn't have had it done I would be dead [basically,

C4: [yeah

S: left there to die [but well they traced me through them ((pointing to his tattoo's))

C4: [yeah

S: which is good, so being a rebel is good

Example 1. Pretraining conversation one. S = person with TBI; C4 = paid caregiver.

The conversation pretraining was dominated by the person with TBI with few opportunities for C4 to contribute. The person with TBI gave excessive information about his tattoos and how they help him to recall his children's birthdays and how they helped police identify him when he had his injury. The majority of contributions by C4 were to simply acknowledge and confirm what the person with TBI had said (i.e. "yeah"). The two questions asked by C4 only required a "yes/no" response and there was no attempt to clarify, rephrase or organise the information given by the person with TBI. For example, C4 did not clarify the answer given by the person with TBI following the question "but you like the tattoos then?" when he said "no" and then gave positive reasons for getting a tattoo. On several occasions the person with TBI went off topic (e.g. talking about his mother's reaction to him getting a tattoo and the assault). Rather than redirect him, C4 acknowledged what was said and offered an opinion after several turns of the conversation. There was also little to suggest that the person with TBI or C4 gained enjoyment or satisfaction from the interaction. Despite this, the blind raters perceived an interaction that "mostly" acknowledged and revealed the competence of the person with TBI on the MSC. Moreover, the blind rater perceived that the interaction was appropriate, interesting, rewarding with reduced effort on "most occasions" on the Global Impression Scales. Clearly, C4 was a good communicator prior to the commencement of training. So, the aim of training was to develop the communication skills of C4 to create a more equal, organised and rewarding exchange of information with the person with TBI.

C4: so, what are your hobbies? What things do you [like (.) do you like hobbies +/-.

S: I like fishing, coarse [fishing

C4: [((smiles)) so still to do with fish?

S: yeah I still um I still quite often go up and down a mackerel or two [catch one or two big ones

C4: [yeah

S: recently caught a few big ones and on my phone here somewhere ((pulls out his phone))

C4: so where is it you actually fish?

S: um (.)

C4: near to home?

S: yeah not far away at all ((looking at phone)) that's me dog +/-...

C4: is it riverbank fishing or do you have to weigh it in?

S: no it's even on the lake its ah on the bank

C4: yeah, you don't go off in the boat and ((gestures)) +/-...

S: nah I get wet (unin)

C4: ((laughs))

S: where's that fish ((showing a picture on his phone)) that's a particularly good one I caught

C4: wow that is a whopper

S: 24 perk

C4: is that a carp?

S: that's a carp

C4: I was going to say it looks that shape ((smiles))

S: common carp

C4: I do know a bit +/-.

S: that was out of um (.) where was that out of thames (.) thames golf clubbing yeah thames golf club and fishing (.) it was a gravel pit and +/-.

C4: are they easy to hold? I always [think they are slippery

S: [they are a pain in the (.) backside

C4: yeah

S: (be)cause you're trying to hold it and it's going [kick kick

C4: and they've got sharp fins haven't they?

S: some have but carp are pretty pretty soft but +/-...

Example 2. Posttraining conversation one. S = person with TBI; C4 = paid caregiver.

Posttraining, C4 improved on both scales of the MSC and three of the four Global Impression Scales (i.e. appropriate, interesting, rewarding) scales. The blind rater perceived C4 to be “interactionally outstanding” achieving 4.0 (i.e. maximum score) on all these scales. The person with TBI made positive changes in their communicative ability on the MPC. In the posttraining interaction, C4 produced fewer acknowledgements and an increased number of questions and comments to indicate their interest and enthusiasm. For example, C4 showed enthusiasm when the person with TBI showed her a photograph of a fish saying “wow that is a whopper”. Conversational repair was recognised and attempted by C4 to both clarify a response (e.g. “so still to do with fish?” and “you don’t go off in a boat...”) and organise the conversational topic (e.g. “so where is it you actually fish?”). Repair led to an interaction that was more coherent as the conversational topic was sustained for longer on a topic of interest for the person with TBI. Use of gesture by C4 and reference to a photograph on the person with TBI’s phone contributed to a joint understanding of what was being discussed. Conversational turns by the person with TBI were shorter as C4 asked questions to limit the amount of information he gave. For example, C4 gave the person with TBI a choice rather than ask an open-ended question when she asked “is it riverbank fishing or do you have to weigh to put it in?”. C4 also expressed enjoyment of the interaction by smiling and laughing which was not observed pretraining. Training was therefore able to create positive changes in the communication skills of C4 which had an impact on the way information was

exchanged and how rewarding the interaction was for perceived by both participants.

5.2 Conversation Two

The second conversation involved paid caregiver (C3) (see Table 2.1) with a person with TBI (A) (see Table 2.3) pre and posttraining. The paid caregiver was 19 years old at the time of videotaping. She had worked as a caregiver for 4 years but for only a year as a caregiver for people with ABI. The person with TBI was 29 years old and had sustained a severe TBI as the result of a motor vehicle accident four years previously. The person with TBI had been discharged from the residential rehabilitation centre a year earlier and neither the paid caregiver nor the person with TBI had met prior to the videotaped interaction. The conversations are shown in Examples 3 and 4.

C3: What sort of things do you normally do on the weekends?
A: Depends
C3: Sports?
A: ((head:no)) Nah +/.
C3: Not a football fan then?
A: I used to play football and everything but now I don't do no sports (.) but +/.
C3: Gym?
A: Nah. I used to but no more
C3: Ok. Special interests?
A: ((head:no)) No [(laughs)
C3: [You don't watch TV?
A: ((head:no)) [sometimes yeah
C3: [Ok
C3: Do you spend family like time with your family?
A: Sometimes [(laughs)
C3: [Mum and Dad?
A: Sometimes

Example 3. Pretraining conversation two. A = person with TBI; C3 = paid caregiver.

The communicative attempts of C3 pretraining involved closed questions, rapid conversational turns and difficulty encouraging the person with TBI to elaborate. The blind rater perceived C3 to “minimally acknowledge” the competence of the person with TBI on the MSC and the conversation was rated as only “occasionally” appropriate and rewarding on the Global Impression Scales. A closed question was initially asked by C3 to find out what the person with TBI did on the weekend. However, when the person with TBI was unable to answer the question C3 persisted with asking closed questions to find out what he had done. On one occasion, she asked questions about a topic she already knew he was not interested in. For example, when the person with TBI indicated that he did not like sports, C3 continued to probe him on whether or not he liked football or going to the gym. The person with TBI tended to give one word responses so conversational turns were rapid and he did not seem engaged or interested in the content of the conversation. The person with TBI was perceived to only take “occasional responsibility” of the conversation on the MPC. On the single occasion where the person with TBI said that he used to play football, C3 failed to use this as an opportunity to encourage elaboration on a potential topic of interest. Likewise, when the person with TBI indicated that he watched television, C3 went on to ask “do you spend family like time with your family?” rather than ask further questions to find out what his favourite television programs were. C3 also interrupted the person with TBI on 2 occasions to ask questions. As a result, the blind rater perceived a poor interaction which was dominated by C3 and lacked any sense of purpose or cohesion between

participants. C3 needed to learn the skills to successfully create a more engaged and balanced conversation.

C3: What sort of things do you normally do on a weekend?
 A: (..) Depends ((laughs))
 C3: Um (..) any just say [whichever
 A: [Go drinking or play golf watch football
 C3: Oh you play golf?
 A: Yeah
 C3: [something (?)
 A: (((laughs))
 C3: What do you think of golf? Is it relaxing for you?
 A: No
 C3: You just like to bet and see who wins?
 A: No I play golf
 C3: Do you play golf?
 A: I play [golf
 C3: [Actual golf? ((gestures))
 A: Golf yeah
 C3: Wow
 C3: Um what do you think of golf?
 A: Not too bad I used to be a lot better than what I am now
 C3: (..) What changed?
 A: I had an accident it messed me [up
 C3: [Is any difference though
 A: Yea got a weak left side [don't move properly]
 C3: [Ah] but um you supposed to play with right hand don't ya supposed to play with right hand [or supposed to play with left hand]
 A: (((frowns))) play with either
 C3: Oh I didn't know that (laughs)
 A: Different clubs left handed clubs and right handed clubs ((smiles))
 C3: Um what was the other ones that you said? That you used to do golf drinking and (..) any other ones?
 A: And I watch movies

Example 4. Posttraining conversation two. A = person with TBI; H = paid caregiver (C3).

The posttraining conversation was more equal than the pretraining interaction because C3 had learnt strategies to better engage the person with TBI. C3 was perceived to have at least a “basic level of skill” in acknowledging and revealing the competence of the person with TBI on the MSC. The conversation was also perceived to be more appropriate and rewarding (i.e. C3 made a change of 1.0 for both global impression scales) which was the difference between only “occasionally” (i.e. 1.0) and demonstrating “several occasions” (i.e. 2.0) of these behaviours in a conversation. C3 allowed more time for the person with TBI to respond without interrupting or requesting the information in a demanding manner. On two occasions C3 paused to think about what she had wanted to say suggesting an ability to self-monitor. C3 was also able to use gesture to assist the understanding of the person with TBI (e.g. gestures golf) and ask open questions that encouraged elaboration (e.g. “um what do you think of golf?”). Although closed questions were still asked and the person with TBI still gave one word responses these were seen to a lesser degree and there was a greater amount of information exchanged between the two participants. Laughter and smiles were more frequent, natural and relevant to the topic discussed indicating enjoyment of the conversation. The last comment made by C3 redirected the person with TBI to the initial question, reminding him of what he had said. Such a move enabled elaboration of another topic of interest (i.e. movies). Training had taught C3 a range of strategies that resulted in more information exchanged between participants and greater enjoyment of the

interaction than in the pretraining conversations. Although C3 had potential to develop further skills, she had a better ability to communicate to create what was perceived as a more positive and interesting conversation.

5.3 Conversation Three

The third conversation involved a paid caregiver who improved between posttraining and follow-up. The paid caregiver (C2) (see Table 2.1) was 49 years of age and had worked for 12 years in that role but only as a caregiver for people with ABI for a year. The person with TBI (P) (see Table 2.3) was 30 years of age and had sustained his TBI as a result of a motor vehicle accident 11 years earlier. He had left the residential rehabilitation centre 6 months earlier and neither the caregiver nor the person with TBI had met before the commencement of the study. The conversations in Examples 5 and 6 compare how the paid caregiver dealt with communication breakdown from posttraining to follow-up. C2 was perceived to have improved on both scales of the MSC (acknowledging and revealing competence) and the four global impression scales. In fact, C2 was perceived to create a more appropriate, rewarding, interesting and effortless interaction all of the time (compared to “mostly” at posttraining). Moreover, the person with TBI was perceived to have improved on the MPC from posttraining (i.e. 3.0) to follow-up (i.e. 3.5). Therefore, positive changes were perceived for all outcome measures rating the conversational interaction.

C2: (be)cause you said you'd lived in Cambridge for quite a long [time
P: [yeah I got sick of Cambridge. You might notice then. I'm totally comfortable with her, like the place is a her to me. Is is just my language creeping out. What would you call that? It's like (unin) and that was my girl she was my car she [x2]
C2: yeah
P: what is that? What [x3] is that called when you do that sort of thing like (.) dunno [:don't know]
C2: when you can't catch the word? [Is that what you're trying to say?
P: [no. I know it's called a car and I know it's an object but she's mine shhhe's mine. What's that? What is that?
C2: not quite sure +//. what you're driving at P I'm trying to help [you
P: [like say if you were's really [x3] proud of that mug you are holding
C2: yeah
P: and said "woah she's my mug"
C2: you can say that that but by your tone of voice
P: yeah
C2: and your emphasis um indicates that you're proud of your car your mug your home
P: yeah ((frowns))
C2: or she's mine and ooh I'm really proud of her
P: (((laughs))
C2: (((laughs))

Example 5. Posttraining conversation three. P = person with TBI; C2 = paid caregiver.

In the posttraining interaction C2 had difficulty using conversation repair strategies when breakdown occurred. The person with TBI tried to describe the problem of stuttering but C2 perceived it to be related to the “tone of voice”. C2 attempted conversation repair with a clarifying question (i.e. “when you can’t catch the word?”), expressing her confusion (i.e. “not quite sure”) and support (“I’m trying to help you”), however, these strategies were ineffective. Strategy use did lead the person with TBI to rephrase the problem, however, communication breakdown had occurred so quickly and C2 remained confused of what he had described. No attempts were made to slow down the interaction or ask different clarifying questions. In the last few turns of the conversation C2 simply acknowledged what the person with TBI had said (e.g. “yeah”) and made one last attempt at conversational repair, “you can say that but by your tone of voice”. At this point C2 had acknowledged that the breakdown in communication had probably been resolved, however, the frown by the person with TBI suggested otherwise. The person with TBI did not persist in explaining the initial problem. The interaction ended with both participants laughing which was a signal to abandon any further attempts of repair and to change the conversational topic. Clearly, the ability of C2 to use a range of repair strategies had an impact on the success of the interaction she had with the person with TBI.

C2: yeah yeah. Can I ask you something? When you were here at Fen House have you got any feelings or thoughts and feelings on on what it did for you and +/-...?

P: thoughts or feelings?

C2: yeah when you were a resident here

P: yeah ((sighs))

C2: think back a bit kinda the highs and the lows how you felt?

P: ((frowns and looks up)) (.) yeah the highs ((sighs))

C2: yeah what were the things that you think about and think yeah I really enjoyed that [it was good

P: [yeah I was I I was (.) dinner time

C2: yeah

P: I used to like dinner times

C2: (giggles)

P: I used to like when the day come to an end and the day had come to an end and the time was your own time

C2: yeah

P: that was like sitting in the lounge and watching TV with the other clients and that

Example 6. Follow-up conversation three. P = person with TBI; C2 = paid caregiver.

The period from posttraining to follow-up allowed sufficient time for C2 to learn and rehearse strategies that would create more successful interactions with people with ABI. This follow-up interaction demonstrates communication breakdown arising from an unclear question asked by C2, “when you were here at the residential rehabilitation centre have you got any feelings or thoughts and feelings on what it did for you?”. A striking feature of this conversation is that the breakdown occurred because of something C2 had said rather than the person with TBI which made it easier for C2 to implement repair strategies. In this example C2 interpreted the verbal response (i.e. “thoughts or feelings?”) and non-verbal signs (e.g. sighs and frowns) by the person with TBI as poor comprehension. As a result, C2 used strategies that included rephrasing the question (i.e. “think back a bit kinda the highs and the lows how you felt?”) and providing an example that the person with TBI would understand (e.g. “yeah what were the things that you think about and think yeah I really enjoyed that”). The strategies chosen were appropriate to the person with TBI and ensured that repair occurred successfully within a small number of conversational turns. The responses given by the person with TBI at the end of the exchange indicated that the communication breakdown had been resolved. This conversation provides an example of a caregiver that not only maintained but improved her communication skills over the 6 months posttraining. It is likely that C2 would have practiced and self-regulated her use of communication skills with a range of people with ABI to create more positive interactions. This ongoing practice led to a further

development of her skills that was observed in the follow-up interactions. These positive effects demonstrate the long-term impact for training paid caregivers and the need for ongoing practice and rehearsal of skills to consolidate the gains made from training.

