

University of Stirling

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Adaptation of informal care relationships following Acquired Brain Injury

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Abstract

The number of informal carers in the UK is rising, yet the dynamics of care within informal care relationships remain poorly understood. The present research examined adaptation of informal care relationships affected by Acquired Brain Injury.

The research addresses four pairs of questions: (1a) Are there any disagreements and/or misunderstandings between carers and people with Acquired Brain Injury (PwABI) regarding carer identity? (1b) How can the pattern of divergences be explained? (2a) Are there any disagreements and/or misunderstandings between carers and PwABI regarding PwABI identity? (2b) How can the pattern of divergences be explained? (3a) What strategies do carers and PwABI use in collaboration on a joint task? (3b) Is the type of input provided by carers on the joint task comparable to scaffolding as described in the child development literature? (4a) What happens when carers and PwABI collaborate to fill in the Disability Living Allowance (DLA) claim form? (4b) Why do carers see more disability than PwABI when filling in the DLA form?

Four mixed-method data sets were used to answer these questions: (1) numerical ratings given by PwABI and carers to map out convergences and divergences (2) videos of discussions between participants and researcher during rating tasks (3) videos of carers and PwABI engaging in a joint task - planning inviting a friend or relative round for a meal and (4) videos of carers and PwABI filling in part of the DLA claim form. All data was collected from the same 28 PwABI/carer dyads who were two or more years post injury.

Chapter 4 addresses questions 1a and 1b. Carers' and PwABIs' perspective ratings revealed a number of disagreements regarding carer identity. Carers perceived themselves negatively compared to their partners' view of them. Regarding question 1b, carers feel negatively about themselves due to difficulties in the transition to the role of 'carer'. They

experience a lack of recognition for this caring role as a result of concealing the burden of care. Carers require more long term support from health services to help them achieve recognition for their role, such as facilitating attendance at support groups.

Chapter 5 addresses questions 2a and 2b. Carers' and PwABIs' perspective ratings revealed only one disagreement and corresponding misunderstanding regarding PwABI identity. Regarding question 2b, alignment was found between the perspectives of carers and PwABI regarding PwABI due to the relational rating method used. It is carer identity which is the source of most divergences of perspective, not PwABI identity as commonly assumed. Using a relational rating method shows promise as a tool to explore perspectives as it treats all viewpoints as equal and avoids pathologising the perspective of PwABI.

Chapter 6 addresses questions 3a and 3b. Analysis of strategies shows that completing a joint task is a collaborative process. Carers direct the background of the task but PwABI are in charge of the foreground, making task decisions. However, carers dominate the process and control where and how PwABI contribute. Regarding question 3b, the interaction meets the criteria for scaffolding in the strategies chosen and the flexibility of collaboration. However, removal of supports is often an unrealistic goal, leading to frustration in carers. Examination of processes of collaboration has elucidated the strategies used by carers and PwABI and can enhance theoretical discussion of the applicability of the scaffolding metaphor for a cognitively impaired adult sample.

Chapter 7 address questions 4a and 4b. Disagreements were frequent when completing the DLA form. Contestations were almost exclusively in the direction of carers seeing greater disability than PwABI. Regarding question 4b, carers see greater disability due to the communication required to complete the form. Dyads are forced to confront disability, a pattern of interaction they avoid in everyday life. Carers marginalise PwABI

point of view and position themselves as 'expert' on the PwABI. Differences in frames of reference regarding audience, aim and scope lead carers to maximise the disability and PwABI to minimise this. The impact of completing complex forms on relationships and identity needs to be considered during development of disability benefit assessment methods.

A relational approach which studies both halves of informal care partnerships simultaneously allows us to go beyond outcomes of ABI and affords a greater understanding of *processes* of adaptation.

Attestation

I understand the nature of plagiarism, and I am aware of the University's policy on this.

I certify that this thesis reports original work by me during my PhD.

Signature

Date

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Introduction to the Thesis - Rationale for Studying Adaptation of Informal Care Relationships Following Acquired Brain Injury

The Problem of Informal Care

There is growing consensus that the UK's social care system is in crisis (Counsel and Care, 2008). Central to the current debate on care is the issue of informal care. This thesis will use the definition of informal carers provided by The Princess Royal Trust for Carers as "someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems" (2010). There were 5.9 million informal carers in the UK at the time of the 2001 census and unpaid carers outnumber paid carers, 3 to 1 (Doran, Drever & Whitehead, 2003). Unofficial figures for the 2011 census suggest that the number of carers has increased to around 6.4 million with carers estimated to save the nation around £119 billion annually, almost as much as the total cost of the NHS (Toynbee, 2012). Britain's ageing population, increased longevity and rising disability rates are likely to increase demand for care services (Heitmuller & Michaud, 2006), whilst changing family compositions due to lower marriage rates, fewer children, increased geographical mobility and decline in intergenerational co-residence are likely to produce a decline in the supply (Van den Heuvel et al., 2002). The burden of care has been shown to have a profound impact on health and well-being, therefore it is essential that carers' needs are better addressed (Doran et al., 2003). Accordingly, there have been recent calls by government ministers for the NHS to do more to prioritise the needs of carers (Winnett, 2011).

The Problem of Acquired Brain Injury

Long-term dependence on informal carers is a common scenario after Acquired Brain Injury (ABI). ABI is defined as "an injury to the brain, which is not hereditary,

congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth” (Brain Injury Association of America, 2011).

ABI can have a variety of causes, such as trauma, stroke, tumour or haemorrhage.

Advances in medical services have led to increased survival rates following ABI. However, despite improvements in acute and transitional care provided by health services, these services cannot address the long term personal and social difficulties that those with ABI and their families may face (Neary, 2005). It is estimated that around 500,000 people aged 16-74 in the UK are living with long term disability as a result of Traumatic Brain Injury (TBI), and 450,000 people are living with disability after stroke (Headway, 2009). Family members may often provide the majority of the support needed to cope with such long term disability.

Despite the long term care which may be required by people with ABI, the majority of support services for families affected by brain injury are only available in the short-term post ABI (Degeneffe & Olney, 2008). The decrease in available support over time tends to coincide with a narrowing of the social structure (Kozloff, 1987). Kozloff (1987) suggests that as time passes post ABI, social network size decreases and becomes denser. Non-relatives’ input decreases and family members begin to serve increasingly more functions. This alteration in social dynamics can result in pressure on within-family relationships. Successful adaptation of within-family relationships is therefore essential for the well-being and quality of life of all family members.

The Impact of ABI on Relationships: What Happens When Family Relationships Become Informal Care Relationships?

The picture surrounding the impact of ABI on relationships is complex. In terms of outcomes for couples, findings remain contradictory. In their review of marriage after brain injury, Godwin et al. (2011) highlighted the disparate findings across studies relating

to levels of marital breakdown. They report studies such as that by Klonoff et al. (2006) which have found high marriage stability rates. In Klonoff et al.'s study 81% of 93 subjects remained in a stable relationship two years post injury. In large sample studies, divorce rates as low as 15% have been reported (Kreutzer et al., 2007). However, others such as Jacobsson et al. (2009) found lower rates of stability with 45% of their sample experiencing marriage breakdown in the first ten years post injury. The contradictions in findings show the complexity of the marital situation after injury. Godwin et al. (2011) also examined the literature on marital quality after brain injury and found a primarily negative impact of brain injury on marital quality. Maladjustment, dissatisfaction, sexual disruption and social isolation have all been reported in relationships adapting to ABI (Bowen et al., 2010). However, as with stability, there is a diversity of findings, with some studies reporting positive outcomes for couples in relation to sexual and communicative functioning (Godwin et al., 2011). Although the picture surrounding the impact of brain injury on marriage is complex, fracturing of relationships remains a risk after brain injury.

The aetiology of ABI has specific features that can have a profound negative effect on relationships. The complex mix of cognitive, behavioural, communicative and psychological problems that may arise post injury (Trudel, Tyron & Purdum, 1998; Verhaeghe, Defloor & Grypdonck, 2005) can prohibit social recovery measured in terms of the individual resuming work, maintaining his or her position in the family, and relating to others in an appropriate and meaningful way (Wood & McMillan, 2001). For example, families must deal with personality change, which may be frequent, particularly in severe trauma patients (Brooks, 1984), and cognitive impairment which can render engagement in activities of daily living (ADLs) difficult (Evans, 2003; Wood & McMillan, 2001). As a result, PwABI may become care-receivers, dependent on family members.

Simultaneously, family members become care-givers, with responsibility for the care of a relative who is now disabled and often radically altered from the person they once were (Landau & Hissett, 2008). Carers provide emotional, physical, and cognitive support to their partners but often do not receive the emotional, financial and practical support that they in turn require, resulting in feelings of burden and role captivity (Carnes & Quinn, 2005). The transition to roles of care-receiver and care-giver risks relationship harmony as each half of the dyad experiences divergent practical, social and emotional demands.

Although much of the literature has demonstrated the negative effects of ABI on the person with the injury and those close to them, it is important to note that there are many cases where no adverse psychological and health effects are reported and instead positive coping and adaptation has taken place in relationships (Kosciulek, 1994; Perlesz, Kinsella & Crowe, 2000). Close care relationships have been shown to improve quality of life (Hinckley, 2006) and the positive approach of “giving meaning to an event that, at first sight, is meaningless” (Lefebvre, Cloutier & Levert, 2008, p. 539) has been demonstrated by care relationships when discussing the injury after ABI. Close relationships can assist the adaptation process for both carers and PwABI, and carers have been shown to support PwABI to achieve fulfilling integration. Outcomes of adaptation, therefore, vary greatly.

What This Thesis Will add to the Study of Informal Care After ABI

Outcomes of informal care and ABI are well documented. What is under-represented in the literature is the dynamics of care in informal care relationships. *How* do informal care relationships adapt? This research will use a mixed methods approach to go beyond outcomes and explore *processes* of adaptation in informal care relationships following ABI.

Care-givers and care-receivers are often studied separately and at the individual level. However, neither disability nor care is experienced in isolation. Care relationships impact upon the experience of disability and care on both sides of the relationship. This thesis will examine *relationally* how informal care relationships adapt to the altered relationship dynamics that ABI creates. This research will examine care-givers and care-receivers *simultaneously* to examine (1) how relationships adapt to role and identity changes, by mapping patterns of convergences and divergences of perspective and locating their sources (chapters four and five) and (2) how relationships adapt cognitively and practically, by examining processes of interaction and collaboration when engaging in joint activity (chapters six and seven).

Overview of the Thesis

Chapter one will examine the theoretical background to identity adaptation when faced with the onset of disability and informal care. The chapter will introduce previous research in the area and will then put forward a dialogical approach to identity adaptation. The chapter will explore the ways in which a dialogical approach can complement previous research and contribute to relational approaches in the area of informal care and ABI. Two pairs of questions to be addressed by the research will be stated.

Chapter two will examine the theoretical background to cognitive and practical adaptation when faced with the onset of cognitive impairment and informal care. The chapter will introduce a relational approach to such adaptation via the theoretical notion of distributed cognition. Previous research on distributed cognition and scaffolding will be introduced, before exploring the contribution which can be made by observing processes of collaboration on tasks in adult dyads where one person has ABI. Two pairs of questions to be addressed by the research will be stated.