5.4 Summary

These three case illustrations demonstrate how training had a positive effect on the communication skills of paid caregivers. This change led to more positive interactions involving people with TBI. Paid caregivers were able to ask questions, use conversational repair strategies, encourage elaboration and create a more equal interaction by adapting their communication skills for the person with TBI. Changes in the communication ability of paid caregivers facilitated more successful conversations with people with TBI. Although most change occurred from pre to posttraining, improvement was also shown to occur 6 months after the completion of the training program. The following chapter will discuss and interpret the quantitative and qualitative results and main findings from the study.

Chapter 6

Discussion

This thesis presents the positive results from the first single blinded randomised controlled study to have focused on communication training for paid caregivers of people with TBI. Paid caregivers are frequently involved to support people with TBI and the results of this study demonstrate the benefits of communication training to fulfil the roles of being a caregiver. The three preceding chapters presented the quantitative and qualitative results from the study which found that improving the communication skills of a paid caregiver will positively influence conversational interactions that involve people with TBI. This chapter will discuss and interpret these results in the context of the research questions and hypotheses, organised into five areas: (1) Communication skills of the paid caregiver; (2) Communication skills of the person with TBI; (3) Sustaining change 6 months after the completion of training; (4) Perceptions of the family member, person with TBI and paid caregiver and; (5) Experiences of stress and burden for the paid caregiver. Limitations, directions for future research and clinical application of the findings will also be discussed for a range of health professionals that manage people with TBI.

6.1 Communication Skills of the Paid Caregiver

Paid caregivers for people with TBI are rarely mentioned in the research so it was important to firstly identify their characteristics. Paid caregivers were

described in terms of age, sex, educational level, time spent as a paid caregiver, time spent caring for people with a brain injury and a measure of intellectual functioning. In this study all paid caregivers were female ranging in age from between 19 and 58 years (mean = 31.4 years) and leaving school between 15 and 18 years of age (which corresponds to 11 to 14 years in education). Previous studies have identified some paid caregivers to have college or university degrees (Ducharme & Spencer, 2001; McCluskey, 2000), however, this was an exclusive criterion for the current study as most paid caregivers in the residential rehabilitation centre did not have degrees. In fact, the criteria only excluded one paid caregiver. Total time spent as a paid caregiver ranged from several months to 23 years (mean = 7.6 years) with average time spent as a caregiver for people with brain injury to be 2.1 years consistent with Ducharme and Spencer (2001) who reported an average of 1.7 years. The current study also included an estimate of intellectual functioning based on the WTAR (2001). Paid caregivers were estimated to be in the low to average range. Two of the trained paid caregivers scored in the low average range which had implications for the complexity of the training content and the vocabulary used in the manuals. Providing a rich description of paid caregivers characteristics helps to understand the extent with which the effects of training can be generalised to other communication partners of people with TBI.

The communicative attempts of trained paid caregivers were perceived to be more natural and sensitive to people with TBI on the Adapted Measure of Support in Conversation (MSC) (acknowledging competence scale) compared to

a control group. Improvements on this scale are consistent with studies that have shown the positive effects for training communication partners of people with aphasia (Kagan et al., 2001; Legg et al., 2005; Rayner & Marshall, 2003). Three of the five trained caregivers improved by at least 1.0 on the acknowledging competence scale (AC) which was the difference between acknowledging competence “some of the time” (i.e. 2.0) and “mostly” (i.e. 3.0). Communicative attempts were perceived as less patronising, more enthusiastic, more respectful and collaborative. Trained paid caregivers reported a change in the nature of their question asking with people with TBI “instead of being demanding asking them like in a more non-demanding way” (C5) and when describing their conversation “I feel more confident talking to them like sharing the conversation more” (C5). One paid caregiver could recognise posttraining how her communication was patronising and non-supportive, “that’s a bit bossy really, it’s telling them what to do. So now I go in and say have you looked at your timetable, do you realise what time it is?” (C4). The results highlight how trained paid caregivers could communicate in a more adult-like manner thus positively effecting the way people with TBI would understand and respond in a conversation.

Trained paid caregivers were perceived to improve the participation of people with TBI in conversations. Improvements were found on the MSC measure (revealing competence scale) which meant that paid caregivers were more able to reveal the opinions and feelings of the person with TBI. These findings are consistent with earlier studies that reported improvements on the

revealing competence scale for communication partners of people with aphasia (Kagan et al., 2001; Legg et al., 2005; Rayner & Marshall, 2003). Four of the five trained paid caregivers in this study made an improvement of at least 1.0 on the revealing competence scale (RC) which was the difference between “basic level of skill” and “uses techniques”. One caregiver improved by 2.0 which was an improvement from having a “low level of skill” (i.e. 1.0) that minimised participation to “uses techniques” (i.e. 3.0) to promote participation for the person with TBI. Trained paid caregivers were perceived to have better skills to ensure the person with TBI was able to understand and respond appropriately. Information was given more slowly, was better organised and topics of interest were introduced to encourage the person with TBI to express their thoughts, ideas and opinions. Trained paid caregivers would add information to maintain the conversation and ask open and true questions that would encourage the person with TBI to elaborate on what they were talking about rather than repeatedly ask direct yes/no questions. Positive improvements were reported by paid caregivers posttraining such as “learning more about different sorts of questions and how to ask questions instead of asking yes/no questions. It helps me to get more out of the clients... elaborate on things” (C5). Questions and comments that would verify and check what the person with TBI was saying were used especially when conversational breakdown occurred as shown by one paid caregiver, “if I was struggling to have a conversation with somebody I would now be able to think that’s not working so let’s try this” (C11). Trained paid caregivers made significant positive changes to how they interacted and promoted the

participation of people with TBI in conversations. This change led to more positive interactions for both participants.

A rewarding interaction creates a positive environment where the person with TBI may feel motivated, enthusiastic and engaged to talk about how they feel or what they think. Training gave paid caregivers the skills to create an interaction that was perceived to be more rewarding on a global impression scale. This replicated the finding by Togher et al. (2010a) following training for people with TBI and their communication partners. Trained paid caregivers were better skilled at engaging the person with TBI to give information. Ideas were exchanged and facilitated with the use of strategies such as speaking about topics of interest and asking questions to which the answer was not known thus placing the person with TBI into an information-giving role. As a result, participants were able to learn something new about one another such as a good movie to watch or how to play a particular sport. Qualitative reports showed the enjoyment and satisfaction that trained paid caregivers felt from their interactions with people with TBI: “I like to talk to them about their lives” (C4) or “I like finding out more about them” (C5).

Interactions involving trained paid caregivers were also perceived as more appropriate and interesting compared to a control group. In other words, trained paid caregivers were able to create conversations that better engaged the person with TBI with an appropriate exchange of personal information about work and leisure pursuits. However, results for both these global measures were only marginally significant (appropriate $p = 0.05$; interesting $p = 0.03$). Togher et al.

(2010a) demonstrated that conversations involving people with TBI and a familiar communication partner were more appropriate but not more interesting following training. Given that the sample size was larger in the Togher et al., (2010a) study ($n = 44$) than for the current study the results could reflect the real outcome of training, however, the relationship of the communication partner could also be a factor. Someone who is familiar with a person with TBI (i.e. a family member) would have already known their work and leisure pursuits and discussed the daily events prior to the conversation being videotaped. In this study, paid caregivers had not spoken beforehand with the person with TBI. This lack of familiarity would have meant all paid caregivers needed to be more actively involved to ask questions and introduce topics in the conversation that could have been perceived as genuine interest in the person with TBI.

Paid caregivers from both groups were perceived to apply significantly more effort to create a conversation following the training. Bond & Godfrey (1997) reported that increased effort would result in conversations that were less appropriate, interesting and rewarding, however, the results of this study showed otherwise. Work needs to be done in order to achieve better and more successful conversations. Trained paid caregivers needed to rephrase questions and comments, provide frequent pauses and introduce topics of interest to ensure the person with TBI understood and had the opportunity to talk. The effort required is illustrated by one paid caregiver who reported that, "I think I am thinking before I answer, so instead of dive bombing into a situation, stopping to think, they are picking up and why are they picking up. What's the reason?" (C2). Togher et al.

(2010a) found that more successful interactions were perceived to have less effort, however, both the person with TBI and their communication partner were involved in the training and interacted regularly between training sessions. This increased familiarity between participants may have contributed to the perception of less effort. Therefore, it may be the case that the less familiar a communication partner is the more likely work needs to be done to achieve a better and more successful conversation.

Trained paid caregivers were able to identify and describe positive changes that improved their conversations with people with TBI. Prior to the training paid caregivers had little knowledge of strategies to facilitate conversations with a person with TBI. Following training, paid caregivers reported positive improvements such as “it’s definitely improved my skills, it’s definitely made me see things differently and I look at the client’s differently and I speak to them differently” (C4) and “[the training] helped me pick up on ways of approaching and dealing with the clients that I probably would not have done” (C1). Trained paid caregivers reported more successful conversations, increased confidence and less frustration in communicating with people with TBI. These changes led to interactions that were described as more satisfying and enjoyable and reflect the importance of training and education to paid caregivers . However, not all paid caregivers made the same level of improvement highlighting the challenges that occur when training this group of people.

There are several environmental and work-specific factors that may contribute to the degree of improvement made from training for paid caregivers.

Kruijver et al. (2000) reviewed two studies that identified that a caregivers experience is important and that people with less job experience will make the most change. The paid caregiver with the most experience working with people with ABI (i.e. 3.5 years) made the least amount of change. However, two caregivers who had only 3 year's experience were among those who made the most change. Both these paid caregivers were the youngest suggesting that age, which has not been investigated before may have been a factor. However, positive changes were found for two of the older trained paid caregivers (aged 49 and 58). Improvement may also be related to a person's intention to change (Kruijver et al., 2000) with some people more or less responsive to training (Rayner & Marshall, 2003). Theories of adult learning highlight that motivation to change is an important factor to consider when teaching adults new concepts or principles (Wlodkowski, 1985). Whilst inclusion in the training program was voluntary, three of the five paid caregivers (C2, C3 and C4) seemed more motivated to change, responded more positively to constructive feedback and made effort to complete homework tasks and implement strategies. However, these factors are all intrinsic to the individual being trained.

Extrinsic factors may have also affected the outcome of training. The social system of a working environment may have an impact on the level of improvement for paid caregivers following training. A positive working environment can lead nurses to an increased use of communication strategies with patients (Kruijver et al., 2000). Alternatively, a negative working environment with little support from supervisors can be a barrier to change. Burgio et al.

(2001) involved all nursing assistants and registered nurses during training in a nursing home environment. Additional support was provided for registered nurses on supervising the performance of nursing assistants when they interacted with nursing home residents. A staff motivational system was also incorporated with performance incentives for nursing assistants and public recognition for registered nurses who fulfilled their supervision requirements. In the current study, there was little support from supervisors and whilst the trained paid caregivers were committed, those not involved in the study were resentful towards their colleagues. As a result, some trained paid caregivers were apprehensive and anxious about attending training sessions and completing homework tasks. Trained paid caregivers were also aware and frustrated with the poor communication skills of their colleagues. For example, one reported that “I have noticed that when other members of staff don’t do it right, that’s terrible isn’t it?” (C11). Ylvisaker et al. (1993) highlighted the importance of a positive communication culture and the need for supervisors to support what was being taught during training. Training to supervisors may help with encouraging paid caregivers to implement the skills they have learnt during training. Overall, future training programs will need to address both the intrinsic and extrinsic factors that can affect the outcome if positive change is to occur.

6.1.1 Conversation type: structured versus casual conversation.

Improvement made by paid caregivers was confined to the structured conversation with no interaction effects for casual conversations for the primary outcome measures. Lack of improvement for casual conversations could be due

to factors related to the workplace, the training program or the way in which the videotaped conversations were conducted.

Most interactions that occur within the workplace are structured and there are limited opportunities for casual conversations to occur. Structured interactions revolve around activities of daily living within the centre (e.g. personal care, laundry, preparing a simple meal) or tasks within the community (e.g. purchasing toiletries, shopping). Casual conversations are the type of interactions that occur between friends. In a residential rehabilitation centre casual conversations between staff and clients are not entirely professional or appropriate. Increased workplace demands also provided little opportunity for paid caregivers to have casual conversations with people with TBI. Paid caregivers work in daily shifts whose responsibilities involve caring for many different people with TBI in an often busy environment. Few opportunities are available throughout the day to practice casual conversations. The findings from this study therefore may reflect the type of interactions (i.e. structured) that paid caregivers more frequently encountered and were more able to practice and rehearse between sessions. To improve casual conversations, there needs to be a greater recognition, support and time allowed within the workplace for this type of interaction to occur.

Reduced time was spent discussing the importance of casual conversations during the training sessions. While casual conversations were highlighted during training a greater amount of the role-plays and simulated situations involved structured conversations. Equally, paid caregivers were more

likely to discuss problems and seek support from the group for structured conversations such as supporting a person with TBI to choose what to eat for dinner, negotiate what to watch on TV or discussing when their next cigarette was due. Qualitative reports would also suggest that when paid caregivers considered the use of strategies they tended to reflect on people with behavioural problems and interactions such as discussions during personal care or regarding how to conduct a group session. Many of these interactions rarely involved casual conversation. A training program would need to increase the time spent on targeting casual conversations if the intention was to improve this type of interaction.

The method for collecting videotaped conversations in the pretraining, posttraining and follow-up evaluation sessions may have also contributed to the lack of significant change. The structured conversation always preceded the casual conversation tasks. Paid caregivers from both groups applied less effort to the casual conversations over time. However, this pattern of reduced effort in conversation was not found for the structured conversation. The structured conversation may have given the paid caregiver the opportunity to become acquainted with the person with TBI and identify topics of interest. Equally, paid caregivers may have exhausted the range of topics that they could have discussed with a person with TBI during the first 15 minute conversation. A significant difference may have been found if shorter conversations were videotaped. Unfortunately, statistical analyses prevent a direct comparison between the two conversation types and make it difficult to draw firm conclusions.

Future studies may need to consider randomising the order with which conversations are recorded.

This section of the discussion focused on the communication skills of the paid caregiver and the impact they had on the interaction with a person with TBI. The next section will focus on the skills of the person with TBI and the changes they made as a result of changed skills from the paid caregiver.