Chapter three will introduce the methodology used in answering the four pairs of research questions stated in chapters one and two. These are identity ratings tasks which facilitate the mapping of convergences and divergences of perspectives on identity and observations of carers and PwABI engaging in two joint tasks: Planning inviting a friend or relative round for a meal; and filling in part of the DLA claim form. The 28 PwABI/carer dyads who took part in the research will be introduced.

Chapter four maps convergences and divergences of perspective about carer identity and chapter five maps convergences and divergences of perspective about PwABI identity. The chapters then go beyond the ratings to analyse video recordings of talk surrounding the rating tasks to locate the sources of observed convergences/divergences of perspectives.

Chapter six presents the analysis of observations of collaboration on the planning inviting a friend or relative round for a meal joint task. Strategies used by care-givers and care-receivers will be presented and the scaffolding metaphor will be considered in terms of its applicability for use with a cognitively impaired adult sample.

Chapter seven presents the analysis of observations of collaboration on the DLA claim form joint task. Analysis of the video data reveals disagreements when collaborating on the task, thus the chapter will endeavour to locate the source of these disagreements.

Chapter eight summarises the findings of the research and discusses the implications of these findings for the literature. The chapter will also explore the limitations of the research, alongside theoretical and applied contributions.

Chapter One – Identity Adaptation of Care-Recipients and Care-Givers: Moving Towards a Dialogical Approach

Acquired disability resulting in an informal care relationship causes role changes. The person with disability becomes a care-receiver, struggling for independence (Newsom & Schulz, 1998), and at risk of stigmatisation (Goffman, 1963). Simultaneously, family and friends become care-givers, a role which most have not experienced before (Emslie et al., 2009) and which can be demanding and stressful (Simon, Kumar & Kendrick, 2009). Adapting to changed roles and the new identities these create is complex and can result in fractured relationships, with each side experiencing divergent practical, social and emotional demands. Although advances have been made in our understanding of identity when assuming a care-receiver or care-giver role, research has often studied care-receivers and care-givers separately, focusing on analyses at the individual level. A relational approach to identity assumes that identity is developed *through* relationships in the social world. This approach believes that identity is not created and sustained through our isolated viewpoint on ourselves, but is intrinsically linked to the real and perceived views of others. When care-receivers and care-givers are studied at the individual level, these real and perceived perspectives of others and their role in identity are often missed. This PhD research will study care-receivers and care-givers simultaneously using a dialogical approach. This allows not just for different perspectives on identity after the onset of disability to be explored but also the relation between perspectives. Studying care-receivers and care-givers simultaneously facilitates the exploration of whether there are disagreements between care-receivers and care-givers about identity and whether the perspectives of each half of the dyad are understood by the other. The origin of divergences of perspectives can then be traced through the talk which takes place while perspectives are being elicited.

Chapter Outline

This chapter will present theoretical and empirical background to identity in the context of informal care and disability. As previous research has traditionally studied care-receivers and care-givers individually, the chapter will begin by providing an overview of identity research to date in those becoming a care-receiver and those becoming a care-giver separately. The chapter will focus firstly on identity research in those adapting to disability and a care-receiver role. The chapter will then focus on identity research in those adapting to the role of care-giver when a friend or relative acquires a disability. Both sections will highlight what a relational approach to identity can add to existing theory and research and will present relational research on identity adaptation in informal care relationships to date. The chapter will then outline a dialogical approach to identity in informal care relationships and will discuss the implications of taking a dialogical approach for informal care and ABI research. The chapter will conclude with the ways in which using a dialogical approach to study identity change in informal care relationships after ABI will advance the field. Two critiques of the literature and four associated research questions are presented. These research questions will be answered in chapters four and five of the thesis.

Identity When Adapting to Disability: Becoming a Care-Receiver

“Experiencing chronic illness means much more than feeling physical distress, acknowledging symptoms and needing care. It includes metaphor and meaning, moral judgements and ethical dilemmas, identity questions and reconstruction of self, daily struggles and persistent troubles” (Charmaz, 2000, p. 277).

The first part of this chapter will consider previous theory and research on identity change for care-receivers after the onset of chronic illness or disability. Before introducing the literature, I will consider why disability impacts upon the Self and situate research to

date in the context of the change in conceptualisations of disability in society. The dominant narrative approach to identity in disability will then be introduced, followed by theory and research on self presentation, stigma and comparison. As each area of theory and research is introduced, the chapter will consider how taking a relational approach can enhance existing knowledge on disability identity.

Why Does Disability Impact on the Self?

The ways in which disability impacts on the Self are complex and multi-faceted. It is commonly assumed that illness and disability *cause* identity change. However, disability in itself is not a cause of identity change but a condition for it (Yeates, Gracey & McGrath, 2008). The Self is built up out of content: specific ideas about oneself and ones abilities, and thus how disability affects the Self varies with a person's pre-disability identity and the nature of their disability, that is, how it interacts with their existing identity. Thus, identities are not all equivalent. Instead, they are collections of ideas about the Self which have a logical structure. Thus it is not 'identity' which is upset by illness, but a belief such as 'I don't get sick' which is disrupted.

Despite differences between people in the experience of illness and disability and its impact on the Self, people generally wish to carve out a positive identity for themselves and strive to be perceived in a favourable light (Cadinu, Arcuri & Kodilja, 1993). This formation of a positive identity is made difficult by chronic illness and disability as physical, psychological, social, economic and work functioning may all be compromised (Livneh & Antonak, 2007). A loss of previous functioning can leave the Self vulnerable and fragmented. Key roles are now unable to be fulfilled, thus the content and logic of identity is disrupted. For many with disability, a return to work is impossible and thus a

belief about Self such as ‘I’m a hard worker, breadwinner and provider for my family’ is upset. A loss of roles as a result of disability leads to aspects of the Self to be lost.

Beyond the impact of role disruption, the way others perceive us is affected by illness and disability and this in turn affects the Self. In the case of ABI, disability is often hidden as there may be no physical signs of impairment, yet there are observable changes in behaviour. Reputation is affected as assumptions are made about the reasons for the person’s behaviour. These can be negative assumptions, such as that the person is ‘drunk’, ‘crazy’ or ‘on drugs’. When reputation is affected this is personally experienced as affecting the Self (James, 1890).

As mentioned above, illnesses and ensuing disability vary in many ways, such as in onset, be it congenital or acquired later in life; trajectory, an illness which an individual will eventually recover from versus a disability which can never be fully ameliorated; or whether a disability is overt or hidden. These differences will affect the way in which disability is incorporated into identity (Livneh & Antonak, 2007). As this research is based on the case of ABI, this chapter will only focus on identity in the case of acquired illness and disability from which a complete recovery is unlikely, as this most closely resembles ABI.

The Context of Disability Research: From the Medical Model to a Social Model of Disability

In order to orient to theory and research on identity after acquiring disability, it is necessary to first provide context to the ways in which cultural conceptualisations of disability have changed over time. The medical model of disability and associated discourse dominated until the late 1970’s. This model locates disability issues *within* the afflicted person (Oliver, 1996) and places emphasis on organic impairments and reliance on medical professionals for care or cure. The negative connotations associated with

dependence and medical conceptualisations of deficit residing within the person can have harmful effects on identity, and thus this model has been vehemently rejected by people with disabilities (Riddell & Watson, 2003). Disability rights groups have resisted these negative connotations and fought to manufacture an identity which is positive (Barton, 2001). This movement has developed a voice which challenges the assertion that disabled people are different from others in a negative way and emphasises independence, opportunity and pride (Barton, 2001; Barnes & Mercer, 2001). Campaigns for equal rights and opportunities have impacted upon legislation and have raised public consciousness of disability issues (Barnes & Mercer, 2001). As a result, the social model of disability emerged (Oliver, 1996). This model locates disability outside the person and places the emphasis on society. Disability is considered the result of societal oppression and disabling environments. Thus the emphasis moves from cure to transformation (Shakespeare, 2006) and places impetus on societal structures to remove the barriers holding disabled people back. Although thinking which is in line with the medical model has not disappeared, the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) has attempted to accommodate issues raised by the social campaign. In addition to a list of body structures and functions, the ICF incorporates domains of activity and participation, considering the impact of social and environmental factors, thus conceptualising illness and disability as more than deficits which reside 'within' the individual (World Health Organization, n.d.).

The social model of disability has been criticised for the problems created by its simplicity. For example, the model's emphasis is on disability residing entirely in society and not on impairment. This means that any attempts by medical staff to help treat an impairment shifts the emphasis away from removing barriers in the social environment and as such should be "treated with suspicion" (Shakespeare, 2006, p. 31). This model also

challenges the fact that there are different classifications of disability and asserts that all should be considered under the same umbrella. This implies the rejection of services focused upon a single impairment which undermines much of the good work that such services do (Shakespeare, 2006). However, the movement to a social conceptualisation of disability remains positive for the identity of disabled people and creating a society where those with disabilities are able to achieve full participation remains a critical and urgent challenge (Barton, 2001).

Approaches to Identity Research in Care-Recipients

A narrative approach to identity construction after the onset of disability

Identity is often constructed in the illness and disability literature as formed through narrative or biography (Bury, 1982; Lawton, 2003). A narrative is defined as a “story represented with language and other symbols, which meaningfully connects concrete events” (Nochi, 1998, p. 870). Narratives should be continuous and comprehensible to place Self in the world and provide meaning. Bury (1982) conceptualises chronic illness as “biographical disruption”. Disruption can occur when all that is taken for granted and rarely considered consciously is brought into sharp focus as the body does not behave in the expected way. Reappraisal of the way one conceptualises Self is required to deal with disruption and this reappraisal can involve stark alterations in a person’s biography. Disruption does not just occur at the level of Self but affects relationships. Bury discusses the case of arthritis where, “the erstwhile taken-for granted world of everyday life becomes a burden of conscious and deliberate action” (p. 176). As a result people may attempt to withdraw from social interaction and yet rely upon others physically, thus resulting in a “breach of norms of social reciprocity and mutual dependency” (Lawton, 2003, p. 26).

Bury's 1982 work sparked debate and much further research. Williams (1984) studied people at a further point from their diagnosis of arthritis. He used the term "narrative reconstruction" to depict the strategies utilised by people in making sense of their world whilst living with chronic illness. For a biography to be constant and coherent, events such as arthritis need to be incorporated into the life story in a meaningful and valid way (Lawton, 2003). Incorporating illness into the life story helps to "reconstitute and repair ruptures between body, self and world by linking and interpreting different aspects of biography in order to align present and past and self and society" (Williams, 1984, p. 197).

The notion of biographical disruption has gained a lot of support in the literature. However, some writers challenge this notion. Participants are often seen to speak positively rather than negatively about illness experiences (Silverman, Nutini, Musa, Schoenberg & Albert, 2009) and some chronic illnesses have been demonstrated to *reinforce* biographies rather than disrupting them, for example among haemophilic men who are diagnosed with HIV (Carricaburu & Pierret, 1995).

Alternatively disability can provide biographical continuity rather than disruption (Sanders, Donovan & Dieppe, 2002). Pound, Gompertz and Ebrahim (1998) found that rather than stroke being conceptualised as a 'life shattering' event in an elderly population, they instead found descriptions of stroke as 'not that bad', due to respondents having already navigated a difficult existence which had been filled with loss and ill health. Thus, the stroke represented just another challenge in participants' hard-earned lives (Cornwell, 1984). Therefore, the impact of illness on narrative and identity is not as simple as the biographical disruption model suggests. As mentioned earlier, identities are not all

equivalent, so illness can be seen as disruptive or reinforcing, positive or negative, depending on the content of identity.

The life narrative approach to the study of identity change and adaptation has been applied to the area of ABI (Nochi, 1998, 2000; Hinckley, 2006). As in other disabilities, there is evidence in the literature for positive life narrative adjustment and also of barriers to successful adjustment. Fraas and Calvert (2009) interviewed people in the medium to long term after ABI to assess the shared characteristics of those who were considered to have successfully adapted to their injury. Through their narratives, participants outlined four major themes in successful adaptation. These were a need for a strong social support network, ability to cope and manage emotions, taking part in activities which provided a sense of empowerment and accepting their new identity. Focusing on the last theme, a precursor to redefining the Self was acceptance of their brain injury. This is a difficult and emotional process which may take some time to be fully realised. The authors proposed that taking on a new identity requires “shedding one’s old skin” and participants reported having seen a change in themselves and subsequently accepted that they were “not who they used to be” (p. 322) and that they now had new roles to fulfil and alternative goals to strive for.

In looking at successful adaptation to aphasia, Hinckley (2006) described the most successful adjustment as coming from individuals who had “quest” narratives. A quest narrative relates to perception of the illness or disability as a journey, in which some kind of meaning is sought. Successful identity adaptation after aphasia is related to the acknowledgement that you become a different person who will live a different life. A new image of oneself must be created and accepted which is positive in outlook. However, this successful adjustment of life narratives may be difficult to achieve (Hinckley, 2006).

Cognitive deficits such as memory problems after ABI may exacerbate the interruption of life narrative and as a result a person's sense of who they are. According to a narrative approach, if a person cannot remember the past then this will impact negatively on identity as many people build up a sense of who they are from previous narratives (Nochi, 1998). Gaps in knowledge about the injury itself due to coma or post-traumatic amnesia will worsen the problem (Cloute, Mitchell & Yates, 2008). People are forced to fill in gaps in their narratives by the use of external information, such as objective information about their injury, hearsay, guesswork or the information provided by significant others (Nochi, 1998; Cloute et al., 2008).

Cloute et al. (2008) highlight that the information provided by significant others to fill in gaps in a narrative is significant in understanding identity adaptation in PwABI. However taking a relational approach assumes that the role of significant others in adjusting to disability is more than just filling in narrative gaps. Narrative approaches which study people at the individual level can miss the ways in which narratives are co-constructed. Negotiation within relationships, of roles and shared intersubjective meaning impacts upon adaptation of identity (Nochi, 1998, 2000), thus "sense making resources are embedded within social relationships" (Yeates, Henwood, Gracey & Evans, 2007, p. 153). The review of the narrative literature has revealed that disability poses a potential threat to narratives, and that creating a coherent narrative is important for identity adaptation after the onset of disability. Creating narratives after ABI is complex and may rely on relational sense making resources. This PhD research will add to existing theory and research by exploring the ways in which processes of relational sense making operate and the ways in which narratives are created within relationships after ABI.

Self presentation and the maintenance of a positive identity image

There is often a struggle to maintain a positive identity image in the face of chronic illness and disability. Self presentation refers to the case where, in any given social interaction where an actor comes before observers, the actor provides a 'performance' to give off expressions which will attempt to influence not only the definition of the situation the actor finds himself in, but also the impressions that the observers form of him (Goffman, 1959). Effective self presentation has the potential to buffer against the negative effects of disability on identity. A study by Sabat and Collins (1999) examined attempts to maintain self-esteem in those with Alzheimer's Disease (AD). They describe the "presented self" or persona as the way one displays their "point of view in the world" coupled with the "dynamic totality of personal attributes" (p. 18). This persona can be multiple and managed with different attributes brought to the fore depending on audience. The persona that is presented will be interpreted by others who will then place their own judgements of attributes onto the person. It is highlighted that in order to present a Self or aspect of Self, it is essential that there is cooperation with at least one other person. Past research has shown that those with AD will try to present former, more positive aspects of self via storytelling. The authors highlight the complex interplay within the AD sufferer between the negative attributes now believed to be held as a result of the disease and the former positive attributes that a person feels they once owned. A third set of beliefs about the inability to display former valued attributes due to the symptoms of the disease is also present in those with AD. To achieve the maintenance of valued identity and self-esteem, people first need to find another person with whom to construct a presented self. This 'other' must provide at least equal weight to positive and negative attributes and if possible downplay the current Alzheimer's related attributes. The problem with this is that the person with AD is vulnerable as they rely on the cooperation of others in this self

construction. Also others are often more likely to focus on defects related to AD and also to manage the person as patient rather than interact with them making construction of an identity-enhancing persona difficult (Sabat & Collins, 1999).

To take a relational approach to identity maintenance makes another aspect of self presentation visible. As Goffman (1959) notes, self presentation doesn't just rely on others to cooperate, it is often a joint performance. This is salient in the case of informal care. Krefting (1990) argues that there is conflict between the public and private performances of those with ABI. Only close carers are privy to the private performances of PwABI as they attempt and often fail to achieve even simple tasks. In brief public interactions with friends, family and acquaintances the PwABI can seem perfectly normal - even though it may take a great deal of effort to hide their disability in front of others. Carers can "perform" with care-receivers in public performances, by using subtle strategies with the person with brain injury to assist and augment their cognition (Gillespie, Moore, Murphy & Place, in prep.). Carers may conceal the amount of input required from them to assist the care-receiver to appear to be functioning well (Gillespie, Murphy & Place, 2010), co-creating the public image that the care-receiver is coping adequately. Self presentation operates at many levels, as even though care relationships co-perform together, there will also be self presentation dynamics between even the closest care-givers and care-receivers. The present research will explore self presentation within informal care relationships, between care-givers and care-receivers, and will also examine the strategies used to co-perform to others outside the relationship.

The impact of stigma on identity

When people engage in self presentation, they may be trying to avoid stigma. Stigma is an area which has received a great deal of attention in the literature. Stigma is a

frequent consequence of chronic illness and disability, described as referring to an attribute of a person that is “deeply discrediting” (Goffman, 1963, p. 13), a personal flaw. However, an attribute or personal characteristic itself is not enough to confer stigma. It is not the mark in and of itself that is discrediting but the individual that is discredited by the interpretation put on them (Spicker, 1984). Thus stigma is defined and perpetuated socially. Stigma renders an individual at risk both socially, in terms of being ostracised, and personally, in terms of experiencing feelings of shame and low self-esteem (Charmaz, 2000; Spicker, 1984). A person is separated as a result of difference and this difference becomes the defining feature of that individual with all alternative identities such as ‘mother’ and ‘academic’ being subsumed under a defining label, such as ‘disabled’ or ‘AIDS victim’ (Charmaz, 2000). Stigmatisation occurs in interaction and can be equally damaging whether perceived or real (Link, Struening, Rahav, Phelan & Nuttbrock, 1997). Feelings of shame, guilt and fear are powerful emotions which can last far longer than the stigmatising experience and can pervade even after a person has recovered from illness (Link et al., 1997). Experiences of stigma can change and emerge over the course of an illness, such as HIV (Alonzo & Reynolds, 1995).

“Enacted stigma dramatises difference and thus magnifies loss” (Charmaz, 2000, p. 285). These feelings of loss and shame will affect a person’s decision to disclose their illness and may lead people to utilise self-management strategies to try and cover up in order that their illness or disability does not become their total identity (Jones, 2006). An invisible disability affords a person a level of choice about disclosure. Normalising efforts and public displays may allow the person to conceal their condition, however, despite the ability to conceal, hidden disabilities bring their own problems in terms of stigma. For example, normalising displays may require huge effort and even cause set-backs in terms of health (Bury, 1982). With a hidden disability, people are judged in comparison to those

who are not disabled and anger may be cast their way if they are seen to be utilising resources such as disabled toilets (Charmaz, 2000). Those with a hidden disability can be accused of being lazy or shirking responsibility in the face of poor performance and experience “private doubts about what is real” (Charmaz, 2000, p. 285).

To take a relational approach to identity in disability it is necessary to consider the impact of stigma more widely, as significant others may be tarnished by the stigma of blame for another person’s illness/disability. Goffman (1963) introduced the concept of courtesy stigma, where a person may be tarnished by the stigma of another through association. Singh (2004) describes the blame which is conferred to parents of children with Attention Deficit/Hyperactivity Disorder (ADHD). Singh highlighted the “oppressive cultural ideology of the good mother” (p. 1204) and the need mothers had to medicalise their son’s behaviour to separate this from them and conceptualise the ADHD as something beyond their control. Gaining a diagnosis and treatment allowed mothers to transform their narratives from “mother-blame” to “brain-blame” (p. 1201). However, even with a medical diagnosis, mothers are often still stigmatised, considered by others in society as responsible for their child’s ADHD due to bad parenting, and the decision to use Ritalin to treat the ADHD is considered a ‘quick fix’ for problems which are socially oriented. This PhD will examine the ways in which stigma is dealt with at the level of the relationship after ABI, and how it impacts not only on the PwABI, but on care-givers also.

Comparison as a research method to explore identity after ABI

Comparing individual ratings of current and previous selves is another approach to identity research following injury or illness. Identity change after TBI has been highlighted by findings of a discrepancy between the way survivors of TBI view themselves currently compared with how they see Self pre-injury (Gracey et al., 2008). Current ratings of Self

after TBI differ markedly from and are more negative than ratings of both pre and future Self with a strong link between pre and future Self ratings suggesting a desire and expectation of a return to previous Self (Tyerman & Humphrey, 1984). A similar discrepancy exists between pre-injury and current Selves in a sample of post rehabilitation stroke survivors (Ellis-Hill & Horn, 2000). Ratings of current self were more negative on a number of dimensions including seeing themselves as less capable, interested, independent, in control, satisfied and active.

However, these studies only included own ratings of Self. Studies which took the ratings of relatives also showed differences between current ratings of the PwABI and ratings of the PwABI before injury. Personality in a population after severe blunt head trauma was seen to be changed in many cases and this was often perceived by significant others as a negative change, with reduced self-reliance, reduced sensitivity and increased irritability reported as soon as three months after injury (Brooks & McKinlay, 1983). Taking a relational approach highlights the importance of the perspectives of others, be these real or imagined, in creating a full picture of identity change after injury. In a qualitative study of personal constructs elicited through group exercises to examine pre-injury, current and ideal Selves in a TBI population, the most salient construct was that of “experience of self in the world”. This theme was more important to participants than either “basic skills” or “self in relation to self” (Gracey et al., 2008). This suggests that individuals understand themselves in terms of interaction with the social environment first and foremost. Previous research on self and other comparisons before and after injury has highlighted the ways in which both PwABI’s perspectives on self and relative’s perceptions are affected by ABI. This research will add to such studies by considering the perspectives of both PwABI and care-givers simultaneously to examine the alignment between perspectives on identity in informal care dyads.