6.2 Communication Skills of the Person with TBI

Communication skills of paid caregivers at baseline had both a positive and negative impact on interactions that involved people with TBI. No significant differences between groups were found at baseline on the Measure of Support in Conversation (MSC) or Bond and Godfrey (1997) Global Impression Scales, however, inspection of the raw scores revealed differences between the interactions involving the same person with TBI. These differences highlight the impact a paid caregiver can have on the success of a conversational interaction. For example, the conversation between one person with TBI (Adam) and one paid caregiver (C3) was perceived as 1.0 on the appropriate scale (occasionally) but 3.0 (mostly) with a different paid caregiver (C7) on the same day. Similarly, the conversation between another person with TBI (Sally) and one paid caregiver (C5) was perceived as 2.5 on the interesting scale (sometimes) but 4.0 (always) with a different paid caregiver (C6). These differences were observed for the Global Impression Scales despite similar ratings on the Measure of Participation in Conversation (MPC) for the skills of people with TBI. For example, the first person with TBI (i.e. Adam) was perceived to have only “occasionally”

participated in both conversations with a rating of 1.5 on the MPC (interaction) scale. Likewise, the second person with TBI (i.e. Sally) was perceived to have conveyed content “most of the time” for both conversations with a rating of 3.5 on the MPC (transaction) scale. The fact that there was no change in the skills of the person with TBI means that the communication skills of the paid caregiver affected the outcome of the conversation in different ways. This finding highlights the integral role communication partners play within an interaction and the importance of including them in the rehabilitation process. Therefore, training that improves paid caregivers abilities should have a significant impact on the communication skills and functioning of the person with TBI during conversation.

The communication skills of the person with TBI did not improve on the adapted measure of MPC (interaction and transaction) as a result of training for paid caregivers. In contrast, a recent study that trained family members found significant improvements for the person with TBI (Togher et al., 2010a). However, this study had included the person with TBI in all the training sessions, was run for 10 weeks rather than 6 weeks and had a greater number of participants than the current study. Family members also interacted in the home environment with the same person with TBI during the 10 week training program. Paid caregivers in the current study were interacting with a range of people with brain injury in a residential rehabilitation centre during the study. Rather than acquiring specific skills and strategies for interacting with one person with TBI, paid caregivers had to adapt and be flexible in their use of strategies to facilitate interactions with a range of people who had chronic cognitive impairments (Tate, 1999). These

included people that were passive and withdrawn, verbose and egocentric or non-verbal. A lack of improvement may also indicate that the measures were not sensitive to change for the communication skills of the person with TBI. Excellent levels of inter-rater reliability were difficult to achieve for several of the MPC (interaction and transaction) scales. Lower levels of inter-rater reliability indicate that there was greater variability between the judges when rating the skills of the person with TBI on these scales. This variability could be due to each person with TBI presenting quite differently. Equally, this study had a small sample size and an effect may have been shown with a larger sample size.

Trained paid caregivers were able to create interactions that reflected better performance by people with TBI. Despite no change shown for the communication skills of the person with TBI, interactions were perceived as more appropriate, rewarding and interesting on a global measure of communicative ability. These measures take the skills of both the person with TBI and the paid caregiver into account. A rater's perception of an interaction may have been more influenced by the improved skills of the paid caregiver than the person with TBI. This finding illustrates the importance of including a range of outcomes that measure the skills of the individual and of the conversation as a whole. There could be elements in a global measure that better capture the success of an interaction than the MPC (interaction and transaction) measure.

6.3 Sustaining Change

Significant improvements made by trained paid caregivers in the structured conversation posttraining were maintained at 6 months follow-up.

Demonstrating that the improved skills of a paid caregiver are sustainable is paramount to the success and efficacy of the intervention. Interaction effects that compared posttraining with follow-up scores for trained paid caregivers in the structured conversation revealed no difference. This finding indicates that there was neither an improvement nor a decline in the communication skills of the trained paid caregivers. Therefore, improved skills can be maintained for 6 months posttraining without the need for additional input or support.

Several factors related to the working environment and trained paid caregiver themselves could threaten the long-term maintenance of skills. Each paid caregiver was provided with a toolbox of communication strategies to identify skills that needed further improvement or consolidation. Use of the toolbox was dependent on a paid caregiver's desire and motivation to change. In addition, paid caregivers need to work within an environment that is supportive of the skills learnt from training to lead to an increased use of positive strategies (Kruijver et al., 2000). Whilst trained paid caregivers did not receive any ongoing assistance from the trainer or managers posttraining, skills were maintained in the short-term (i.e. 6 months). For paid caregivers to retain skills for longer periods of time, other factors and strategies would need to be considered.

Paid caregivers identified strategies that would assist the maintenance and further improvement of skills following training. Burgio et al. (2001) introduced training to supervisory staff and the use of a staff motivational system to ensure the effects of training were maintained over an 8 week period for nursing assistants of people with dementia. Supervisory staff were trained to

monitor the performance of two to five nursing assistants and provide verbal feedback to facilitate the effects of training. In the current study, trained paid caregivers suggested refresher or booster sessions, more opportunities to involve people with TBI during training and the ability to be supported in practicing the use of skills in more natural settings. Providing opportunities posttraining for support from the trainer could impact a paid caregiver's motivation and desire to make long-term changes to their communication skills. Consideration and use of strategies such as those described here may affect the longer term outcome of training.

6.4 Perceptions of Family Member, Person with TBI and Paid Caregiver

Training for paid caregivers did not result in significant improvement on measures of perceived communicative ability by the person with TBI and their family member. McDonald et al. (2008) found that a family member not involved in training did not perceive a significant change in perceived communicative ability, however, nor did the person with TBI who was included in the training though this could be due to reduced insight. In the current study, neither the person with TBI nor the family member were involved in the training or given feedback about the outcome of their interactions. Joint involvement in the training may have produced a significant result. Including both people would allow time for the person with TBI to develop awareness of their communication impairments and improve their skills with a family member who is being trained to use a range of positive communication strategies.

A main effect for time was found for perceived communicative ability by a family member. This finding is most likely due to a small sample size. Inclusion of only five people with TBI meant that the scores of family members were duplicated within both the control and training group. Duplication of scores for two particular family members was likely to have contributed to the main effect. Both family members perceived improvement from positive life-events where one person with TBI was moving into her own home and the other had returned to college. The main effect was more likely the result of these changes rather than the training itself.

Training did not have a significant impact on the paid caregiver's perception of communicative ability for the person with TBI. This lack of change may reflect the severity and chronicity of communication impairments for the person with TBI. Paid caregivers interacted with the person with TBI on only three occasions and may have found it difficult to observe and rate changes in communicative behaviours in such a short period of time (i.e. 30 minutes). Despite this, paid caregivers reported more successful and collaborative interactions with people with ABI with whom they interacted regularly in the residential rehabilitation centre. More frequent and lengthier interactions may therefore have altered the paid caregivers' perception of communicative ability for the person with TBI

6.5 Experiences of Stress and Burden

Negative experiences of caring differentiated training and control groups at baseline. All caregivers were randomised and recruited from the same location

and no significant difference was found between groups at baseline for positive experiences of caring. Paid caregivers reported enjoyment, happiness and a sense of purpose from interacting and caring for people with TBI consistent with earlier studies (Knight et al., 1998; Machamer et al., 2002). However, paid caregivers assigned to the training group identified greater stress, burden and frustration at baseline. This difference could be the result of personal and workplace factors not measured by the modified burden questionnaire. For example, trained paid caregivers may have cared for more complex and challenging people with TBI or had lower levels of support and a much busier workload. Nonetheless, as trained paid caregivers reported more negative experiences this group had either more to gain from inclusion in the training program or were going to be much harder to train.

No interaction effects were found for stress and burden. There was, however, a group main effect for negative rather than positive experiences of caring. So, it is likely that the initial difference between the groups at baseline was not a major factor on the effect of training. However, qualitative reports from trained paid caregivers show increased confidence, less frustration and more enjoyment from interacting with people with TBI. These changes did not lead to a reduction in the negative experiences of caring highlighting that other personal and workplace factors not measured by the modified burden questionnaire may have had an impact. Workplace factors not measured that are known to affect experiences of stress and burden include role ambiguity, stress linked to lack of staff support, working in what they perceived as a low status job and working

longer than contracted hours (Hatton et al., 1995). Stress and burden could also be related to the presence of challenging behaviour which has been shown for family members of people with TBI (Kreutzer et al., 1994) and paid caregivers of people with developmental disabilities (Jenkins et al., 1997). In the case of one trained paid caregiver, personal stresses that included a family bereavement during the training may have had an effect on how much she learnt and the level of improvement made. The findings from the study would need to be confirmed with larger numbers, however, these results demonstrate that the emotional experiences of caring are multi-faceted. Future training programs would need to consider the range of factors that could impact upon experiences of stress and burden for paid caregivers of people with TBI.

6.6 Limitations and Directions for Future Research

Several limitations of the research were evident not least the pilot scope of the study. The small numbers reduced the statistical power of any analyses and made it difficult to match one person with TBI with one paid caregiver. Marginally significant results (i.e. the findings on the appropriateness and interesting scales for structured conversation) would need to be confirmed with larger sample sizes. All paid caregivers were also recruited from the same location raising the possibility that caregivers were not completely blinded which is a challenge for field studies that use randomisation of participants (Kruijver et al., 2000).

Lack of significant change could reflect limitations related to the content of the training program and exclusion of people with TBI from the training process. Significant changes were only found for structured conversations which

frequently occur for paid caregivers and were the primary focus of the training program. Paid caregivers had few opportunities to practice and rehearse casual conversations. Future research would need to investigate the different conversation types commonly encountered in the workplace and how the working environment can impact a paid caregiver's ability to interact with people with TBI. However, a lack of change could be related to the paid caregiver being the only person involved in the training. As outlined earlier, Togher et al. (2010a) demonstrated improved communication skills for the person with TBI and a family member following training that involved both participants. Similar improvements have been shown for training that involved the communication partners of people with aphasia (Lyon et al., 1997) and developmental disabilities (Money, 1997). Therefore, it is likely that inclusion of the person with TBI during training would have had a significant impact on improving their own communication skills.

A limitation of the qualitative analysis would be the focus within a residential rehabilitation centre. The extent with which the results can be generalised to paid caregivers within other contexts (e.g. acute setting, home environment, community day-care centre) is limited. Future research should consider exploring the perspectives of paid caregivers within many different contexts to further understand the range of experiences for paid caregivers that work with people with TBI. While the advantages were acknowledged of having the interviewer as both the clinician and trainer, including more independent researchers in the analysis of the transcripts would help to prevent further bias. In addition, the data analysed in the study came solely from focused interviews.

Creswell (2009) suggests a triangulation of data from various sources (e.g. observations, field notes, feedback by paid caregivers during training sessions, feedback on homework exercises, comments about components of each training session, feedback from people with TBI) to verify the categories of a study. The qualitative results did provide possible reasons to understand non-significant findings and insight into how the training could be improved in the future. In spite of the limitations, significant improvements were found for structured conversations that involved trained paid caregivers and people with TBI.

6.7 Clinical Implications

Education and training of paid caregivers is important to improve their interactions with people with TBI. Paid caregivers are frequently involved in the lives of people with TBI and this study would support training in strategies that facilitate more positive interactions. Strategies should encourage independence, collaborative and equal conversations and enable opportunities for the person with TBI to express their thoughts, ideas and opinions. Moreover, methods for training should involve the use of practical based approaches, reduce the use of terminology and amount of information taught and tailor training to the working environment of the paid caregiver. Booster or refresher sessions, training for managers to assist staff development and ongoing support from a speech pathologist should be considered to ensure skills are maintained and consolidated over time. Effective education and training for paid caregivers is critical to improving the interaction skills of a person with TBI.

Trained paid caregivers can assist the rehabilitation team in improving social and community integration for people with TBI. Paid caregivers can model appropriate social behaviour, encourage independence within the home and community and provide a positive and rewarding environment that can influence the functioning of a person with TBI. Paid caregivers can help people with TBI to pursue appropriate leisure and social opportunities that will reduce the likelihood of social isolation, low self-esteem and loneliness. Therefore, the findings of the study have strong implications for those responsible for training including, managers, psychologists, speech pathologists, occupational therapists, physiotherapists, care agencies and family members.

The current study provides preliminary evidence for rehabilitation services to include initial and ongoing communication training for paid caregivers that work with people with TBI. McCrea and Sharma (2009) highlight the importance of induction programs into a rehabilitation service to include training of behaviour management strategies for paid caregivers . The current study would extend this further to illustrate the importance of training positive communication strategies for interacting with people with TBI. All paid caregivers, irrespective of whether they have months or years of experience caring for people with TBI should be included in the training as all paid caregivers in the current study were able to make positive changes to their communication skills. Training should also be offered on an ongoing basis to ensure the long-term maintenance of skills and development of new skills and strategies. Involving supervisors to monitor the performance of paid caregivers and introducing a staff motivational system

similar to Burgio et al. (2001) may contribute to the maintenance of skills over time.

Training a range of communication partners should also play an important part of any rehabilitation effort for a person with TBI. Whilst this study specifically focused on paid caregivers, Togher et al. (2010a) demonstrated improved conversational interactions from training parents and spouses. In addition, people with TBI can interact with friends, other relatives and members of the community. Therefore, rehabilitation professionals should identify those that are most important to the person with TBI and provide education and training to improve conversational interactions. Involving a range of people will aid generalisation of skills and ensure people with TBI can function as independently as possible in a range of contexts.

Rehabilitation professionals involved in the management of people with TBI should: (i) involve the communication partners of people with TBI particularly paid caregivers; (ii) consider the type of strategies and contexts to train; (iii) take into account the barriers and facilitators that will best promote learning and; (iv) incorporate approaches to ensure the maintenance and consolidation of skills.

6.7.1 Features of an effective training program.

Quantitative and qualitative analysis highlighted particular components of the training program that both promoted and hindered learning for paid caregivers of people with TBI. The communication partner training enabled paid caregivers to improve their knowledge of strategies, the success and quality of conversations and level of confidence and enjoyment when interacting with

people with TBI. In addition, paid caregivers could articulate barriers to learning and provide suggestions to overcome such difficulties. As a result, there are a range of components that should be considered when designing and implementing a communication training program for paid caregivers of people with TBI. Such components include;

- a) Conduct training in small groups in order to encourage group discussion and feedback between paid caregivers.
- b) Use of practical or performance based approaches over didactic based ones (e.g. role-play, discussion, feedback, videotaping).
- c) Teach a range of collaboration and elaboration conversation strategies to create more equal, successful conversations.
- d) Demonstrate strategies for a range of situations that paid caregivers experience in the workplace.
- e) Use language that is simple and accessible. Avoid the use of jargon and technical terms.
- f) Minimise the volume of written information and increase the use of visual and picture-based resources.
- g) Consider inclusion of people with TBI in the training to demonstrate the effect of strategies and different ways of communicating.
- h) Involve paid caregivers at all levels within an organisation to assist in creating a positive communication culture within the workplace.

- i) Consider providing paid caregivers with videotapes of their own interactions to encourage self-reflection.
- j) Consider refresher or booster training sessions to ensure maintenance and continued improvement of skills long-term.

6.8 Conclusion

This thesis describes an approach to improve the communication skills of people with TBI by training the communication partner. Gains made from impairment based interventions are often limited due to the difficulties faced with specifically training the person with TBI who has severe cognitive impairments, impaired ability to learn and difficulty generalising skills to contexts outside of the clinical environment. Training the communication partner can overcome many of these difficulties and have a significant impact on positively influencing the conversational interactions that they have with people with TBI. Paid caregivers were chosen as the communication partner to train as this group of people are rarely mentioned in the research and yet have a significant impact on community reintegration outcomes for people with TBI.

Paid caregivers require education and training to support people with TBI to be as independent as possible. The current study presents preliminary evidence from a single blinded randomised controlled study for the training of paid caregivers of people who have sustained a severe TBI in a long-term residential rehabilitation centre. Trained paid caregivers had improved conversations when compared to a control group that received no communication training. Specifically, the communication of trained paid caregivers was perceived

by blind raters as being more sensitive and adult-like and as a result, the person with TBI was perceived to have been given increased opportunities to communicate. The improved communication skills of a paid caregiver were sustained for 6 months posttraining demonstrating the long-term effects of training. While the person with TBI was not perceived to have improved their communication skills the training resulted in interactions that were perceived as more appropriate, interesting and rewarding compared to those of the control group. Caregivers reported that using the new strategies in workplace situations was helpful, as they incorporated their skills into the daily care routines of the people with TBI. The results of the study have strong implications for the initial and ongoing training of paid caregivers that work with people with TBI.

Results further highlight the wider importance of involving communication partners in the management of people who have sustained a severe TBI. Communication partners can have a positive effect on the success of an interaction and ensure that people with TBI have conversations that are more socially appropriate. Better conversations will assist people with TBI to develop and maintain friendships and can help to foster improved independence for them in the long-term both in the home and community.

Chapter 7

References

- Australian Institute of Health and Welfare. (1999). *The definition, incidence and prevalence of acquired brain injury in Australia*. Canberra: Australian Institute of Health and Welfare,.
- Australian Institute of Health and Welfare. (2008). *Hospital separations due to traumatic brain injury, Australia 2004–05*. Canberra: Australian Institute of Health and Welfare
- Backhaus, S. L., Ibarra, S. L., Klyce, D., Trexler, L. E., & Malec, J. F. (2010). Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers. *Archives of Physical Medicine and Rehabilitation, 91*(6), 840-848.
- Bellon, M. L., & Rees, R. J. (2006). The effect of context on communication: a study of the language and communication skills of adults with acquired brain injury. *Brain Injury, 20*(10), 1069-1078.
- Bloomberg, K., West, D., & Iacono, T. A. (2003). PICTURE IT: an evaluation of a training program for carers of adults with severe and multiple disabilities. *Journal of Intellectual and Developmental Disability, 28*(3), 260-282.
- Boles, L., & Bombard, T. (1998). Conversational discourse analysis: appropriate and useful sample sizes. *Aphasiology, 12*(7/8), 547-560.

- Bond, F., & Godfrey, H. P. (1997). Conversation with traumatically brain-injured individuals: a controlled study of behavioural changes and their impact. *Brain Injury, 11*(5), 319-329.
- Bourgeois, M. S., Dijkstra, K., Burgio, L. D., & Allen-Burge, R. (2001). Memory aids as an augmentative and alternative communication strategy for nursing home residents with dementia. *Augmentative and Alternative Communication, 17*, 196-210.
- Bracy, C. A., & Douglas, J. (2005). Marital dyad perceptions of injured partners' communication following severe traumatic brain injury. *Brain Impairment, 6*(1), 1-12.
- Brooks, N., McKinlay, W., Symington, C., Beattie, A., & Campsie, L. (1987). Return to work within the first seven years of severe head injury. *Brain Injury, 1*(1), 5-19.
- Bruns, J., Jr., & Hauser, W. A. (2003). The epidemiology of traumatic brain injury: a review. *Epilepsia, 44 Suppl 10*, 2-10.
- Burgio, L. D., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., Jackson, E., & Bankester, L. (2001). Come talk with me: improving communication between nursing assistants and nursing home residents during care routines. *Gerontologist, 41*(4), 449-460.
- Burleigh, S. A., Farber, R. S., & Gillard, M. (1998). Community integration and life satisfaction after traumatic brain injury: long-term findings. *American Journal of Occupational Therapy, 52*(1), 45-52.

- Carney, N., Chesnut, R. M., Maynard, H., Mann, N. C., Patterson, P., & Helfand, M. (1999). Effect of cognitive rehabilitation on outcomes for persons with traumatic brain injury: A systematic review. *Journal of Head Trauma Rehabilitation, 14*(3), 277-307.
- Cicchetti, D. V. (1994). Guidelines, Criteria, and Rules of Thumb for Evaluating Normed and Standardized Assessment Instruments in Psychology. *Psychological Assessment, 6*(4), 284-290.
- Coelho, C. (1999). Discourse analysis in traumatic brain injury. In S. McDonald, L. Togher & C. Code (Eds.), *Communication disorders following traumatic brain injury* (pp. 55-80). East Sussex: Psychology Press.
- Coelho, C., Liles, B. Z., & Duffy, R. J. (1991a). Analysis of conversational discourse in head-injured adults. *Journal of Head Trauma Rehabilitation, 6*(2), 92-99.
- Coelho, C., Liles, B. Z., & Duffy, R. J. (1991b). Discourse analyses with closed head injured adults: evidence for differing patterns of deficits. *Archives of Physical Medicine and Rehabilitation, 72*(7), 465-468.
- Correll, A., van Steenbrugge, W., & Scholten, I. (2009). Judging conversation: How much is enough. *Aphasiology, 24*(5), 612-622.
- Corrigan, J. D., Selassie, A. W., & Orman, J. A. (2010). The epidemiology of traumatic brain injury. *Journal of Head Trauma Rehabilitation, 25*(2), 72-80.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, California: SAGE Publications.

- Creswell, J. W. (2009). *Research design: Qualitative, quantitative and mixed methods approaches* (3rd ed.). Thousand Oaks, California: SAGE Publications.
- Creswell, J. W. (2012). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (4th ed.). Boston: Pearson Education Inc.
- Dahlberg, C., Cusick, C. P., Hawley, L. A., Newman, J. K., Morey, C. E., Harrison-Felix, C. L., & Whiteneck, G. G. (2007). Treatment efficacy of social communication skills training after traumatic brain injury: a randomized treatment and deferred treatment controlled trial. *Archives of Physical Medicine and Rehabilitation, 88*(12), 1561-1573.
- Dahlberg, C., Hawley, L., Morey, C., Newman, J., Cusick, C. P., & Harrison-Felix, C. (2006). Social communication skills in persons with post-acute traumatic brain injury: three perspectives. *Brain Injury, 20*(4), 425-435.
- Deb, S., Lyons, I., Koutzoukis, C., Ali, I., & McCarthy, G. (1999). Rate of psychiatric illness 1 year after traumatic brain injury. *American Journal of Psychiatry, 156*(3), 374-378.
- Dobson, S., Upadhyaya, S., & Stanley, B. (2002). Using an interdisciplinary approach to training to develop the quality of communication with adults with profound learning disabilities by care staff. *International Journal of Language and Communication Disorders, 37*(1), 41-57.

- Douglas, J. M. (2010). Relation of executive functioning to pragmatic outcome following severe traumatic brain injury. *Journal of Speech, Language, and Hearing Research, 53*(2), 365-382.
- Douglas, J. M., Bracy, C. A., & Snow, P. (2007a). Measuring perceived communicative ability after traumatic brain injury: reliability and validity of the La Trobe Communication Questionnaire. *Journal of Head Trauma Rehabilitation, 22*(1), 31-38.
- Douglas, J. M., Bracy, C. A., & Snow, P. (2007b). Exploring the factor structure of the La Trobe Communication Questionnaire: insights into the nature of communication deficits following traumatic brain injury. *Aphasiology, 21*(12), 1181-1194.
- Douglas, J. M., O'Flaherty, C., & Snow, P. (2000). Measuring perception of communicative ability: the development and evaluation of the La Trobe Communication Questionnaire. *Aphasiology, 14*(3), 251-268.
- Douglas, J. M., & Spellacy, F. J. (2000). Correlations of depression in adults with severe traumatic brain injury and their carers. *Brain Injury, 14*(1), 71-88.
- Ducharme, J. M., & Spencer, T. F. (2001). Training brain injury rehabilitation therapists to use generalized teaching and interaction skills. *Brain Injury, 15*(4), 333-347.
- Elsass, L., & Kinsella, G. (1987). Social interaction following severe closed head injury. *Psychological Medicine, 17*(1), 67-78.

- Ergh, T. C., Hanks, R. A., Rapport, L. J., & Coleman, R. D. (2003). Social support moderates caregiver life satisfaction following traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology, 25*(8), 1090-1101.
- Fann, J. R., Katon, W. J., Uomoto, J. M., & Esselman, P. C. (1995). Psychiatric disorders and functional disability in outpatients with traumatic brain injuries. *American Journal of Psychiatry, 152*(10), 1493-1499.
- Field, A. (2009). *Discovering statistics using SPSS* (3rd ed.). London: SAGE Publications Ltd.
- Flanagan, S., McDonald, S., & Togher, L. (1995). Evaluating social skills following traumatic brain injury: the BRISS as a clinical tool. *Brain Injury, 9*(4), 321-338.
- Fleming, J., Tooth, L., Hassell, M., & Chan, W. (1999). Prediction of community integration and vocational outcome 2-5 years after traumatic brain injury rehabilitation in Australia. *Brain Injury, 13*(6), 417-431.
- Foreman, P., Arthur-Kelly, M., & Pascoe, S. (2007). The impact of partner training on the communicative involvement of students with multiple and severe disability in special schools. *Journal of Intellectual and Developmental Disability, 32*(4), 233-247.
- Galski, T., Tompkins, C., & Johnston, M. V. (1998). Competence in discourse as a measure of social integration and quality of life in persons with traumatic brain injury. *Brain Injury, 12*(9), 769-782.
- Goldblum, G., & Alant, E. (2009). Sales assistants serving customers with traumatic brain injury. *Aphasiology, 23*(1), 87-109.

- Haahr, M. (1998). List randomiser. Retrieved 22 March 2008, from www.random.org/lists/
- Hanks, R. A., Rapport, L. J., & Vangel, S. (2007). Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning. *NeuroRehabilitation, 22*(1), 43-52.
- Harrison, C. L., & Dijkers, M. (1992). Traumatic brain injury registries in the United States: an overview. *Brain Injury, 6*(3), 203-212.
- Hartley, L. L., & Jensen, P. J. (1992). Three discourse profiles of closed-head-injury speakers: theoretical and clinical implications. *Brain Injury, 6*(3), 271-281.
- Hatton, C., Brown, R., Caine, A., & Emerson, E. (1995). Stressors, coping strategies and stress-related outcomes among direct care staff in staffed houses for people with learning disabilities. *Mental Handicap Research, 8*(4), 252-271.
- Hatton, C., & Emerson, E. (1993). Organizational predictors of staff stress, satisfaction, and intended turnover in a service for people with multiple disabilities. *Mental Retardation, 31*(6), 388-395.
- Hatton, C., Emerson, E., Rivers, M., Mason, H., Mason, L., Swarbrick, R., Kiernan, C., Reeves, D., & Alborz, A. (1999). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research, 43* (Pt 4), 253-267.

- Hickey, E. M., Bourgeois, M. S., & Olswang, L. B. (2004). Effects of training volunteers to converse with nursing home residents with aphasia. *Aphasiology, 18*(5/6/7), 625-637.
- High Jr, W. M. (2005). Effectiveness of TBI rehabilitation programs. In W. M. High Jr, A. M. Sander, M. A. Struchen & K. A. Hart (Eds.), *Rehabilitation for traumatic brain injury* (pp. 14-28). New York: Oxford University Press, Inc.
- Hodgkinson, A., Veerabangsa, A., Drane, D., & McCluskey, A. (2000). Service utilization following traumatic brain injury. *Journal of Head Trauma Rehabilitation, 15*(6), 1208-1226.
- Howe, T. J. (2008). The ICF contextual factors related to speech-language pathology. *International Journal of Speech-Language Pathology, 10*(1-2), 27-37.
- Howell, D. C. (1997). *Statistical methods for psychology* (4th ed.). London: Wadsworth Publishing company.
- Hyder, A. A., Wunderlich, C. A., Puvanachandra, P., Gururaj, G., & Kobusingye, O. C. (2007). The impact of traumatic brain injuries: a global perspective. *NeuroRehabilitation, 22*(5), 341-353.
- Jenkins, R., Rose, J., & Lovell, C. (1997). Psychological well-being of staff working with people who have challenging behaviour. *Journal of Intellectual Disability Research, 41* (Pt 6), 502-511.
- Jennett, B., & Teasdale, G. (1981). *Management of head injuries*. Philadelphia: F.A. Davis Co.

- Johnson, J. C., Avenarius, C., & Weatherford, J. (2006). The active participant-observer: Applying social role analysis to participant observation. *Field Methods, 18*(2), 111-134.
- Kagan, A., Black, S. E., Duchan, F. J., Simmons-Mackie, N., & Square, P. (2001). Training volunteers as conversation partners using "Supported Conversation for Adults with Aphasia" (SCA): a controlled trial. *Journal of Speech Language Hearing and Research, 44*(3), 624-638.
- Kagan, A., Winckel, J., Black, S., Duchan, J. F., Simmons-Mackie, N., & Square, P. (2004). A set of observational measures for rating support and participation in conversation between adults with aphasia and their conversation partners. *Topics in Stroke Rehabilitation, 11*(1), 67-83.
- Knight, R. G., Devereux, R., & Godfrey, H. P. (1998). Caring for a family member with a traumatic brain injury. *Brain Injury, 12*(6), 467-481.
- Knox, L., & Douglas, J. (2009). Long-term ability to interpret facial expression after traumatic brain injury and its relation to social integration. *Brain Cognition, 69*(2), 442-449.
- Kovarsky, D., & Curran, M. (2007). A missing voice in the discourse of evidence-based practice. *Topics in Language Disorders, 27*(1), 50-61.
- Kraus, J. F., Black, M. A., Hessol, N., Ley, P., Rokaw, W., Sullivan, C., Bowers, S., Knowlton, S., & Marshall, L. (1984). The incidence of acute brain injury and serious impairment in a defined population. *American Journal of Epidemiology, 119*(2), 186-201.