Identity of Care-Givers Adapting to Caring for Someone With Illness and Disability

The above has focused on experiences of chronic illness and disability from the perspective of the person who is directly experiencing illness or disability and relational factors have been considered in terms of care-receiver identity. However, a regular consequence of acquiring disability is a need for informal care and support from significant others. As the role of care-receiver is created, so the role of care-giver is born. Therefore, it is also essential to assess the impact of illness and ensuing care on the identity of people close to those directly experiencing illness. This section of the chapter will examine disability and informal care from the perspective of those providing care. The literature focuses more heavily on experiences of care, be these positive or negative, rather than identity per se. Thus, this section will first introduce literature on experiences of care, both positive and negative before moving onto research into identity in informal carers. This section will consider the contribution of a relational approach to identity in carers.

The negative impact of providing care

Although there is considerable variability in outcomes for care-givers of PwABI (Carnes & Quinn, 2005), there tends to be a negative impact on health (Braun et al., 2009), subjective well-being (McPherson, Pentland & McNaughton, 2000) and quality of life (Greenwood, Mackenzie, Wilson & Cloud, 2009). In addition to the primary stressors arising directly from the needs of those being cared for, care-givers also experience secondary stressors such as significant subjective burden as a result of their role (Parker, 1990). Care-givers may even experience more distress than those they are caring for (Badr, Acitelli & Carmack-Taylor, 2007). Care-giver role-captivity leads to problems in social functioning with less reported engagement in leisure activities (Carnes & Quinn, 2005) and increases in depression and anxiety (Kreutzer, Gervasio & Camplair, 1994). One study

described the experience of being a carer as a “disintegration of one’s life” (Williams et al., 2009, p. 789).

Can care-giving ever be positive?

Despite the emphasis in the literature on the negative aspects of care-giving, some authors show that providing care to a loved one can be a positive experience from which people derive meaning (Lefebvre et al., 2008). Care-giving has even been shown to reduce mortality rates for those caring 14 hours a week or more (Brown et al., 2009). Marks (1998) found that care-giving can have positive effects on well being if role conflict is reduced. Other authors have highlighted that positive effects can arise from the care-giving process. Greenwood et al. (2009) conducted a qualitative study of care-givers of people who had experienced a stroke. Participants were interviewed three times over a three month period, beginning shortly after stroke onset. It was found that although uncertainty dominated, participants were able to talk positively about care-giving and the situation, in relative and absolute terms, particularly if they were experienced carers.

Role change and its impact on identity

There has been less research into the identity of care-givers than there has into the identity of care-receivers. However, several authors have examined the process of negotiating and reconstructing identity as one adapts to the role of informal carer. Much of the research has focused on roles and role changes. Becoming a carer is often described in terms of identity loss (Skaff & Pearlin, 1992), however, it could be argued that becoming a carer does not entail identity loss but the gaining of a new identity, that of carer. Role identity theory assumes that when an individual takes on a role, all the culturally and socially constructed norms of behaviour for that role are internalised. The combination of all the various social roles, such as wife, mother, psychologist, daughter, which are fielded by a person at any one time constitute the Self. Furthermore, self-esteem derives from the

ease with which a person is able to fulfil the various behaviours required for the different roles (Blumer, 1969). The organisation of modern society produces conflicting demands between roles which may lead to stress and burden. The caring role creates great conflict due to the time which must be devoted to caring. This results in a dramatic restructuring of other areas of life. Restructuring results in a narrowing of normal or pleasurable activities for the carer and has been described as leading to a “shrinkage of self” (Skaff & Pearlin, 1992, p. 656). The greater the engulfment of the caring role, as evidenced by reduced alternative roles and fewer external contacts with significant others in leisure pursuits, the greater the impact on the Self. However, although the carer role saturates the person who is ‘becoming carer’, it can be argued that the other roles and associated identities that the carer held before are not lost and the self is not ‘shrunk’. Previous roles and identities are still present but become layered with the new role of carer, and the various identities are in tension with each other. It can be argued that it is this tension between roles and their associated identity content which is negative for carers rather than taking on the caring role itself.

Considering care-giver identity from a relational standpoint

An important part of care-giver identity is likely to be their relationship to the care-receiver and as such the disability, the care-receiver, and their changed relationship with the care-receiver are all part of the carer’s identity transition. To take a relational approach makes these connections visible. Losing something loved is highly salient in the case of adapting to a new identity of care-giver (Skaff & Pearlin, 1992). Carers must adjust to the ambiguous loss associated with the person with disability still being present but radically altered (Landau & Hissett, 2008). This is particularly the case in ABI, when personality change and cognitive impairment can be a frequent outcome.

Adjustment to the new role of care-giver is particularly difficult in married partnerships (Thomsen, 1974). The adjustment to being married to someone who is at once both the person they married and a totally different person is hard for spousal carers to face. Examining identity in the context of relationships, Hayes, Boylstein and Zimmerman (2009) demonstrated that perceived identity change in a romantic partner with AD forced a change in identity for the care provider and that this affected marital intimacy in both positive and negative ways. Negative effects centred on the inability of the person with AD to reciprocate social intimacy and this led to a decline in physical intimacy. Female participants described their identity as 'spouse' as diminished and spoke of distancing themselves from defining the relationship as spousal due to the inability of their husband to reciprocate. Instead carers chose to view the relationship as more like that between parent and child as this was deemed less painful. However, despite this study displaying a clear theoretical stance of identity being constructed through interactions with others, only care-givers were included in the research. The present research will add to the picture, by including both care-receivers and care-givers in the methodology.

Carers see the relationship as an extension of themselves and seek to protect it

Another study examined the effects on care-givers of viewing Self as part of a couple and subsequently incorporating this relationship into self-concept (Badr et al, 2007). It was found that perceiving the relationship as an "extension of oneself" (p. 211) helped to reduce negative effects of identity disruption and actually increased the positive effects of care-giving on the psychological well-being of carers. From a symbolic interactionist viewpoint, Perry (2002) posits that spouses of those with a diagnosis of AD engage in "interpretive caring". This is described as a "complex cognitive, emotional and behavioural process through which wives operationalise their knowledge and understanding of their spouse, the disease process and themselves in order to maintain both

partners” (p. 310). After recognising changes in spousal behaviour and own behaviour as a result of change in the other, wives were found to compensate for the deteriorating abilities of the partner with AD. They assumed their husband’s responsibilities and took over their role as much as possible whilst still allowing their husbands to experience some sense of achievement by leaving to them tasks which wives judged them to be able to handle. In order to protect care-receiver’s identity and assist care-receivers to experience a sense of achievement and increased feelings of independence and confidence, carers may conceal the burden of care work they provide (Thomas, Morris & Harman, 2002; Gillespie et al., 2010), mask their emotional distress about caring (Farmer & Stucky-Ropp, 1996) or conceal knowledge about the diagnosis and symptoms of a disease such as AD (Hutchinson, Leger-Krall & Skodol Wilson, 1997).

The impact of concealment on recognition

Findings on taking on a care-receiver’s previous roles, as well as the care-giver’s own, and then concealing the burden of care raise issues for carer recognition. If the carer is concealing the burden of their caring role then they are unable to receive recognition for all that goes into being a carer - the physical work of caring, the effort expended in concealing this work and also the emotional work that goes into caring for a loved one who is not the person they were before (Lezak, 1988). A lack of recognition from others can impact negatively upon the way carers view themselves. As James wrote:

No more fiendish punishment could be devised, were such a thing physically possible, than that one should be turned loose in a society and remain absolutely unnoticed by all the members thereof. If no one turned around when we entered, answered when we spoke, or minded what we did, but if every person ‘cut us dead,’ and acted as if we were non-existent things, a kind of rage and impotent despair would long well up in us, from which the cruellest bodily torture would be a relief. (1890, p. 293-294)

We have esteem needs and these are met from the outside in (Maslow, 1943).

Recognition from others for what we do is essential for this sense of well-being (Laing,

1960). Thus, carer's difficulties in identity transition may be compounded if they choose to conceal the burden of care.

There has been much research into identity following the onset of illness and disability and the creation of roles of care-receiver and care-giver. Research in these areas has begun to highlight relational issues which are pertinent during the process of identity adaptation. The present research will add to existing relational study on identity after the onset of disability by using a dialogical approach to systematically assess the viewpoints of care-givers and care-receivers with ABI simultaneously to explore patterns of convergences and divergences of perspectives within relationships and their sources.

Identity is Constructed *Through* Relationships: A Dialogical Approach to Identity

This research will take a dialogical approach to identity adaptation in informal care relationships. This approach assumes that it is not enough to simply 'add' social factors, such as social support, to the individual as influencing variables in the formation of identity (Rogoff, 1998). A dialogical approach assumes that it is *through* social relationships and interactions that identity is constructed and negotiated. Theoretical support for this position comes from the work of theorists such as Mead, James and Bakhtin, culminating in the Theory of the Dialogical Self (Hermans, Kempen & Van Loon, 1992). The dialogical approach will be introduced and then the implications of taking this approach for research on identity after ABI are discussed, with particular attention to how research assuming a dialogical approach can contribute to the literature on adaptation of identity in informal care relationships.

Mead (1934) proposes that the way we view ourselves and construct our identity is influenced by our interactions with those around us in the social world. According to Mead, Self is a social structure and perception of Self first arises from the Selves of others,

so from the “outside in” (Mead, 1934). Consciousness of own Self is largely a reflection of others attitudes towards us. So for consciousness and a sense of Self to develop one must “become other”, and thus be able to take the stance of other towards oneself (Mead, 1934; Gillespie, 2005). As a result, what we think others think about us can have a strong impact on the way we not only perceive ourselves but ultimately how we behave (Whittaker, 2008). Not only does this consciousness develop through interactions with others but also through internal interactions or conversations with oneself and imaginary others (Mead, 1934).

This notion of internal dialogue leads on to the Theory of the Dialogical Self (Hermans et al., 1992). The Theory of the Dialogical Self draws upon the earlier work of James (1890) regarding the Self and Bakhtin’s (1973) theory of the polyphonic novel. James (1890) theorised a distinction between Self as known (or me) and Self as knower (or I).

The Self as known, which can also be termed the ‘Self as object’, includes not just one’s physical Self but also other people, objects and thoughts. Anything can be considered part of the Self providing that if this ‘thing’ is affected in any way it will be perceived as affecting the Self. For example, one’s reputation can be considered part of the Self so long as when reputation is affected (either via its elevation or demise) this is personally experienced as affecting the Self (either positively or negatively). Although a variety of people, objects and thoughts are incorporated in the Self, some will be more central to the Self than others. Various ‘Selves as known’ take on the form of ‘characters’ which may be in conflict with one another and must be chosen between.

The Self as knower or I on the other hand is highly flexible, as a thought within the stream of consciousness, which although different to those thoughts that have gone before,

relates to and is aware of everything prior and all that the prior thoughts possessed (me) forming an I-Me combination. This allows for continuing conflict and although any I-Me combination may be dominant there can at any one time be opposing thoughts. As Barresi (2002) highlights it is this I-Me distinction and relation alongside the plurality of Selves which was of interest to Hermans in constructing his theory. In Hermans' view there are different me's who can be provided with the chance to speak by being allocated an I (or I-position) to speak for them.