- Kreutzer, J. S., Gervasio, A. H., & Camplair, P. S. (1994). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury, 8*(3), 211-230.
- Kreutzer, J. S., Seel, R. T., & Gourley, E. (2001). The prevalence and symptom rates of depression after traumatic brain injury: a comprehensive examination. *Brain Injury, 15*(7), 563-576.
- Kruijver, I. P., Kerkstra, A., Francke, A. L., Bensing, J. M., & van de Wiel, H. B. (2000). Evaluation of communication training programs in nursing care: a review of the literature. *Patient Education and Counseling, 39*(1), 129-145.
- Leach, L. R., Frank, R. G., Bouman, D. E., & Farmer, J. (1994). Family functioning, social support and depression after traumatic brain injury. *Brain Injury, 8*(7), 599-606.
- Legg, C., Young, L., & Bryer, A. (2005). Training sixth-year medical students in obtaining case-history information from adults with aphasia. *Aphasiology, 19*(6), 559-575.
- Leith, K. H., Phillips, L., & Sample, P. L. (2004). Exploring the service needs and experiences of persons with TBI and their families: the South Carolina experience. *Brain Injury, 18*(12), 1191-1208.
- Levin, H., & Kraus, M. F. (1994). The frontal lobes and traumatic brain injury. *Journal of Neuropsychiatry and Clinical Neurosciences, 6*(4), 443-454.
- Lippert-Gruner, M., Kuchta, J., Hellmich, M., & Klug, N. (2006). Neurobehavioural deficits after severe traumatic brain injury (TBI). *Brain Injury, 20*(6), 569-574.

- Lyon, J. G., Cariski, L., Keisler, L., Rosenbek, J., Levine, R., Kumpula, J., Ryff, C., Coyne, S., & Blanc, M. (1997). Communication partners: enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology*, *11*(7), 697-708.
- Machamer, J., Temkin, N., & Dikmen, S. (2002). Significant other burden and factors related to it in traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, *24*(4), 420-433.
- Marston, L. (2010). *Introductory statistics for health and nursing using SPSS*. London: SAGE Publications Ltd.
- McCluskey, A. (2000). Paid attendant carers hold important and unexpected roles which contribute to the lives of people with brain injury. *Brain Injury*, *14*(11), 943-957.
- McCrea, J. D., & Sharma, R. (2009). Training support staff to work with people with executive disorders. In M. Oddy & A. D. Worthington (Eds.), *The rehabilitation of executive disorders: a guide to theory and practice* (pp. 341-349). New York: Oxford University Press.
- McDonald, S. (1992). Differential pragmatic language loss after closed head injury: ability to comprehend conversational implicature. *Applied Psycholinguistics*, *13*, 295-312.
- McDonald, S. (1993). Pragmatic language skills after closed head injury: ability to meet the informational needs of the listener. *Brain and Language*, *44*(1), 28-46.

- McDonald, S., & Pearce, S. (1998). Requests that overcome listener reluctance: impairment associated with executive dysfunction in brain injury. *Brain and Language, 61*, 88-104.
- McDonald, S., Tate, R., Togher, L., Bornhofen, C., Long, E., Gertler, P., & Bowen, R. (2008). Social skills treatment for people with severe, chronic acquired brain injuries: a multicenter trial. *Archives of Physical Medicine and Rehabilitation, 89*(9), 1648-1659.
- McMillan, T. M., & Oddy, M. (2001). Service provision for social disability and handicap after acquired brain injury. In R. L. Wood & T. M. McMillan (Eds.), *Neurobehavioural disability and social handicap following traumatic brain injury*. East Sussex, UK: Psychology Press Ltd.
- McVicker, S., Parr, S., Pound, C., & Duchan, J. (2009). The communication partner scheme: A project to develop long-term, low-cost access to conversation for people living with aphasia. *Aphasiology, 23*(1), 52-71.
- Mentis, M., & Prutting, C. A. (1991). Analysis of topic as illustrated in a head-injured and a normal adult. *Journal of Speech and Hearing Research, 34*(3), 583-595.
- Money, D. (1997). A comparison of three approaches to delivering a speech and language therapy service to people with learning disabilities. *European Journal of Disorders of Communication, 32*(4), 449-466.
- Murrey, G. J., & Starzinski, D. (2004). An inpatient neurobehavioural rehabilitation programme for persons with traumatic brain injury: overview

- of and outcome data for the Minnesota Neurorehabilitation Hospital. *Brain Injury*, 18(6), 519-531.
- Newton, A., & Johnson, D. A. (1985). Social adjustment and interaction after severe head injury. *British Journal of Clinical Psychology*, 24 (Pt 4), 225-234.
- Novack, T. A., Bergquist, T. F., Bennett, G., & Gouvier, W. D. (1991). Primary caregiver distress following severe head injury. *Journal of Head Trauma Rehabilitation*, 6, 69-77.
- Oddy, M., Coughlan, T., Tyerman, A., & Jenkins, D. (1985). Social adjustment after closed head injury: a further follow-up seven years after injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, 48(6), 564-568.
- Oddy, M., & Humphrey, M. (1980). Social recovery during the year following severe head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, 43(9), 798-802.
- Oddy, M., Humphrey, M., & Uttley, D. (1978). Stresses upon the relatives of head-injured patients. *British Journal of Psychiatry*, 133, 507-513.
- Olver, J. H., Ponsford, J. L., & Curran, C. A. (1996). Outcome following traumatic brain injury: a comparison between 2 and 5 years after injury. *Brain Injury*, 10(11), 841-848.
- Prutting, C. A., & Kirchner, D. M. (1987). A clinical appraisal of the pragmatic aspects of language. *Journal of Speech and Hearing Disorders*, 52(2), 105-119.

- Purcell, M., McConkey, R., & Morris, I. (2000). Staff communication with people with intellectual disabilities: the impact of a work-based training programme. *International Journal of Language and Communication Disorders*, 35(1), 147-158.
- Rayner, H., & Marshall, J. (2003). Training volunteers as conversation partners for people with aphasia. *International Journal of Language and Communication Disorders*, 38(2), 149-164.
- Rose, J., Jones, F., & Fletcher, B. (1998). Investigating the relationship between stress and worker behaviour. *Journal of Intellectual Disability Research*, 42 (Pt 2), 163-172.
- Russell, W. R., & Smith, A. (1961). Post-traumatic amnesia in closed head injury. *Archives of Neurology*, 5, 4-17.
- Saldana, J. (2009). *The coding manual for qualitative researchers*. Thousand Oaks, California: SAGE Publications.
- Sander, A. M. (2005). Interventions for caregivers. In W. M. High, Jr., A. M. Sander, M. A. Struchen & K. A. Hart (Eds.), *Rehabilitation for traumatic brain injury* (pp. 156-175). New York: Oxford University Press Inc.
- Selassie, A. W., Zaloshnja, E., Langlois, J. A., Miller, T., Jones, P., & Steiner, C. (2008). Incidence of long-term disability following traumatic brain injury hospitalization, United States, 2003. *Journal of Head Trauma Rehabilitation*, 23(2), 123-131.

- Shelton, C., & Shryock, M. (2007). Effectiveness of communication/interaction strategies with patients who have neurological injuries in a rehabilitation setting. *Brain Injury, 21*(12), 1259-1266.
- Shorland, J., & Douglas, J. M. (2010). Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. *Brain Injury, 24*(4), 569-580.
- Shrout, P. E., & Fleiss, J. L. (1979). Intraclass correlations: Uses in assessing rater reliability. *Psychological Bulletin, 86*(2), 420-428.
- Siegl, A. F. (1990). Multiple t tests: Some practical considerations. *TESOL Quarterly, 24*(4), 773-775.
- Simmons-Mackie, N., Kagan, A., Christie, C. O., Huijbregts, M., McEwen, S., & Willems, J. (2007). Communicative access and decision making for people with aphasia: Implementing sustainable healthcare systems change. *Aphasiology, 21*(1), 39-66.
- Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A., & Cherney, L. R. (2010). Communication partner training in aphasia: a systematic review. *Archives of Physical Medicine and Rehabilitation, 91*(12), 1814-1837.
- Sink, C. A., & Stroh, H. R. (2006). Practical significance: The use of effect sizes in school counseling research. *Professional School Counseling, 9*(5), 401-411.
- Snow, P., Douglas, J., & Ponsford, J. (1995). Discourse assessment following traumatic brain injury: a pilot study examining some demographic and methodological issues. *Aphasiology, 9*(4), 365-380.

- Snow, P., Douglas, J., & Ponsford, J. (1997). Conversational assessment following traumatic brain injury: a comparison across two control groups. *Brain Injury, 11*(6), 409-429.
- Snow, P., Douglas, J., & Ponsford, J. (1998). Conversational discourse abilities following severe traumatic brain injury: a follow-up study. *Brain Injury, 12*(11), 911-935.
- Sohlberg, M. M., & Mateer, C. A. (2001). *Cognitive rehabilitation: an integrative neuropsychological approach*. New York: The Guildford Press.
- Spence, S. E., Godfrey, H. P. D., Knight, R. G., & Bishara, S. N. (1993). First impressions count: a controlled investigation of social skill following closed head injury. *British Journal of Clinical Psychology, 32*, 309-318.
- SPSS Inc. (2008). *SPSS Statistics 17.0*. Upper Saddle River, NJ: Prentice Hall.
- Stalnacke, B. M. (2007). Community integration, social support and life satisfaction in relation to symptoms 3 years after mild traumatic brain injury. *Brain Injury, 21*(9), 933-942.
- Strube, M. J. (1988). Some comments on the use of magnitude-of-effect estimates. *Journal of Counseling Psychology, 35*(3), 342-345.
- Struchen, M. A. (2005). Social communication interventions. In W. M. High, A. M. Sander, M. A. Struchen & K. A. Hart (Eds.), *Rehabilitation in specific cognitive impairments* (pp. 88-117). New York: Oxford University Press.
- Struchen, M. A., Clark, A. N., Sander, A. M., Mills, M. R., Evans, G., & Kurtz, D. (2008a). Relation of executive functioning and social communication

- measures to functional outcomes following traumatic brain injury. *NeuroRehabilitation*, 23(2), 185-198.
- Struchen, M. A., Pappadis, M. R., Mazzei, D. K., Clark, A. N., Davis, L. C., & Sander, A. M. (2008b). Perceptions of communication abilities for persons with traumatic brain injury: validity of the La Trobe Communication Questionnaire. *Brain Injury*, 22(12), 940-951.
- Tabachnick, B. G., & Fidell, L. S. (2001). *Using Multivariate Statistics* (4th ed.). Needham Heights: Allyn & Bacon.
- Tate, R. L. (1999). Executive dysfunction and characterological changes after traumatic brain injury: Two sides of the same coin? *Cortex*, 35, 39-55.
- Tate, R. L., McDonald, S., & Lulham, J. M. (1998). Incidence of hospital-treated traumatic brain injury in an Australian community. *Australian and New Zealand Journal of Public Health*, 22(4), 419-423.
- Togher, L. (2000). Giving information: the importance of context on communicative opportunity for people with traumatic brain injury. *Aphasiology*, 14(4), 365-390.
- Togher, L., Hand, L., & Code, C. (1997a). Analysing discourse in the traumatic brain injury population: telephone interactions with different communication partners. *Brain Injury*, 11(3), 169-189.
- Togher, L., Hand, L., & Code, C. (1997b). Measuring service encounters with the traumatic brain injury population. *Aphasiology*, 11(4/5), 491-504.

Togher, L., McDonald, S., Code, C., & Grant, S. (2004). Training communication partners of people with traumatic brain injury: A randomised controlled trial. *Aphasiology*, *18*(4), 313-335.

Togher, L., McDonald, S., Tate, R., Power, E., & Rietdijk, R. (2009). Training communication partners of people with traumatic brain injury: Reporting the protocol for a clinical trial. *Brain Impairment*, *10*(2), 188-204.

Togher, L., McDonald, S., Tate, R., Power, E., & Rietdijk, R. (2010a). *Training communication partners of people with traumatic brain injury (TBI) improves casual conversation interactions*. Paper presented at the Eighth World Congress on Brain Injury.

Togher, L., McDonald, S., Tate, R., Power, E., Ylvisaker, M., & Rietdijk, R. (2011). *TBI Express: A Social Communication Training Manual for people with TBI and their communication partners*. Sydney, Australia: Australian Society for the Study of Brain Impairment.

Togher, L., Power, E., McDonald, S., Tate, R., & Rietdijk, R. (2010b). Measuring the social interactions of people with traumatic brain injury (TBI) and their communication partners: The adapted Kagan scales. *Aphasiology*, *24*(6-8), 1464-5041.

Togher, L., Taylor, C., Aird, V., & Grant, S. (2006). The impact of varied speaker role and communication partner on the communicative interactions of a person with traumatic brain injury: a single case study using systemic functional linguistics. *Brain Impairment*, *7*(3), 190-201.

- Tomberg, T., Toomela, A., Ennok, M., & Tikk, A. (2007). Changes in coping strategies, social support, optimism and health-related quality of life following traumatic brain injury: a longitudinal study. *Brain Injury, 21*(5), 479-488.
- Turkstra, L., Brehm, S. E., & Montgomery Jr, E. B. (2006). Analysing conversational discourse after traumatic brain injury: Isn't it about time? *Brain Impairment, 7*(3), 234-245.
- Turner, S., & Whitworth, A. (2006). Conversational partner training programmes in aphasia: A review of key themes and participant's roles. *Aphasiology, 20*(6), 483-510.
- Uomoto, J. M., & Brockway, J. A. (1992). Anger management training for brain injured patients and their family members. *Archives of Physical Medicine and Rehabilitation, 73*(7), 674-679.
- Watts, A. J., & Douglas, J. (2006). Interpreting facial expression and communication competence following severe traumatic brain injury. *Aphasiology, 20*(8), 707-722.
- Wechsler, D. (1997). *WAIS-III administration and scoring manual*. San Antonio, TX: The Psychological Corporation.
- Wechsler, D. (2001). *Wechsler Test of Adult Reading (WTAR)*. San Antonio, Tex: Psychological Corporation.
- Whelan-Goodinson, R., Ponsford, J., Johnston, L., & Grant, F. (2009). Psychiatric disorders following traumatic brain injury: their nature and frequency. *Journal of Head Trauma Rehabilitation, 24*(5), 324-332.

- Wiseman-Hakes, C., Stewart, M. L., Wasserman, R., & Schuller, R. (1998). Peer group training of pragmatic skills in adolescents with acquired brain injury. *Journal of Head Trauma Rehabilitation, 13*(6), 23-38.
- Wlodkowski, R. (1985). *Enhancing adult motivation to learn*. London: Jossey-Bass.
- Wood, R. L. (2001). Understanding neurobehavioural disability. In R. L. Wood & T. M. McMillan (Eds.), *Neurobehavioural disability and social handicap following traumatic brain injury* (pp. 3-27). East Sussex: Psychology Press.
- Wood, R. L., & McMillan, L. (Eds.). (2001). *Neurobehavioural disability and social handicap following traumatic brain injury*. East Sussex: Psychology Press.
- Worrall, L., & Yiu, E. (2000). Effectiveness of functional communication therapy by volunteers for people with aphasia following stroke. *Aphasiology, 14*(9), 911-924.
- Worthington, A. D., Matthews, S., Melia, Y., & Oddy, M. (2006). Cost-benefits associated with social outcome from neurobehavioural rehabilitation. *Brain Injury, 20*(9), 947-957.
- Ylvisaker, M., & Feeney, T. (1998). *Collaborative brain injury rehabilitation: positive everyday routines*. London: Singular Publishing Group Inc.
- Ylvisaker, M., Feeney, T., & Urbanczyk, B. (1993). Developing a positive communication culture for rehabilitation: communication training for staff and family members. In C. J. Durgin, N. D. Schmidt & L. J. Fryer (Eds.), *Staff development and clinical intervention in brain injury rehabilitation* (pp. 57-81). Gaithersburg, MD: Aspen

- Ylvisaker, M., Jacobs, H. E., & Feeney, T. (2003). Positive supports for people who experience behavioral and cognitive disability after brain injury: a review. *Journal of Head Trauma Rehabilitation, 18*(1), 7-32.
- Ylvisaker, M., Sellers, M., & Edelman, L. (1998). Rehabilitation after traumatic brain injury in preschoolers. In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: children and adolescents* (2nd ed., pp. 303-329). Newton, MA: Butterworth-Heinemann.
- Ylvisaker, M., Szekeres, S. F., & Feeney, T. (2001). Communication disorders associated with traumatic brain injury. In R. Chapey (Ed.), *Language intervention strategies in aphasia and related neurogenic communication disorders* (4th ed., pp. 745-808). Maryland: Lippincott Williams & Williams.
- Zencius, A. H., & Wesolowski, M. D. (1999). Is the social network analysis necessary in the rehabilitation of individuals with head injury? *Brain Injury, 13*(9), 723-727.

Appendix A

BIRT Ethics Approval

Founded in 1979
Patron:
Her Grace
The Duchess of
Northumberland

Vice Patrons:
Lord Evans of Watford
Baroness Uddin

Life President:
Stephen E. Love MA

Life Vice-Presidents:
Norman C Thody
Barbara Besant-Hutchins
Graham Anderson



25 April 2008

Mr N Behn
Brain Injury Rehabilitation Trust
Fen House
ELY

Dear Mr Behn

Re: Research Project

Thank you for your recent submission of your proposed research on "*the effectiveness of communication training on the interaction between a rehabilitation support worker (RSW) and person with a traumatic brain injury*".

I am pleased to confirm that the Trust's Ethics Committee has considered your request for approval of this project and thereby grant approval for it to commence.

I wish you well in your endeavours.

Yours sincerely



MIKE O'CONNOR
Director of Quality Assurance



INVESTOR IN PEOPLE



BRITISH QUALITY FOUNDATION

INCORPORATING:
The Brain Injury
Rehabilitation Trust
Dysons Wood Trust
Hamilton Lodge Trust

A Company limited by guarantee incorporated in England and Wales under no. 2334589 and registered as a charity in England and Wales under no. 800797 and in Scotland under no. SC038972.
Registered office as shown.

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Appendix B

Paid Caregiver Information Questionnaire

Name: _____

Age: _____

Sex: M / F (Please circle)

Educational Status

Please tick which of the following you have completed.

- GCSE's
- A-Levels
- Did not complete school. I left at the age of _____
- Completing an NVQ in _____
- Completed an NVQ in _____
- College course in _____
- Other (eg.training courses; 1 day workshops/seminars):

Work Experience

How many years have you worked as a support worker/carer (include time spent in other fields not just brain injury if this applies)? _____

Please indicate other areas you have worked as a support worker/carer and the number of months/years (please circle that which applies):

- Dementia/elderly care for _____ months/years
- Learning disability for _____ months/years
- Stroke for _____ months/years
- Other: _____ for _____ months/years

How long have you worked at Fen House? _____ months/years

Appendix C

Toolbox of Communication Strategies

	Your Specific Strategies
<p>“What’s right for this situation?” Communication rules</p>	
<p>“We’re doing this together.” Collaborative intent</p>	
<p>“What can help make this easier?” Cognitive support</p>	
<p>“I’m with you – it’s OK.” Emotional support</p>	
<p>“What can I ask to help you contribute?” Questions</p>	
<p>“I’m interested in sharing conversation.” Turn taking</p>	
<p>“We’ll choose topics which keep things going – in this conversation and into the future.” Elaboration of topics</p>	
<p>“I’ll help organise the conversation so we can talk in more detail.” Elaborative organisation</p>	
<p>“If the message gets lost, we’ll try to work it out together.” Repairing conversational problems</p>	

Appendix D

Sample Exercises from Training Program

Exercise One

Simple and Complex Questions

- Distribute and discuss ECP H5-5.
- Play role-plays demonstrating the use of simple and complex questions when ‘joining a library’.
- Use the complex questions on ECP H5-5. Ask communication partners to suggest ways the complex questions could be rephrased in a simpler form, and complete the relevant sections on the worksheet.
- One dyad can attempt to continue to use simple questions while planning what to buy when going out into town on a ‘personal shop’ time. Other dyad to practice using complex questions and for the group to feedback the difference between the interaction.

Simple and Complex Questions

It is usually best to use simple and short questions in conversations.

Simple and Short	Long and Complex
Need only brief attention	Require longer attention
Takes up “less room” in memory	Takes up “more room” in memory
Simple relationships between concepts in the sentence	More complicated relationships between concepts in the sentence
Faster to process the information	Need more time to process the information

Examples of Complex Questions - How could these be made simpler?

Where was it you were going to be going on your upcoming holiday?

Weren't you going to not bother about going to that party next month?

Do you want to go home via McDonalds or KFC or would you rather go home and have a sandwich or a meat pie?

What was it you did before breakfast this morning?

Should we go to the shops on the way home this afternoon to go to the bank to pay the bill and the post office to get the stamps?

How can we avoid using complex questions?

- Break complex ideas down into smaller parts
- Offer two choices at a time, rather than three or four
- Use simple sentence structure rather than using lots of words
- Make it clear what you are talking about by using specific words (e.g. the party vs that thing you've got on this weekend)

Exercise Two

Putting it all together

- Observe a videotape of a client conversing with their significant other. Using ECP H5-10 make a mark as to which questions were used by the significant other. Discuss how he/she could have made the interaction better.
- Watch a videotape between a client and another (Ziggy & Tony). Use ECP H5-10 to indicate the type of questions used. Discuss how this is different to the questions used in casual conversation.
- Dyads may take turns to have a conversation about planning a meal for dinner. Get them to think about the type of questions they ask.

Conversational Interaction

Questions

Watch out for any questions used in the conversation. Place a tick in the boxes that apply to the question.

Open Questions		Closed Questions	
Simple Questions		Complex Questions	
Follow-up Questions		Primary Questions	
Neutral Questions		Loaded Questions	
True Questions		Testing Questions	

Homework Exercises

Module 5 Homework Tasks

Reflection on information from group

What kind of questions are you already doing well with using?

What kind of questions do you need further practice with using?

Conversation Practice

Conversation 1: Using Follow-up Questions and Dynamic Questions

- After a period of time (an afternoon, day or weekend) which you spent apart, have a conversation about what the other person did (e.g. What have you been doing this afternoon?)
- Aim to use follow-up questions to keep the topic going for as long as possible, rather than changing the topic rapidly.
- Aim to use dynamic questions to keep the conversation progressing:

Conversation 2: Avoiding “Testing” Questions

- Try and get the opportunity to run a group looking at magazines/articles. One person might read it out loud, or just read it through silently.
- Aim to have a conversation using “true” questions or comments, rather than “testing” questions (that you already know the answer to).

Conversation 3: General Question Practice

- Try and take a client on a personal shop or out into the community.
- Aim to mainly use the following question types in your conversation
 - Balance of open and closed questions as appropriate
 - Simple and short questions (rather than long and complex)
 - Follow-up questions and dynamic questions (keep the conversation going)
 - True questions (rather than testing questions)
 - Neutral questions (rather than loaded questions)

Appendix E

Modified Burden Questionnaire

Name: Date:

	Never feel that way	Rarely	Sometimes	Quite frequently	Nearly Always
1. Do you feel happy when you are around clients?					
2. Do you feel embarrassed over the client's behaviour?					
3. Do you and the clients share pleasurable experiences?					
4. Do you feel angry when you are around the clients?					
5. Do you feel strained when you are around clients?					
6. Do you feel that your health has suffered because of your involvement with the clients?					
7. Do you feel good about your ability as a caregiver?					

8. Do you feel happy to have had the opportunity of caring for the clients?					
9. Does caring for the clients give you a sense of purpose or meaning?					
10. Do you feel uncertain about what to do about the clients?					
11. Do you feel you should be doing more for the clients?					
12. Do you feel you could be doing a better job caring for the clients?					
13. Do you feel that the client is demanding when they communicate?					
14. Do you enjoy talking and interacting with the clients?					
15. Do you feel frustrated when talking with the clients?					
16. Do you feel nervous about talking with the clients?					
17. Do you feel in control when running a session or task with a client?					

18. Do you feel that clients are able to follow and understand your instructions?					
19. Do you feel that clients are able to contribute equally to a conversation when you are talking with them?					
20. Do you feel burdened by what you need to do when working with the clients?					
21. Do you feel satisfied and happy with how you work?					
22. Do feel confident when running sessions with a group of clients?					

Appendix F

Structured Questions

1. **How are you?**
2. **Where did you come from?**
 - Clarify where they live and who with
3. **How did you feel about being at the long-term residential rehabilitation centre?**
 - Seek clarification re: what they did when they were a resident, who they were friends with.
4. **Can you tell me about the sort of work/study you do/did previously?**
 - Seek clarification re: time with current employer, previous types of work, preferred aspects of the job, future plans.
5. **What sort of things do you normally do on the weekends?**
 - Seek clarification re: sport, special interests, time spent with family.
6. **Do you have any particular favourite TV programs?**
 - Seek clarification re: reasons for preferences, together with questions re: recent films/movies seen, and preferences re: videos/cinema.

Appendix F

Focused Interview Protocol

Opening probe question

- “Tell me about your experiences talking and communicating with the clients at Fen House”.

Prompt questions

- “how about getting clients to sessions?”
- “whats your thoughts on talking to clients when running a group?”

Clarifying/checking questions

- “Can you explain what you mean by that?”
- “Could you provide an example of that?”

Positive experiences

- “Tell me about what you enjoy most when talking with clients?”
- “What makes you feel confident when talking with a client?”

Negative experiences

- “Explain what frustrates you most when communicating with a client who has had a brain injury?”

Finalise discussion

- “Is there anything else you want to raise?”
- “So overall what you’re saying is...am I understanding that correctly?”

Additional questions (posttraining group only)

Opening probe question

- “Your experiences with the communication program are important to us. We’d like to know more about your opinion on how it has been to participate in the course. We’ll start with a very general question.... tell me about your experiences with the program”

Other topics probes if not covered

- “What were your impressions of...” and “ How do you feel about ...”
- “You’ve talked about X, tell me about...”

To pull out change

- “Can you compare that to before the program/now?”
- “Can you provide some examples?”

Clarifying/checking questions

- “So do you mean.....?” and “are you saying....?” and “It sounds like...”
- (only use yes and no questions here).

Improvements to program

- “If we revised the program, what would you like to keep?”

Member check

- “And what would you like to change?”

Finalise discussion

- “Is there anything else you want to raise?”
- “So overall what you’re saying is...am I understanding that correctly?”

Appendix H

Measure of Support in Conversation (MSC)

Think in terms of skill of ECP in providing 'support'. Appropriateness is key (a well executed but overused technique would result in a lower score).

A. Acknowledging Competence	
Natural adult talk appropriate to context	<ul style="list-style-type: none"> • Feel and flow of natural adult conversation appropriate to context, <ul style="list-style-type: none"> ◦ e.g., social chat vs. interview; respectful approach to verification (verifying that the conversation partner has understood rather than verifying that adult with brain injury knows what they want to say; not over-verifying) • Not patronizing (loudness, tone of voice, rate, enunciation) • Appropriate emotional tone / use of humour • Uses collaborative talk (rather than teaching / testing) • Establishes equal leadership roles in the conversation • Uses true questions rather than testing questions
Sensitivity to partner	<ul style="list-style-type: none"> • Incorrect / unclear responses handled respectfully by giving correct information in a non-punitive manner • Sensitive to TBI's attempts to engage in conversation, Confirms partner's contribution. • Encourage when appropriate, Shows enthusiasm for partner's contribution. • Acknowledge competence when adult with brain injury is frustrated e.g., "I know you know what you want to say.", Acknowledges difficulties. • "Listening attitude", Demonstrates active listening (e.g. acknowledging, back-channelling) • Takes on communicative burden as appropriate / making adult with brain injury feel comfortable • Communicates respect for other person's concerns, perspectives and abilities • Questions in a non-demanding, supportive manner • Takes appropriate conversational turns
Score MSC Acknow Comp:	<p style="text-align: center;"> 0 0.5 1 1.5 2 2.5 3 3.5 4 </p> <p style="text-align: center;"> Not supportive Basic skill in support Highly skilled support </p>

A. Acknowledging Competence Anchors

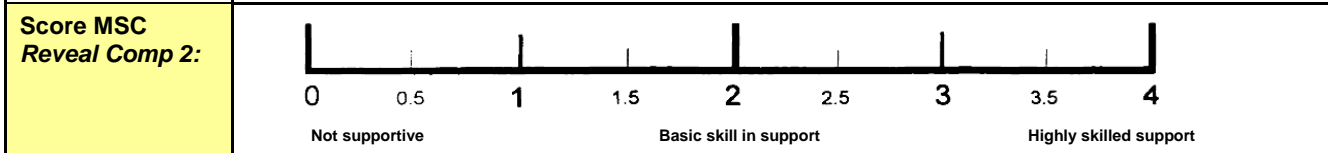
NONE	0	Competence of person with TBI not acknowledged . Patronising.
	1	Minimally acknowledges competence of person with TBI.
SOME	2	Basic level of skill. Some acknowledgement of the competence of person with TBI.
	3	Mostly acknowledges the competence of person with TBI.
FULL	4	Interactionally outstanding. Full acknowledgement of the competence of the person with TBI.