Bakhtin's (1973) conception of the polyphonic novel, which arose from his study of Dostoevsky has also majorly influenced the theory of the dialogical self. As Hermans et al. (1992) explicate, the notion of the polyphonic novel "expands on the narrative conception of the I as an author and the Me as an observed actor" (p. 28). According to Bakhtin, each utterance a person makes is 'double voiced'. Double voiced discourse "has a twofold direction - it is directed both toward the referential object of speech, as in ordinary discourse, and toward another's discourse, toward someone else's speech" (Bakhtin, 1973, p. 185) and is thus dialogical. A polyphony of voices arises from any individual being granted the ability to live in a number of worlds, each with an author telling a different story, largely autonomous from the authors and their corresponding stories in other worlds and no author maintains a privileged position (Barresi, 2002). As dialogue is at the core of all thought, the Self is an emergent entity rather than one that is provided (Hermans et al., 1992) thus this position also posits that the Self arises from interaction with others. The notion of Self as an emergent entity is a paradigmatically different assumption about the Self than that assumed by much of the literature presented in the first part of this chapter, which treated the Self as a stable, internal structure.

The theory of the dialogical self proposes that “self can be described in terms of a dynamic multiplicity of voiced positions in the landscape of the mind, intertwined as this mind is with the minds of other people” (Hermans, 2003, p. 90). A number of *I* positions can be held by any one individual, and these can be internal, such as *I* as academic, or external, relating to significant others, such as the position of father. These *I* positions reflect the number of different roles and thus different internal voices that can be held. The *I* fluctuates among different positions depending upon the situation and time and *I* positions may be in opposition to one another. The theory proposes that the individual has the ability to provide an internal voice to each *I* position which will create dialogical relations between voices (Hermans, 2001). Thus the Self is “spatially structured and embodied, populated by the voices of other people, decentralized with highly open boundaries, and historically and culturally contextualized” (Hermans, 2003, p. 90). This notion of the Self takes the potential for study of identity far beyond the boundaries of Self as an individual, stable, internal structure as much previous ABI literature has assumed.

Dialogical relations can take different forms and can be observed. Wertsch (1991) described the Bakhtinian process of ventriloquation where the voices of others, institutions and cultures are heard within the speech of an individual. Dialogical relations can also be revealed when a person speaks about another person’s viewpoint, mimics them or tells a story through which their voice can be heard. In chapter four of the thesis, the ways in which carers ventriloquate significant others and the impact of this ventriloquation on carer identity will be considered. Conflict between *I* positions can also be seen in more subtle ways, for example, tensions and hesitations in speech can highlight conflicting voices within the self.

A relational approach which elicits through talk the viewpoints of individuals on themselves and their partners, elicits the perceived viewpoint of others on the self, and compares this to the real views of others has the potential to elucidate dialogical relations within carers and PwABI, something which has not been done in the ABI literature before. It is this methodology which will be used in the present research.

What are the Implications of a Dialogical Approach for Informal Care Relationships Adapting to ABI?

What are the implications for identity adaptation in relationships to the roles of care-receiver and care-giver after ABI if we are to accept the notion of self as social and dialogical in nature? Communication is at the heart of how we all make and maintain relationships and communication skills have been demonstrated as major predictors of marital satisfaction (Braun et al., 2009). After ABI, people have been described as being able to talk but not necessarily communicate as the pragmatics of language may be impaired (Friedland & Miller, 1998). Therefore, the sudden onset of ABI may disrupt communication and this can have a substantial impact on relationships. In addition, we have seen that the ability to appropriately orient to the other is key to the formation and maintenance of identity (Mead, 1934). If individuals are not able to fully orient to the other then this has implications for identity as well as the relationship.

Adjustment of Care-Givers and Care-Recipients to the Perspective of the Other

The notion of intersubjectivity can be used to conceptualise adaptation following ABI. For a relationship to adapt there needs to be adjustment by both parties to the perspective of the other (Mead, 1934, Gillespie, 2006). Both parties must be able to take the role of the other for the exchange of meaning in social interaction (O'Toole & Dubin, 1968). Ongoing communicative feedback assists individuals in aligning their knowledge and beliefs about self and other (Pickering & Garrod, 2004). However, in the case of ABI

there may be incongruence between representations held on either side of the informal care relationship, as the very process of intersubjectivity is compromised as a result of the deficits experienced by those with ABI. Cognitive and communicative difficulties impair the ongoing feedback required for the process of constant repositioning of perspective. Therefore, carers may be relying on prior, but now outmoded, representations of their family member, thus convergence cannot occur. This in turn may lead to misunderstandings about the desires and/or requirements of the other, affecting perceived social support and understanding within the relationship, factors imperative to relationship satisfaction and feeling able to cope (Allen & Thompson, 1984; Lawrence et al., 2008). Lack of self-awareness in the person with ABI (Prigatano & Altman, 1990) and denial in family members may also further complicate the process of taking the perspective of the other (Romano, 1974).

Informal Care Relationships Experience Difficulties in Perspective Taking

It has been suggested that communication, cognition and self-awareness are key factors exacerbating the difficulties faced in perspective taking. Each will be considered briefly to ascertain its precise role in the perspective taking process.

Communication problems

PwABI have been shown to demonstrate problems with interactional features of conversation. For example, PwABI fail to initiate as much interaction, fail to use reinforcers during their partner's conversational turn and show less interest in their partner (Hartley, 1995). However, interactional problems do not just lie with PwABI. Interruptions in the pragmatics of conversation also come from carers. Carers have been shown to withhold feedback and miss opportunities for repair which lead to misunderstandings in conversation (Friedland & Miller, 1998). Significant others are also more likely to dismiss their partners' communicative efforts. Cloute et al. (2008) found that PwABI were

positioned as 'passive' in dialogue and without credibility. This is in line with previous findings in dementia study where Shakespeare and Clare (2005) found that people with a recent diagnosis of dementia were positioned as "less than full members" (p. 329) of interaction. Another dementia study by Sabat and Harré (1992) highlighted that significant others may marginalise prior and important facets of a person's Self whilst engaged in interaction, which can cause anguish for care-receivers.

Social cognitive deficits

Social cognitive impairments in the PwABI can often compound problems in taking the perspective of the other. Both the recognition and processing of perspectives on self and other may be reduced leading to inter-personal misunderstanding (Yeates et al., 2008). Specifically the recognition of basic emotions has been shown to be impaired after ABI (Henry et al., 2006). PwABI may have difficulty in recognising and interpreting both their own emotions and also the mental states of others (known as mentalizing or Theory of Mind) (Bowen et al., 2010). Where lesions in the orbitofrontal cortex occur, the ability to process emotional signals may be impaired, leading to difficulties in social decision making (Bechara, 2004). In addition, lack of expression is common in people with cognitive impairment and this has been shown to leave relatives 'uncertain' about the 'true' perspective of their partner towards them (Gosling & Oddy, 1999).

Self-awareness deficits

ABI theorists consider the presence of self-awareness deficits as a major source of problems in relationships adapting to ABI and as a barrier to taking the perspective of the other. Clare, Rowlands, Bruce, Surr and Downs (2008) define awareness in this context as "an accurate appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications" (p. 2367). Specifically, lack of awareness of deficits is often focused on the areas of cognition and interpersonal skills and patients frequently

demonstrate problems in self monitoring (Prigatano, Altman & O'Brien, 1990; Bogod, Mateer & Macdonald, 2003). Difficulty in identifying deficits is shown both in patients' self-reports and also their artistic expressions (Prigatano & Altman, 1990).

Deficits in self-awareness may cause conflict with family members, who may be seen by the injured individual as "overly protective or negative" (Ponsford, Sloan & Snow, 1995, p. 236). PwABI may need more directed communication and feedback which takes some of the pressure away from PwABI being able to make inferences about communication. However, family members have been shown to find it difficult to give the PwABI realistic feedback regarding changes (Ponsford et al., 1995).

Previous Research on Taking the Perspective of the Other in Care-Receiver and Care-Giver Relationships

Theory on intersubjectivity and perspective taking suggest that divergences of perspective will be common within informal care relationships. Indeed, divergent perspectives within informal care relationships have been found on a range of issues, including, the disability (Horowitz, Goodman & Reinhardt, 2004), risk (Heyman & Huckle, 1993), needs (Walters, Iliffe, See Tai & Orrell, 2000), stress (Robinson et al., 2007), health services (Noble & Douglas, 2004), and level of knowledge (Bar-Tal, Barnoy & Zisser, 2005). Disagreements about care-givers focus on their overprotectiveness (Ridley, 1989; Larson, 1998; Croteau & Le Dorze, 2006), embarrassment (Pot, Deeg, van Dyck & Jonker, 1998), independence (Gosling & Oddy, 1999), and confidence (Semple, 1992).

Disagreements do not just centre around care-givers. Personality changes, which may be pervasive, particularly in cases of severe injury (Brooks, 1984), can cause long-term problems for family and friends (Perlesz, Kinsella & Crowe, 1999) and lead to divergent perspectives on PwABI. Care-givers characterize PwABI as hostile (Kreutzer et

al., 1994), angry (Farmer & Stucky-Ropp, 1996), disinhibited (Brooks, 1984), child-like (Thomsen, 1974), irritable (Thomsen, 1984), self-centred (Farmer & Stucky-Ropp, 1996), passive (Yeates et al., 2007), and dependent (Ridley, 1989). However, the literature on informal care for PwABI has been criticised for neglecting the perspective of the people being cared for (Williams et al., 2009). Disagreements about care-receivers and care-givers were often reported by care-givers in studies assessing just one half of the informal care relationship rather than being elicited in studies which systematically assess disagreements on both sides of the care relationship simultaneously.

In a specific literature review of dyadic approaches to the study of care-giving in AD (Braun et al., 2009), it was found that the majority of studies focused either on care-provider or care-receiver with experiences and perspectives of the other half of the dyad only indirectly taken into account. Only five studies examined the dyad directly and none of these addressed identity issues. In ABI study, Yeates et al. (2007) addressed both PwABI and significant others' views in interviews to assess family contexts for awareness of disability. The study found incongruity in sense-making in family relationships, resulting in divergences in accounts within relationships. Gill et al. (2011) explored the views of 18 PwABI and their partners regarding intimacy. Using in-depth interviews, the authors highlighted both the barriers and facilitators to intimacy from both perspectives. Some key factors which facilitated intimacy were open communication and skills to cope and factors which hindered intimacy were found to be role conflict and communication problems. A study which systematically assessed identity on both sides of the care relationship was Gillespie et al. (2010) who explored the situation for people with aphasia after stroke and their care-givers. Gillespie et al. found that there were divergences of perspective on both sides of the relationship. This research discovered that there were divergences about how confident and independent care-givers and care-receivers were.

These divergences were due to the strategies used to navigate the dilemma of the care-receiver needing care but not wishing to appear to need care. Carers helped care-receivers to navigate the dilemma by protecting them, concealing the care they provided whilst simultaneously providing positive encouragement.