B. Revealing Competence

<p>1. Ensure adult understands (e.g. topic, questions)</p>	<ul style="list-style-type: none"> • Verbal (e.g. short, simple sentences; redundancy; is there some verbal adaptation?) • Nonverbal <ul style="list-style-type: none"> ○ Gesture Meaningful; slightly exaggerated; used to emphasize or clarify ○ Writing Clear and visible; appropriate key words ○ Resources Used only when necessary (would something simpler suffice?) • Response to communicative cues (e.g., reacting to facial expressions indicating confusion?) • Gives cues in a conversational manner • Provides an appropriate level of cognitive support (e.g. referring to diary, making notes) • Organises information in the conversation as clearly as possible to support comprehension (e.g., sequential order, causality, similarity and difference, association) • Makes connections between topics, reviews organisation of information (e.g. summarises)
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<p>2. Ensure adult has means of responding (and elaborating)</p>	<ul style="list-style-type: none"> • Response to communicative cues (e.g., giving enough time to respond) • Establishes equal leadership roles in the conversation • Introduces and initiates topic of interest • Allows partner to take appropriate conversational turns • Maintains the topic by adding information • Invites elaboration (e.g. uses open-ended questions, statements, links to experiences of TBI) • Uses questions appropriate to person’s ability (e.g. simple or closed questions when necessary) • Helps partner express thoughts when struggle occurs
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<p>3. Verification (Accuracy of adult’s response not assumed)</p>	<ul style="list-style-type: none"> • Response to communicative cues (e.g. infers intended message of the person with brain injury, based on all available cues) • Confirms understanding of what has been said (paraphrasing, checking) • Uses clarifying questions as appropriate • <i>Note:</i> Verification often involves checking in a different way (e.g., using a yes/no question)
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B. Revealing Competence Anchors

NONE	0	No use of techniques to reveal competence. Inhibits the potential participation of the person with TBI.
	1	Low level of skill in revealing competence. Minimises the potential participation of the person with TBI.
SOME	2	Basic level of skill. Uses techniques to maintain the potential participation of the person with TBI. Able to get some information from the person with TBI.
	3	Uses techniques to promote the potential participation of the person with TBI.
FULL	4	Technically outstanding. Uses techniques to maximise the potential participation of the person with TBI. May not always succeed, but applies techniques flexibly and in a sophisticated way.

Appendix I

Global Impression Scales

Think in terms of interactional social behaviour in conversation.

Appropriateness/Style	
Guide	<ul style="list-style-type: none"> Degree of relevance, suitability and aptness of the subjects' contributions within the conversation that occurs (how do they respond to inappropriateness?). This includes choice of subject matter, how well content logically follows on from what has been said, and how general or specific and personal or impersonal the content. Consider the content (relevant to the context and the people involved)
Score Approp:	
Effortful	
Guide	<ul style="list-style-type: none"> Degree of difficulty and amount of work required to initiate and maintain the conversation. E.g., spontaneous and flowing versus stilted and forced interaction. Note scale reversal Consider effort required to create a spontaneous and flowing interaction.
Score Effort:	
Interesting	
Guide	<ul style="list-style-type: none"> Degree to which the subjects can engage, hold the attention of, and stimulate a spontaneous response in each other (e.g. eye contact, body language, fillers, responses to questions).
Score Interesting	
Rewarding	
Guide	<ul style="list-style-type: none"> Degree of gratification or enjoyment to be derived from the interaction Consider what has been learnt and achieved by the interaction.
Score Rewarding	

Rating Anchors		
NONE	0	Not observed throughout for the communication partner and person with TBI
	1	Observed occasionally in the communication partner and/or person with TBI
SOME	2	Observed on several occasions throughout the interaction by both the communication partner and person with TBI. Clear attempts seen.
	3	Observed on most occasions throughout the interaction by both the communication partner and person with TBI.
FULL	4	Observed throughout the entire interaction.

Appendix J

Primary Rater Scores of Interactions

Table K1

Primary rater scores of structured interactions

Rating Form													
Rater 1													
Sample	TBI	PC	MPC		MSC					GIS			
			Interaction	Transaction	AC	RC Ave	R1	R2	R3	A	E	I	R
001_C3_pre_SC	Adam	C3	1.5	1.5	1.5	1.33	1.5	1.5	1	1.5	1.5	2	1
001_C3_post_SC	Adam	C3	1.5	1.5	2.5	2.83	3	2.5	3	2.5	1	2	2
001_C3_FU_SC	Adam	C3	1.5	1.5	1	1.5	1.5	1.5	1.5	2.5	1.5	2	2
002_C1_pre_SC	Lisa	C1	3	3.5	2.5	2.83	3	2.5	3	3.5	3	2.5	2
002_C1_post_SC	Lisa	C1	3.5	3.5	2.5	2.83	3	2.5	3	3.5	3	2.5	2.5
002_C1_FU_SC	Lisa	C1	2.5	3	3	2.5	2.5	2.5	2.5	3	2.5	2.5	2
003_C4_pre_SC	Simon	C4	2.5	3	3	3	3	3	3	3.5	3.5	3.5	3
003_C4_post_SC	Simon	C4	3	3.5	4	4	4	4	4	4	3.5	4	4
003_C4_FU_SC	Simon	C4	3	3.5	4	3.67	4	3.5	3.5	4	3.5	4	4
004_C5_pre_SC	Sally	C5	3	3.5	2.5	2	2	2	2	3	2	2.5	2
004_C5_post_SC	Sally	C5	3.5	3.5	3.5	3.17	3.5	3	3	3.5	3.5	3	3
004_C5_FU_SC	Sally	C5	3	3.5	3	3.17	3.5	3	3	3.5	3	3	2.5
005_C2_pre_SC	Paul	C2	3	3	3	3	3	3	3	3.5	3.5	3	3
005_C2_post_SC	Paul	C2	3	3	3	2.67	2.5	3	2.5	3	3	3	2.5
005_C2_FU_SC	Paul	C2	3.5	3.5	3.5	3.83	4	3.5	4	4	4	4	3.5
007_C10_pre_SC	Lisa	C10	3.5	3.5	4	3.67	3.5	4	3.5	3	4	4	3.5
007_C10_post_SC	Lisa	C10	3.5	3.5	3	2.83	3	3	2.5	3.5	3.5	3	3.5
007_C10_FU_SC	Lisa	C10	3	3	2.5	2.17	2	2.5	2	3	3	2.5	2.5

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008_C9_pre_SC	Paul	C9	3	3.5	2	2	2	2	2	3	3	2.5	2.5
008_C9_post_SC	Paul	C9	2.5	2.5	1.5	1.5	1.5	1.5	1.5	3	1.5	1.5	1.5
008_C9_FU_SC	Paul	C9	2.5	3	1.5	1.5	1.5	1.5	1.5	3	2	2	2
009_C7_pre_SC	Adam	C7	1.5	2	3.5	3.33	3.5	3.5	3	3.5	2	2.5	2
009_C7_post_SC	Adam	C7	2.5	2.5	2.5	2.5	2.5	2.5	2.5	3	2.5	3	2
009_C7_FU_SC	Adam	C7	1.5	2	3	3	3	3	3	3	2	2	2
010_C8_pre_SC	Lisa	C8	3.5	3.5	3.5	3.5	3.5	3.5	3.5	4	3	3	3.5
010_C8_post_SC	Lisa	C8	3.5	3.5	3	3.17	3.5	3	3	3.5	3	3.5	3
010_C8_FU_SC	Lisa	C8	3	3.5	3	3	3	3	3	3	3	3	3
011_C6_pre_SC	Sally	C6	3.5	3.5	3.5	3.33	3.5	3.5	3	3.5	3.5	4	3.5
011_C6_post_SC	Sally	C6	3	3	2	2	2	2	2	2.5	2.5	2.5	2
011_C6_FU_SC	Sally	C6	3.5	3.5	3	3.17	3.5	3	3	3.5	3.5	4	3.5

Note. TBI = traumatic brain injury; PC = paid caregiver; MPC = Measure of Participation in Conversation; MSC = Measure of Support in Conversation; GIS = Global Impression Scales; AC = acknowledge competence; RC Ave = reveal competence average; R1 = reveal competence 1; R2 = reveal competence 2; R3 = reveal competence 3; A = appropriate; E = effortful; I = interesting; R = rewarding; SC = structured conversation.

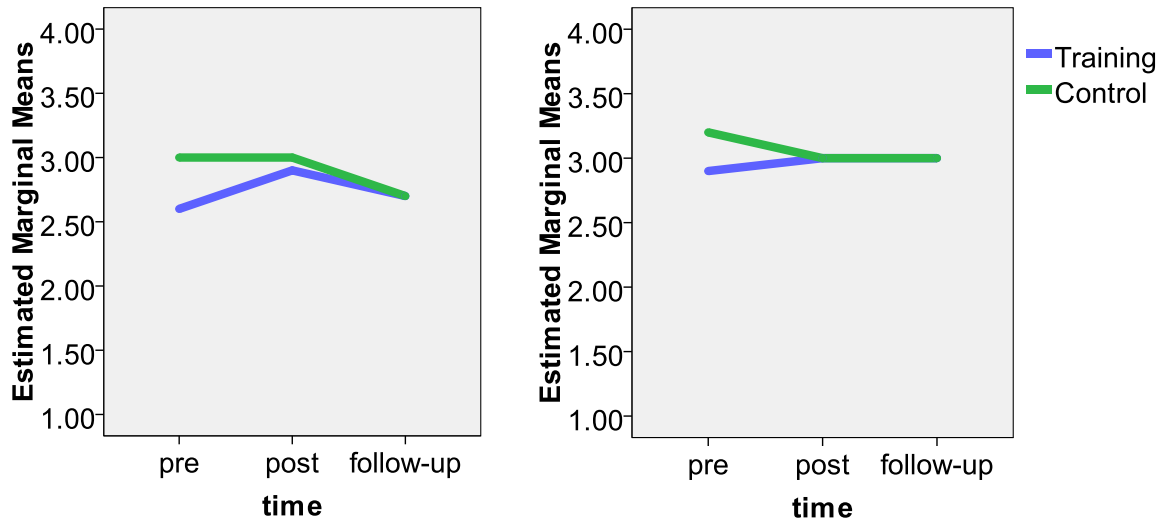
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010_C8_pre_CC	Lisa	C8	2	2	2.5	2	2	2	2	2	2	2	2
010_C8_post_CC	Lisa	C8	3	3	3	3	3	3	3	3.5	3	3	3
010_C8_FU_CC	Lisa	C8	3	3	3	2.83	3	3	2.5	3.5	3	2.5	2
011_C6_pre_CC	Sally	C6	3	3	1	1.17	1.5	1	1	2.5	2	2.5	2.5
011_C6_post_CC	Sally	C6	3.5	3	3.5	3.17	3.5	3	3	4	3.5	3.5	3
011_C6_FU_CC	Sally	C6	3.5	3	3.5	3.17	3	3	3.5	3	3.5	3.5	3

Note. TBI = traumatic brain injury; PC = paid caregiver; MPC = Measure of Participation in Conversation; MSC = Measure of Support in Conversation; GIS = Global Impression Scales; AC = acknowledge competence; RC Ave = reveal competence average; R1 = reveal competence 1; R2 = reveal competence 2; R3 = reveal competence 3; A = appropriate; E = effortful; I = interesting; R = rewarding; SC = structured conversation.

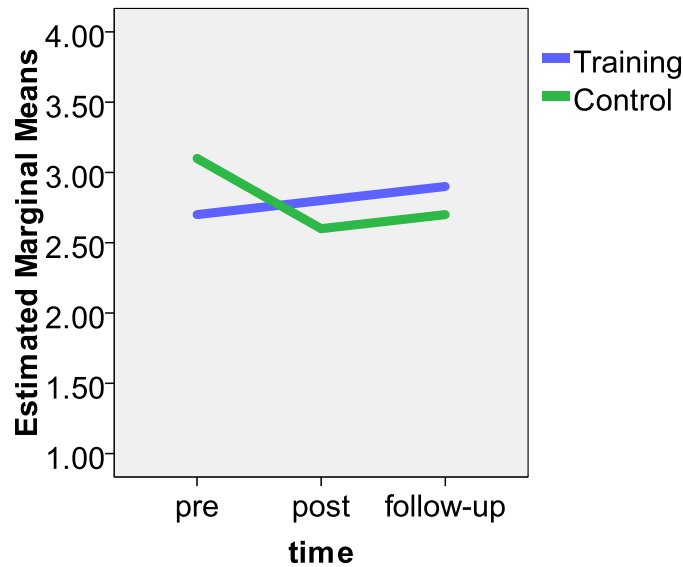
Appendix K

Primary Outcome Measures: Non-Significant Results



a) Interaction

b) Transaction



c) Effort

Figure L1. Mean scores for pre, posttraining and follow-up primary outcome measures that did not reach significance in the structured conversation condition.