The Contribution of the Research

The research on identity in this thesis takes a dialogical approach, examining the perspectives of both care-giver and care-receiver simultaneously, and also what they each estimate that the other thinks (Gillespie & Cornish, 2010). This dialogical approach allows us to go beyond the research on identity change in relationships after ABI, advancing the field in two ways:

Critique One: Distinguishing disagreement from misunderstanding

First, research fails to distinguish disagreements from misunderstandings. Laing, Phillipson and Lee (1966) define disagreement as both parties having differing views on the same object. Misunderstanding is defined as one party attributing an incorrect view to the other party. Thus there can be disagreement with understanding (that is, there is awareness of the disagreement), or disagreement with misunderstanding (that is, there is a perception of agreement despite actual disagreement). Evidence suggests that disagreement itself is not problematic, but rather it is misunderstanding which can be problematic (Sillars, Koerner & Fitzpatrick, 2005). Accordingly, the first research aim is to map out both disagreements and misunderstandings to answer question *1a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding carer identity?* and question *2a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding PwABI identity?*

Critique Two: Divergences of perspective are considered to be detrimental and due to the PwABI, family therapy is advised

Second, divergences of perspective are considered relatively common in informal care relationships. The ABI literature contains an implicit assumption that it is the sequelae associated with brain injury, such as communicative, cognitive and self-awareness deficits which lead to divergences in perspectives in informal care relationships. However, relatives are also likely to be responsible for any observed divergences as they experience grief (Landau & Hissett, 2008) and need to come to terms with their radically altered roles, increased responsibility and the PwABI becoming dependent on them. Ponsford et al. (1995) note that family members may find it difficult to pinpoint or acknowledge that there are changes in their loved one and what these changes may be. Coming to terms for relatives is exacerbated by the frequent presence of depression and anxiety, along with high subjective burden (Perlesz et al., 1999). When divergences of perspective occur, these are sometimes assumed to be problematic and require therapeutic intervention (for example, Walls, Másson & Werner, 1977; Robinson et al., 2007; Cruice, Worrall, Hickson & Murison, 2005; Yeates et al., 2007). For example, Bowen, Yeates and Palmer (2010, p. 134) suggest bringing “all aggrieved groups to the table” in family therapy to “talk about what they each see as different in themselves and each other.” This relational intervention avoids viewing the problem as inherent in one of their members, thus allowing partners to blame the illness not the person with the illness. However, this approach still assumes that any divergence is problematic. Our dialogical approach assumes that divergences of perspective are sometimes deliberate creations, produced through self-presentation and even manipulation. In response to critique two, the second aim is to identify the sources of disagreements and misunderstandings to answer questions *1b and 2b: How can patterns of divergences be explained?*

Chapter Two – Cognitive and Practical Adaptation in Informal Care Relationships: Towards a Relational, Process Oriented Approach

Deficits in the ability to engage in goal-directed behaviour as a result of cognitive impairment make participation in ADLs difficult (Evans, 2003; Wood & McMillan, 2001). There are few effective treatments available for such deficits and external input is often required to help those with cognitive impairment to participate in ADLs (Evans, 2003; O’Neill, Moran & Gillespie, 2010). Care-givers are thought to provide such assistive input, using subtle strategies to augment care-receiver cognition (Gillespie et al., in prep; Shakespeare & Clare, 2005) with the aim of increasing participation and helping care-receivers to lead fuller lives (Mihailidis, Barbenel & Fernie, 2004). Although close informal care relationships are known to improve outcomes for care-receivers (Lyons, Sullivan, Ritvo & Coyne, 1995; Hinckley, 2006), we know little about the *processes* involved in the type of assistive and augmentative collaboration which occurs within informal care dyads adapting to ABI. This PhD research will provide detailed information on processes of collaboration by closely observing informal care partnerships interacting on joint tasks.

Chapter Outline

This chapter will emphasise the need to study *processes* of collaboration between care-givers and care-receivers with cognitive impairment in the achievement of everyday goals. This chapter will examine the theoretical background to the notion that cognition stretches beyond the realms of the individual and is an intrinsically social phenomenon (Rogoff, 1998). Literature will be presented that suggests that cognition is distributed both with media in the external environment, such as Assistive Technologies for Cognition (ATCs), and with other people (Clark & Chalmers, 1998). Previous research on the role of

distributed cognition in informal care relationships will be presented, paying particular attention to the strategies used when care-givers and care-receivers collaborate on ADLs.

The chapter will then move on to discuss the scaffolding metaphor. The scaffolding metaphor is regularly used to describe the type of assistance that experts provide to novices in the child development literature and has been applied to atypical child learners (Stone, 1998). However, this concept has gained relatively little attention in the clinical literature with atypical adult learners. The chapter will consider previous theory and research to assess whether the metaphor shows promise for use in an adult sample with cognitive impairment.

Previous research on collaboration and scaffolding has focused on relatively simple tasks. This chapter will also consider more complex tasks which are required to be completed after acquiring disability, such as filling in benefit claim forms to secure financial assistance to help with the costs of living with a disability. These forms are highly complex and completing them is a lengthy and stressful process (Banks and Lawrence, 2005). Collaboration on complex tasks, in particular applying for Disability Living Allowance (DLA), is considered in terms of implications for cognition and identity. The chapter will end with three critiques of the literature and four associated research questions which will be addressed by this PhD research. The research questions will be answered in chapters six and seven of the thesis.

The Sociocultural Approach to Distributed Cognition

Traditionally, psychologists have taken the individual as the basic unit of study and analysis (Rogoff, 1998). In particular, cognition is an area regularly studied at the individual level (Rogoff, 1998). Taking a relational approach to cognition, by considering social factors, provides a complementary approach to conceptualisations at the individual

level and can make visible different aspects of cognition; for example, the ways in which cognition is regularly distributed with objects and people in the physical and social environment (Clark & Chalmers, 1998).

One of the main goals of neuro-rehabilitation programmes is to increase independence (Barnes, 2003) with dependency regarded as an unfavourable outcome. However, achieving total independence after ABI may be an unrealistic goal (Williams & Robinson, 2001). Everyone is dependent to some extent on the objects and people around us (Rogoff, 1998) and positive interactions with others help us to derive our sense of self-worth (Williams & Robinson, 2001). In cases of illness or disability, the presence of family care-givers is essential for the smooth running of day-to-day life and family members not only help to compensate for physical, cognitive and communicative impairments but also provide a “safety net for compensatory strategies” (Lefebvre et al., 2008, p. 539).

Cognition can be Distributed with Artefacts in the External Environment

Humans tend to rely heavily on environmental supports. It has been suggested that the external media that humans rely on can link with the human organism to create a coupled system that is, in and of itself, a cognitive system which augments capabilities beyond those possible when the human organism acts alone (Clark & Chalmers, 1998). All components in the system, both internal and external, play an active and causal role and together they govern behaviour in a similar fashion to the way internal cognition does. Throughout history, cognition has relied on ‘technologies’ to assist and enhance functioning. This reliance on technology is ever increasing and with the possibilities that technological development holds, it could be said that we are moving towards an eventual “technological simulation of consciousness” (McLuhan, 1964, p. 3). As Wegner (1986)

noted, “we seem to record as much outside our minds as within them” (p. 187). This reliance on the external can be so simple that it is almost transparent, such as the use of one’s fingers to assist during a counting task (Wyndham & Saljo, 1999). Alternatively, reliance on technology may involve having a complex computerised assistant which not only provides alarms for when medication is to be taken but also provides step by step guidance on how to recognise the medication, what to take the medication with and how to prepare for the next dose (LoPresti, Mihailidis & Kirsch, 2004). The use of calendars and diaries is widespread and accepted within society without stigma. The commonality in these examples is that the brain carries out some operations, while the rest are delegated to manipulations of external artefacts. Most importantly, all these external media assist individuals in achieving everyday tasks (Clark & Chalmers, 1998).

If cognition can be distributed with ‘technologies’ outside the human body then this implies that cognitive deficits experienced as a result of illness, disability or ageing can be effectively compensated for to some extent using external media. Baltes’s (1987) theoretical work on life-span development stresses the role of compensation with declining cognitive capacity. He suggests that as individuals develop through the lifespan, there is the joint occurrence of gain (growth) and loss (decline). At no point in development is change related only to gains or losses (Baltes, 1987). With normal ageing the gain/loss ratio in adaptive capacity shifts towards a pattern of greater losses and fewer gains. Baltes and Baltes (1990) propose a general process of adaptation, selective optimisation with compensation, as a theory of successful aging. This model proposes that as individuals age, selection is required because a loss in the range of adaptive potential places increasing restrictions within a person’s existence to fewer domains of functioning. As a result, individuals must select domains of expertise that are high priority to focus on. People can then ‘optimise’, which involves directing energies towards behaviours which will

maximise the life course chosen at the selection stage. When abilities dip below the level required for functioning, the individual will turn to compensatory strategies such as ATCs or psychological compensation efforts from within the person, such as use of mnemonics (Baltes & Baltes, 1990). Compensatory strategies can be automatic and biological in nature and/or deliberate behavioural compensation strategies (Bäckman & Dixon, 1992).

This is a theory of development for a normal population, however, the theory has applications for those who experience cognitive impairment. With the assistance of carers and rehabilitation professionals, individuals can compensate for their cognitive deficits by distributing cognition with external artefacts. Domains of life that a person wishes to achieve mastery in can be chosen and both carers and appropriate technology can assist with compensation and mastery of these chosen life areas.

Assistive Technologies for Cognition can assist and augment cognition

One of the major ways of helping individuals with cognitive impairment to participate in the world around them is via the use of ATCs (also known as cognitive orthoses or cognitive prostheses) (LoPresti et al., 2004). An ATC should “act as a compensatory strategy for people with deficits in cognitive processing which, when added to the environment of the person, increases their capacity to function in an effective manner” (Alm et al., 2004, p. 118). As a result of this compensation, independence and psychosocial wellbeing should be increased (Wherton & Monk, 2008).

For all ATC interventions, the aim of compensation is achieved via devices that either partially take the place of the impaired ability or that translate the problem into something that can be approached using the client’s strengths (LoPresti et al., 2004). Ideas for how to develop an appropriate ATC have been suggested. For example, systems should be accessible to the user in terms of cost and ease of use (Gartland, 2004) and be able to be

tailored and thus personalised to the individual user (LoPresti et al., 2004). Cole (1999) provided a list of attributes that he deems necessary for a device to be called an ATC. These are (1) that the device is designed specifically for rehabilitation purposes; (2) that it directly assists the individual in performing some of their everyday activities; (3) is highly customisable to individual requirements; and (4) uses computer technology.

This last point is problematic. ATCs have been utilised for years and some of the simplest ATCs such as a pen and paper are among the most effective. It could be argued that one negative aspect of the development of assistive technologies since the 1980s has been the preoccupation with technology and the resultant complexity of devices. This is counter-intuitive when developing devices to assist someone who has cognitive deficits as complexity is something that should be avoided. Based on Alm et al.'s (2004) definition, computer technology is not always a requirement. Cole's (1999) list of attributes excludes a number of useful devices which meet the criteria for the above definition.

For example, Talking Mats, a low tech communication tool which will be used in this PhD research, involves a mat and graphical symbols. Talking Mats have been shown to effectively assist individuals with communication impairments to voice their requirements and preferences and increases ability to participate in interactions, thus assisting clients to function in a more effective manner in the communicative domain (Murphy, Gray & Cox, 2007). This could be considered an ATC under Alm et al.'s (2004) definition but not Cole's (1999). In fact it has been argued that technology such as Talking Mats are an effective means of assisting communication and thinking precisely because of their simplicity and ease of use (Murphy, 1998a). Talking Mats will be used in the present research to assist the process of data collection with participants.

It can be argued that functionality of devices should be the major aim in ATC development. The main reasons cited for effectiveness failures in ATCs is that they were too complex for users to master and required lengthy training programmes and instruction manuals filled with complex jargon (Bergman, 2002), were too expensive (Gartland, 2004) or were placing too many cognitive demands on users in working the device before they could attempt the task at hand (LoPresti et al., 2004; O'Neill & Gillespie, 2008). In fact, simplicity is the most important factor for many users, with many choosing more traditional aids such as calendars, watches and diaries over state of the art electronic aids (Gartland, 2004). The primary concern in the production of devices should be that the device reflects the requirements of its use, that is, what does the device need to assist the user to do and does it achieve this in the most effective way possible?

In summary, humans regularly distribute cognition with artefacts in the environment and the ATC industry has been developed to produce devices which facilitate this process and help to assist and augment cognition in those with disability. However, the ATC industry can be criticised for being at times pre-occupied with the technology it uses and must remain focused on the ultimate purpose, improving the ability of people with cognitive impairment to participate in daily life.

Cognition can be Distributed Socially

O'Neill and Gillespie (2008) have argued that rather than complex devices, it is people who are the best 'assistants for cognition'. The next section of this review will consider the distribution of cognition with other people, as it is distribution of cognition with other people which will be explored in this PhD research.

Distributing cognition with other people, especially those who are well known to a person, can elevate cognitive abilities beyond the realms of individual capabilities

(Wegner, 1986). For sociocultural theorists, the development of individual's cognition is "inherently involved with the sociocultural activities in which they engage with others in cultural practices and institutions, in a mutually constituting relationship" (Rogoff, 1998, p. 686). This implies that cognition is a process of active collaboration which requires a method of analysis which emphasises the achievement of shared thinking. Thus, the unit of analysis according to the sociocultural approach will not be the individual but the sociocultural activity (Rogoff, 1998).

If the sociocultural approach is adopted and cognition is seen as an active and collaborative process, not bounded within the individual but instead distributed with people and artefacts in the environment then what does this mean for relationships and in particular for relationships adapting to cognitive impairment?

A great deal of cognitive activities are shared with other people, or more importantly are performed in collaboration with others (Johansson, Andersson & Rönnerberg, 2005; Rogoff, 1998). In some cases this distribution may be equally shared, such as when collaborating on a joint research project (Arcidiacano, 2007), or in reciprocal peer interactions (Duran & Monereo, 2005). In other cases, such as after ABI, this distribution may be less equally shared. In his theory of transactive memory, Wegner (1986) discusses the notion of group mind, which involves the combination of individual memories and group communication. Each individual's memory can hold different information that when combined can demonstrate an impressive array of knowledge. The most successful transactive systems are formed when individuals within the group have a lot of knowledge about other group members' expertise. This could mean that all one person in a group needs to remember is the location of a piece of information rather than the information itself. For example Bob is in charge of social arrangements so he will

know the details about Jane's party. So for Sandra to be at the right party at the right time she does not need to know the details herself but just to know that Bob knows the details. Married couples are a partnership who have a great deal of shared knowledge about each other's expertise and areas of knowledge and thus should prosper in terms of collaborative remembering (Johansson et al., 2005). Couples may effectively distribute memories and knowledge within their partnership to lead to a whole that is greater than the sum of its parts, that is partnerships may outperform the two people individually. However, there are mixed results in research on whether collaborating in couples actually enhances task performance. One explanation for the less than impressive findings on couples collaborative remembering is that many laboratory studies use artificial tasks and this may explain the mixed results found. For example, Johansson et al. (2005) used arbitrary semantic memory tasks which did not reflect the day to day distributions of memory that couples are likely to make.

Distributed cognition and informal care relationships

If cognition is distributed with other people in equal relationships leading to enhanced cognitive functioning of individuals then this suggests that in relationships which are less equal, such as those between expert and novice, cognition can be enhanced by input from experts (O'Neill & Gillespie, 2008). This has implications for relationships that are affected by cognitive impairment, as cognitive deficits/decline may be effectively compensated for through assistance from other people. According to Alm et al. (2004), the role of assistive technology is to "act as a compensatory strategy...that increases capacity to function in an effective manner" (p. 118). Thus, on the basis of this definition, carers can be considered to be assistants for cognition, as O'Neill and Gillespie (2008) have argued.

We know that caring relationships enable people to carry out everyday tasks (Mihailidis et al., 2004) and that input from carers has been related to positive outcomes for those with ABI (Lyons et al., 1995). However, outcome oriented research has been favoured over process oriented research. Consequently there is little empirical information about the ways in which collaboration between care-giver and care-receiver facilitates successful participation in and completion of ADLs, and the specific ways in which carers act as assistants for cognition at the microgenetic level. Information is required on the strategies that care-givers and care-receivers use when collaborating to achieve everyday tasks (O'Neill & Gillespie, 1998) and this has the potential to be useful for relationships currently adapting to a brain injury.

What strategies do informal care partnerships use?

The type of strategies used in informal care relationships can be classified into emotional coping strategies or behavioural coping strategies. Emotional coping strategies have been the focus of research to date and comparatively little attention has been paid to the concrete, behavioural strategies that care-givers and care-receivers employ when adapting to cognitive impairment (Gitlin et al., 2002). Studies which have addressed behavioural strategies are presented below.

McCluskey (2000) looked at the strategies used by paid carers of those with Traumatic Brain Injury. Although this sample is of formal carers rather than informal carers, 60% of the carers had never worked in care prior to their current employment and thus the results demonstrate the instinctual use of strategies by those providing care. The first strategy used was to modify the external environment to assist those they cared for. If an action was to be learned, strategies used were encouraging practice and repetition of a new skill, progressing the skill and using incentives and rewards. Other strategies that were

used by the paid carers were active listening, offering guidance, supporting and encouraging, setting rules and limits without being too controlling or domineering, and managing conflict and difficult behaviour. Although useful indicators of the types of input carers provide, these strategies were self-reported during interviews so were not actually observed to take place in interaction in this study.

Gitlin et al. (2002) developed the Task Management Strategy Index (TMSI) on the basis of behavioural observations, clinical techniques and theory on the ecology of ageing. The TMSI was operationalised to establish the sort of behavioural actions that carers use in interaction with care-receivers with AD when assisting them to complete ADLs. When using the TMSI, the authors found that carers self-reported regular use of strategies to assist partners to complete ADLs. Across the 202 carers surveyed, a mean of 10.5 strategies were reported to be used during ADLs either sometimes, often or always and the type of strategies used were more frequently positive facilitative strategies than negative, criticism-oriented strategies. The type of strategies used involved modifying the external environment to assist care-receivers engagement in the ADL, such as using labels or pictures to identify objects in rooms, simplifying the task by laying items out in the order in which they are to be used, or putting items in a prominent place where care-receivers are likely to notice them; or guiding care-receivers throughout the task, such as providing continuous instruction, prompting and demonstrating the correct way to execute actions. However, this study only examined the strategies that carers used, not care-receivers, and strategies were self-reported, not observed.

More detailed information on strategies used in interaction comes from observation of dyads engaging with one another during completion of tasks. There are very few instances in the literature on care where both the carer and cared for are considered

together, as much of the qualitative literature is based on interviews of experiences either of care-giving and care-receiving (see Brown, Lyons & Rose, 2006; Strandberg, 2009; Jumisko, Lexell & Soderberg, 2007; Chaffey & Fossey, 2004). However, to gain information on processes of collaboration, both care-givers and care-receivers must be studied together. One paper on communicative strategies in dyads where one person has aphasia (Simmons-Mackie & Kagan, 1999) and two papers from the dementia literature are worthy of examining in greater detail as all three examined both care-givers and care-receivers simultaneously. The dementia studies are a coping study by Oyebode, Motala, Hardy and Oliver (2009) and an observation study of talk between informal care dyads (Clare and Shakespeare, 2004; Shakespeare and Clare, 2005).

Observation of dyadic interaction where one person has aphasia provides information on communicative strategies used in talk. In research by Simmons-Mackie and Kagan (1999) conversational partners interacting with those with aphasia were categorised as either 'good' or 'bad' interaction partners. Those deemed to be 'good' interaction partners showed patterns of talk which were demonstrated much less in the discourse of those termed 'bad' communication partners. Conversation analysis revealed that good communication partners used acknowledgement tokens which demonstrated receipt of contributions, congruent overlap, accommodation to nonstandard methods of interaction (such as the use of the thumbs up sign to signal agreement) and clarification sequences that were 'face saving' for the person with aphasia. Positive communication strategies are an important precursor to effective enablement of everyday tasks so taking into account the strategies used in conversation is important in an examination of strategies used to enable people to carry out everyday activities.

In the first dementia study by Oyebode et al. (2009), the authors originally set out just to observe coping strategies in individuals with AD when completing tasks. Tasks included recalling a telephone number, naming people in photos and stating where items are to be kept in a kitchen. However, it was acknowledged that gaining assistance from a carer was itself a valid coping strategy, and so participants were told that they could invite their carer to stay whilst they carried out the tasks if they wished. Only two of the 24 participants declined carer presence. In fact the coping strategy of seeking help from a carer during a task was used in the first instance (before even expending effort oneself) in ten of the 24 participants. This study therefore highlights the reliance of those with cognitive difficulties on those that care for them in the achievement of everyday tasks. Strategies that those with AD employed were turning to the carer, asking the carer for a prompt or clue or checking for a response. However, the study did not provide detail on whether the strategies that those with AD employed differed if they relied on the carer at the outset or later if they had tried and failed at the task. Nor does the article give any qualitative information on the type of help that carers gave when called upon for assistance.

In the other dementia study, Shakespeare and Clare (2005; Clare & Shakespeare, 2004) explored talk between those with a recent diagnosis of dementia and a close partner in a five minute task. The authors employed analysis of occasioned talk, that is talk which is “tied to, and facilitates, a specific defined activity” (Shakespeare & Clare, 2005, p. 328). The task was to discuss as a pair and come up with a brief statement or sentence that summed up their present situation. Qualitative analysis revealed that the carer “exercises more interactional rights in terms of topic management in the work of bringing off the task than those with dementia” (p. 333). They liken the role of the carer to that of ‘teacher’, an organising and directing role which employs questioning as a major technique to forward

the interaction. They found that carers placed restrictions on certain areas of conversation, evidenced by the repairs carers made on what were considered to be inappropriate responses to the task. Carers were also seen to regulate emotion, steering their partners away from content the carer judged to be distressing. Carers also spent a lot of time reassuring their partners. The authors describe their participants with dementia as being viewed as “less than full members of the interaction” (p. 329), who are struggling to be heard and as attempting to assert the interactional rights that a full member would have. The authors comment in their discussion that the occasioned talk they saw could be construed as a form of scaffolding but this was not one of their research questions.

It would seem from the information presented above on interactions between care-givers and care-receivers, that care-givers self-report and are observed utilising strategies to assist and augment partner cognition. Carers use physical, emotional, cognitive and communicative strategies to assist care-receivers to complete tasks successfully. Carers frequently take control of tasks and adapt them to make them easier for care-receivers to engage with, such as modifying the environment by organising the items required to complete a task (such as making a cup of tea) so that they are prominent, are arranged in the order that they are needed, and by removing distracting items which will not assist with the task. Carers assist engagement in tasks by breaking tasks down into smaller, more manageable chunks or steps. Carers also facilitate engagement by using strategies such as providing ongoing verbal support through tasks, through prompting, rephrasing or repeating instructions, and by providing emotional support, such as controlling frustration, keeping care-receivers motivated and providing reassurance and encouragement. It would also appear from the research by Oyeboode et al. (2009) that carers are seen as a useful assistive resource by care-receivers who seek out carers when they are uncertain about an aspect of a task. However, there is a risk that care-receivers may be positioned as “less

than full members” of occasioned interactions (Shakespeare & Clare, 2005, p.329). An analysis of strategies used in interaction on a joint task by informal care dyads adapting to ABI and consideration of how these strategies position care-receivers and care-givers will be presented in chapter six of the thesis.