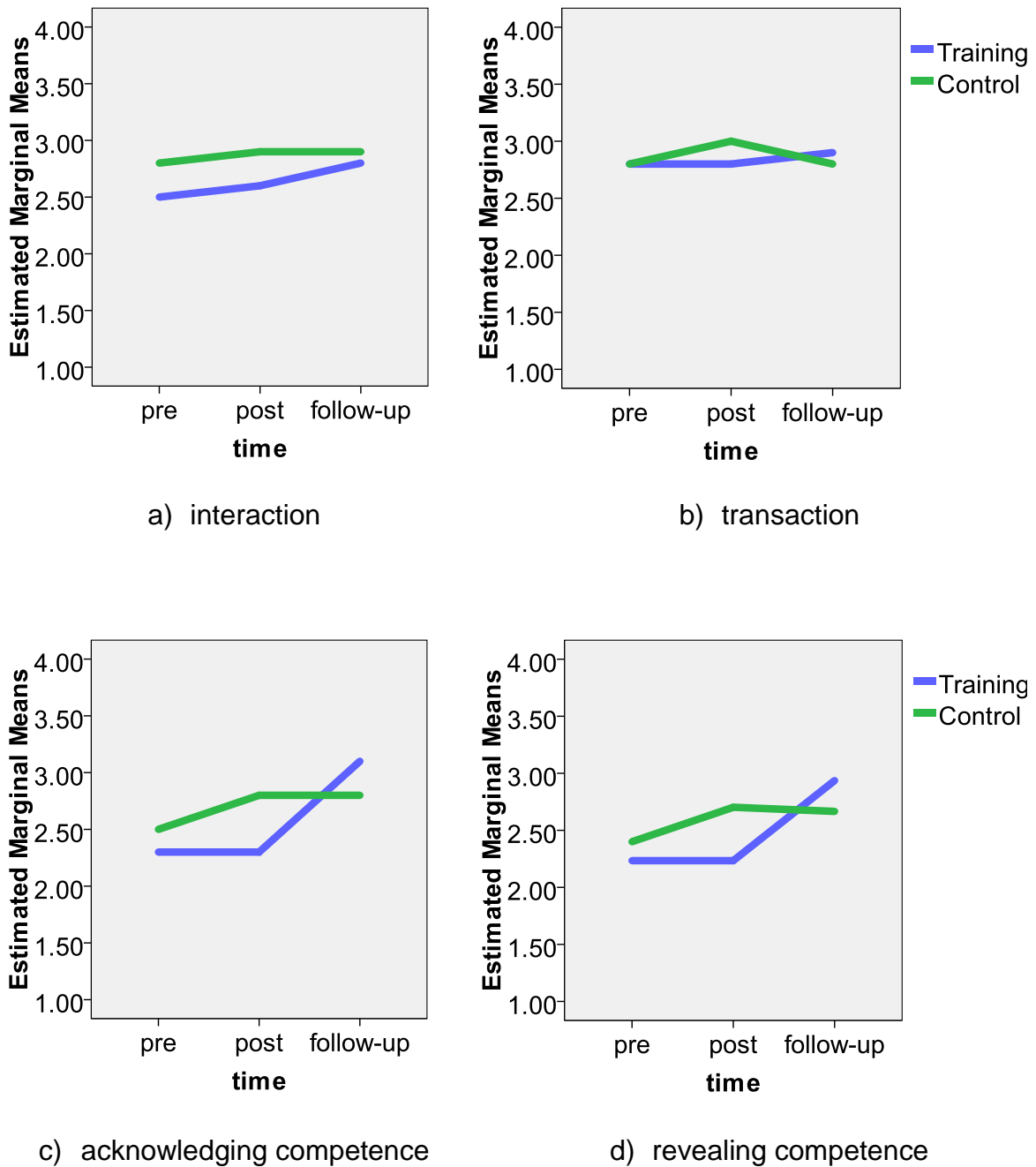
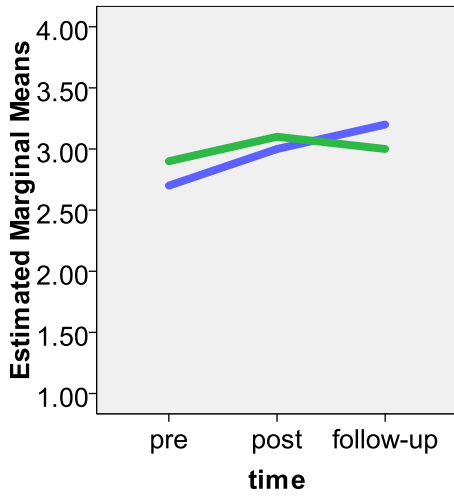
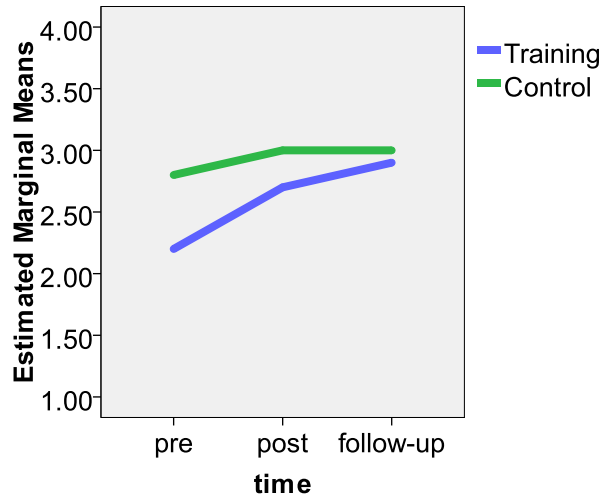


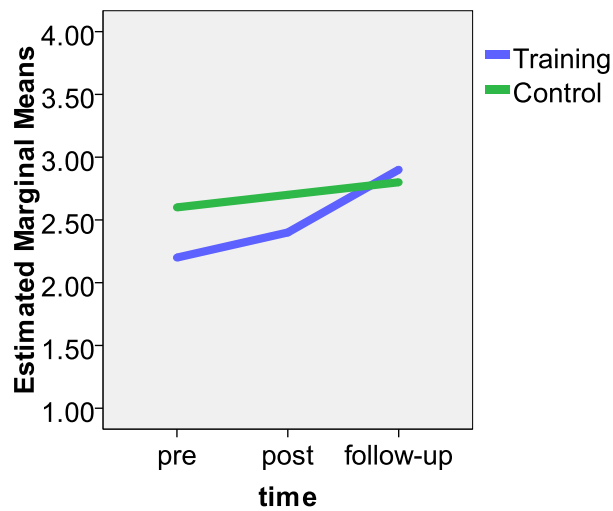
Figure L2. Mean scores for Measure of Participation in Conversation (MPC) and Measure of Support in Conversation (MSC) for pre, posttraining and follow-up that did not reach significance in the casual conversation condition.



e) appropriateness



f) interesting

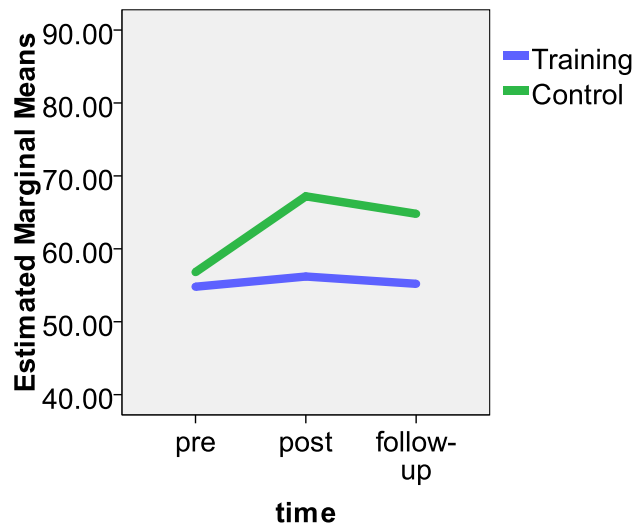


g) rewarding

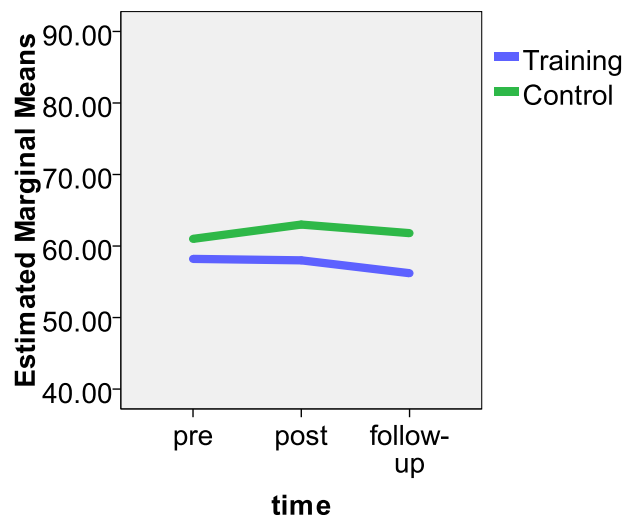
Figure L3. Mean scores for Global Impression Scales for pre, posttraining and follow-up that did not reach significance in the casual conversation condition.

Appendix L

Secondary Outcome Measures: Non-Significant Results



a) LCQ (Paid Caregiver)



b) LCQ (Person with TBI)

Figure M1. Mean scores for pre, posttraining and follow-up secondary outcome measures that did not reach significance. LCQ = La Trobe Communication Questionnaire; TBI = traumatic brain injury.

Appendix M

PostTraining Coded Transcripts

Person	Text	What is this quote saying?	Code
NB	<i>Can you tell me about your experiences have been in talking and communicating with the clients over the last 2 months?</i>		
C3	Communicating wise a lot different, I mean . You know we did all those tutorial things. I mean to talk to someone make them give you more information like from their point . I have worked harder to get it from them and it does work and where I seen where used to ask them questions before where it was yes and no that's helped because I can actually write that down now, because Cas makes us gives us activity forms what they have done who said what and I can actually give her feedback what the clients have said . Behaviour wise when you ask them, there was a question here, are you comfortable or embarrassed talking to some clients. I can be but I can work around it.	Communication Improved clients comm. – impact Provide feedback Strategies/ tools	Self-change Elaboration Collaboration Self-change
NB	<i>What about getting clients to sessions how are finding that now?</i>		
C3	Okay.		
NB	<i>That hasn't changed do you think that's different now?</i>		
C3	That hasn't changed.		
NB	<i>What about running a group talking to clients?</i>		
C3	Find it harder still . That's why I wrote this one, understand instructions, sometimes. The reason is I think sometimes I say wrong things and they don't understand and they don't talk . For me I think I need to work on my English a lot more and how to communicate a lot more to get them to understand .	Challenges Skills to improve	Unsuccessful Monitor

NB	<i>I guess the thing is – what do you enjoy most when you are communicating with the clients?</i>		
C3	I think it's talking about what they like and what I like and then make the work around how we're similar.	Enjoyment	Enjoyment
NB	<i>Can you give me some examples?</i>		
C3	As in Dean I mean I have done Arts & craft with him and he used to use his left hand and he's now using his right hand. And he'll sit there for ages painting we done a poster together and he does enjoy it if he is given a chance, have patience. Ziggy the same, we do little beaded works because it fucks up out of her hand if you take the time and hold it down for her.	Skills - patience	Collaboration Collaboration
NB	<i>What about talking, communicating with the clients, can you give me examples of things that you enjoy when you are talking with them?</i>		
C3	I think Paul know a lot more then what the same things he always says, I think he has come out more. We've gone to his Mums now recently and been saying new stuff, he going out, how his Mum cooks for him, new stuff not just like most. Lisa from the other side and like Carol she's I think not got long here but she going to be able maybe see her daughter.	Identify improvement in communication	Client
NB	<i>What frustrates you most?</i>		
C3	Frustrating is when the client actually switches on you anger-wise and you don't understand what is the purpose of it and you think you have done something and you haven't.	Frustration	Frustration
NB	<i>Ok so what frustrates you about being able to communicate in those situations?</i>		
C3	I mean it happened to me today and I could not get out of it and I asked the client, what is the matter have I done something wrong and the person just said, gave me really rude answers go out of the room or whatever and there was just the one thing and it was coming out of that category where she was really constantly.	Clients communication	Frustration

<p><i>NB</i></p>	<p><i>Sounds like your experiences over the last eight weeks have been a bit of a mixed bag, some things that you are still finding quite hard and almost difficult to manage and other things that are enjoyable. What I want to look at are your experiences with the actual training that you took part in. I guess what I want to know about is what your opinion is on how it's been to actually take part in the training. So can you tell me just a bit about your experiences with the training?</i></p>		
<p>C3</p>	<p>I think it's helped me a lot more. I found it I am a person who can be really, really quiet, because of the training I feel that I am a lot more loud. Because I can express and help someone because I am a lot more louder, the person understands me a lot more. I think the tactic of the sessions I have had and how to play along with the conversations I think worked. I feel a lot more comfortable now, I try it out anytime I can,</p>	<p>Change in communication Style Successful training approaches</p>	<p>Self-change Collaboration Delivery Confidence</p>
<p><i>NB</i></p>	<p><i>Give me examples of when you try it out.</i></p>		
<p>C3</p>	<p>Wendy, she's been I don't know, cause I've had a really good time the last time it happened was Wendy she was really really happy and every time I spoke to her she gave me loads back and I go Wendy sing to me because I heard she used to do it and she sing along in American in the kitchen she was doing self cater she never do a self-cater and she would argue about it and she come out and I say come on you need to do this cause you gonna have to eat sometime soon you're going to feel hungry and she say ok I come and make something. I asked what would you like to make and because she always has cheese on toast. I didn't say cheese on toast. I gave her another two options and she chose one of the two options. We had a long chat, can't remember it was in the kitchen talking about something about butter, she goes a lot more butter feels a lot better, tasting wise.</p>	<p>Improved clients communication Confidence Skills</p>	<p>Client Collaboration Collaboration</p>

NB	<i>What were your impressions the kinda things that we talked about collaboration, we talked about elaboration we talked about questions. What were your impressions about the things that you were learning?</i>		
C3	I mean its confusing I found it really really confusing because I had to read through what I was using all the time.	Confusion Terminology	Language
NB	<i>Did it make more sense as you went along?</i>		
C3	Yeah and to be honest I did not know there was such things as that. I thought everything was one and for it to be broken up.	Simplified?	Language
NB	<i>Can you compare how, I guess you have your progress beforehand before you started the training to now it's very different, you were saying how you have almost changed the way you communicate.</i>		
C3	A lot more, I think I have it has actually helped, I think I feel a lot more comfortable and behaviour wise when someone is angry I can sometimes control some people back to what they actually originally felt and then get them to calm down.	Assertiveness Improved Knowledge	Confidence Self-change
NB	<i>If we were to revise, or change the program what areas, what things what areas would you say we definitely need to stay in it. Like what things did we do that you say to yourself actually you need to keep that there.</i>		
C3	The scenario stuff,	Role-play	Language
NB	<i>In the final session or....</i>		
C3	I think all the way through all the sessions. I think when I am dealing with the staff I think we don't ever put ourselves in the clients shoes. And putting us in the clients' shoes, I think that helps because we don't actually know and when we are in that situation we have to act like the clients. That's a scary thing I think working on the clients more understanding how they feel as well as us, being different.	Importance of role-play	Work Frustration Delivery Collaboration

NB	<i>You were saying that actually you would like to see me do more of the role plays.</i>		
C3	Yes, because you understand, and if we were the client you could ask us the questions.	Importance of role-play	Delivery
NB	<i>How did you find the role plays that I played out with Lisa, were they useful to watch and see?</i>		
C3	Yes. Really really. You worked with clients and that's why it actually helped a lot more and for a client to give you all that information and actually read from a script it's just wow. It's actually helped.	Importance of role-play	Delivery
NB	<i>Is there anything if you could change, I mean if I was to do the program again is there anything you would change?</i>		
C3	I would not change anything maybe add something. Maybe walking, I mean some of them walking outside behave a lot more different.	Genre's	Language
NB	<i>Do you mean the homework kind of thing you would do more?</i>		
C3	Yea I mean when you are doing the recording, or maybe if you could get someone filming you walking. The client's behaviour changes because some other environment.	Community Access	Language
NB	<i>So maybe some community based stuff. Might be a difficult one.</i>		
C3	To see if it would work because when you are out in the community so people work for us.	Community access	Language
NB	<i>So it makes more sense to you to see those kinds of things. Anything else you want to raise anything else to say?</i>		
C3	Only that I have learnt a lot more.	Improved knowledge	Skills

Note. C3 = Paid caregiver; NB = researcher