What Constitutes Scaffolding During Collaboration Between Expert and Novice?

The child development literature provides information on collaboration which occurs when one person has greater knowledge and skills than another person. There is a rich history of research on the concept of scaffolding, a specific technique where experts provide flexible support to a novice to help them achieve a task that is too difficult for the novice to achieve alone (Wood, Bruner & Ross, 1976). Scaffolding appears to be a fairly natural yet pervasive process between parents and their children and clear links have been shown between scaffolding and school competence (Mattanah, Pratt, Cowan & Cowan, 2005). Observation studies have demonstrated some of the techniques that parents use when scaffolding their children. Examples include presenting procedures in the format of steps, providing complete and coherent task information and motivation through praise (Stright, Herr & Neitzel, 2009). Differences in techniques depending on culture have also been demonstrated with autonomous cultures emphasising the goal of increased independence and cultures where a key feature is compliance providing more directive instruction (Stright et al., 2009).

Scaffolding is defined by three key features. Firstly, scaffolding is defined by the type of strategies used. Wood et al. (1976) outlined the key roles that the tutor must fulfil in order to effectively scaffold the child. Experts must evoke interest in the tutor-defined task, simplifying the task in some fashion, often by lessening the number of steps required; keeping as primary focus the pursuit of the goal, through sustained motivation and

direction; highlighting the important differences between the ideal solution and what the child has produced; controlling frustration; and at times demonstrating correct execution of the task at hand. The second feature of scaffolding is its flexibility. Parents have been found to adjust their support of children's efforts depending on skill level (Wood et al., 1976; Rogoff, 1998). The contingent-shift principle or patterns of providing more specific instructions to the child when the child was failing at a task and less specific instructions in periods of mastery have been observed, thus allowing for independent operating whilst at the same time ensuring child success (Mattanah et al., 2005; Rogoff, 1998). Thirdly, the scaffolding metaphor implies the gradual removal of supports as mastery is achieved (Wood et al., 1976; Stone, 1998; Pea, 2004).

Although widely accepted, the concept of scaffolding has not been without its criticisms. Within the concept of scaffolding the focus is on what experts provide for novices (Rogoff, 1998). Scaffolding has often been linked in research to the Zone of Proximal Development (ZPD) (Vygotsky, 1978) with the suggestion that scaffolding within the ZPD will lead to optimal learning in children. However, this approach has been criticised due to the different units of analysis involved in these two concepts (Rogoff, 1998). According to Rogoff (1998), scaffolding ultimately examines the effect of what the expert did with less emphasis on the novice's contribution. The child's contribution is often reduced to whether an appropriate response was provided to a period of scaffolding or not. This results in individual analysis. On the other hand, Vygotsky and Luria (1994) propose a much more active role of the child in collaborative activity, whereby the child engages in "socializing his practical thinking by sharing his action with another person" (p. 117). Learning is achieved through the transfer of responsibility for achieving whatever goal is current within the ZPD (Belmont, 1989). The notion of the ZPD is much more

collaborative which lends itself to a more dialogical analysis of what both the novice and the expert contribute to shared enterprise (Rogoff, 1998).

Conversely, other critics have argued that studies of scaffolding have emphasised the active collaboration required from both expert and novice in achieving goals and the marriage of the scaffolding metaphor and the theory behind the ZPD has elucidated the cognitive and conceptual restructuring that occurs after scaffolding as opposed to just the learning of individual concepts or procedures (Stone, 1998). Stone argues that the scaffolding metaphor does not portray the “adult as moulder of passive child... but instead that the child is actively involved in the ‘continuing cycle of communicational tension and resolution’” (p. 354).

Do Care-Givers Scaffold Care-Recipients with Cognitive Impairment?

Evidence for scaffolding between carers and those with learning disabilities

A major theoretical question that should be asked is: Do carers scaffold those they care for? There is suggestion that the notion of scaffolding may be appropriate for use with atypical learners (Stone, 1998) but this is rarely studied in adults. The results that are currently available in the field of learning disabilities suggest that parents of children with atypical learning trajectories are not providing the most effective scaffolding in these instances (Stone, 1998). Preliminary findings suggest that where the child has a learning disability or behaviour problems, the maternal strategies employed in interaction do not bear the hallmarks of successful expert-novice interaction (Stone, 1998; Gardner, 1994). In a study by Levine (1993) mothers were not seen to make sufficient links between the overall goal of a task and the smaller steps that were required to achieve this end goal, nor to relate the task to other contextually or procedurally similar endeavours. In another study (Wertsch & Sammarco, 1985), parents of children with receptive language disorders often provided assistance in an arranging task for a shorter time than mothers of normally

developing children, before placing items themselves. However, it is important to note that the findings of the above studies are correlational, therefore causality cannot be inferred. In his analysis of scaffolding studies in the field of learning disabilities, Stone (1998) highlights that there needs to be more information gained on *how* significant others scaffold (or fail to scaffold) the performance of those they care for. This suggests the need for more studies on processes of collaboration, providing rich information on scaffolding interactions (O'Neill & Gillespie, 2008).

Evidence for scaffolding in adult samples with cognitive impairment?

Curran (2004) found that verbal, step-by-step scaffolding assisted people with stroke to perform novel tasks more successfully than matched stroke survivors who were not scaffolded through the performance of the novel tasks. However, outside the literature on child interaction, research like that by Curran (2004), which explicitly addresses the question of scaffolding is rare.

To address the question of whether the support that is provided during interaction between adult care-receivers and care-givers adapting to cognitive impairment can be termed scaffolding, we must return to the research on strategies which was presented earlier in the chapter. In terms of carer support, there is some evidence that common strategies which are comparable to those outlined by Wood et al. (1976) are used by care-givers interacting with care-receivers. For example, care-givers manage tasks, simplifying them for care-receivers and care-givers spend a lot of time motivating and controlling the emotions of care-receivers (Gitlin et al., 2002; Shakespeare & Clare, 2005; McCluskey, 2000).

There is a suggestion that the use of strategies is flexible. Gitlin et al. (2002) found that greater use of strategies to assist care-receivers was found where there were greater

deficits in people with AD's ability to participate in ADLs. In another study of individuals with AD, carers were found to adjust their level of assistance depending on the severity of AD and thus how much the care-receiver was able to input to a task independently. A greater number of carers in the moderate AD category provided a greater number of task assistive responses than carers of those with milder dementia (Oyebode et al., 2009). As well as being flexible, use of strategies in supporting those with cognitive impairment is considered instinctual (McCluskey, 2000).

There is a limitation to the extension of the scaffolding metaphor to adult care relationships and that is a potential divergence between the type of scaffolding that parents provide to children compared to that which carers provide to adults with cognitive impairment and this centres on the third feature of scaffolding, gradual removal of supports. Capacity for learning is affected by cognitive impairment. Damage to the frontal lobe in particular can affect the "control of the most complex forms of man's goal linked activity" (Luria, 1973, p. 188), impairing the ability to plan, initiate and complete tasks. As well as planning and execution, frontal lobe damage may lead to impairments in the ability to internalise actions initiated by spoken commands, thus the ability to learn via scaffolding may be reduced (Luria, 1973). Luria (1973) cites evidence of PwABI with frontal lobe injury being able to carry out instructions correctly for a short time only and he found that over the longer term, instructed complex behaviour tends to be replaced by simpler, more basic behaviours. Difficulties in successfully utilising inner speech may also be implicated in the internalisation difficulties of PwABI with frontal lobe damage. If carers are scaffolding care-receivers then this brings about the notion of eventual removing of supports when mastery is achieved and independent task mastery may not be possible. In addition, engaging regularly in scaffolding interactions with no hope of removal of supports can be detrimental to relationships. Scaffolding risks positioning care-receivers as

dependent and child-like (Proot, Crebolder, Abu-Saad, Macor & Ter Meulen, 2000). The experience of scaffolding may be intrusive for care-receivers and can be exhausting and frustrating for carers (Proot et al., 2000).

Can a failure to meet the criteria of removal of supports render the scaffolding metaphor inapplicable to an adult sample with cognitive impairment? Perhaps support can better be described as compensatory. Compensation can be a more long term strategy which does not necessarily imply learning and is the focus of the assistive technology literature. If someone has a device which fits easily in to their life and helps them to achieve an everyday activity then this does not need to be abandoned at any point. It just becomes part of what a person needs to function, just as one needs arms, legs or sight. A distinction between social and technological distribution of cognition is made by Pea (2004) in terms of supports for the process of learning. Pea proposes that at a young age the social axis is more relevant and that this is later built upon with the technological axis. He goes on to suggest that scaffolding is only truly scaffolding if there is ‘fading’ of support, otherwise this is just distributed cognition. This appears to be an argument surrounding labels. If people are able to achieve what they set out to then whether this is labelled distributed cognition, compensation or scaffolding may be immaterial. However, it is important to distinguish between scaffolding and more general guidance (Stone, 2002). To be classified as scaffolding, support must include the particular features outlined above by Wood et al. (1976) and must involve tailored and subtly changing support depending on deficit type and level and increasing task mastery. The scaffolding metaphor will be considered in detail in chapter six of the thesis, on the basis of the data gathered during the planning inviting a friend or relative around for a meal task.

Collaboration on More Complex Tasks: Disability Benefit Claim Forms

What research there is on collaboration between care-givers and care-receivers has focused on relatively simple, artificial tasks. Yet the reality for many adapting to cognitive impairment is that input will be required on more complex tasks also, for example, when completing forms.

Financial burden is a major issue for families adapting to ABI. When faced with a disabling condition many have to give up work or significantly reduce their hours. One study has reported that as few as 41% of people who sustained an ABI are found to be in work two years post injury (Van Velzen, Van Bennekom, Edelaar, Sluiter & Frings-Dresen, 2009). As well as PwABI's reduced capacity for work, carers may also be required to reduce their working hours or stop work altogether in order to assume a caring role (Carers UK, 2007). Only three in ten carers who cared for more than 50 hours a week were in paid employment according to 2001 census figures (Arksey, Kemp, Glendinning, Kotchetkova & Tozer, 2005). Medical costs and costs associated with adaptations or changes which are needed to make the home accessible can place an extreme financial burden on individuals and families. As a result, families adapting to ABI often cite finances as a major source of stress and worry (Jacobs, 1988). As a result of financial hardship many are forced to apply for benefits such as Attendance Allowance (AA) or Disability Living Allowance (DLA).

However, the process of applying for benefits is lengthy and involves filling in long and complex forms. This research will focus on DLA benefit. DLA is a non-taxable, non-means tested benefit for children and adults who need help with personal care or who have mobility problems. Attention has been paid in the literature to experiences of stigma and loss of self-esteem through the *receipt* of social services (Spicker, 1984). However, it

can be argued that even attempts to access these services may have a negative impact on those applying. In one study the DLA claim form was described as “time consuming, complex and stressful and in some cases respondents cited the system as a factor exacerbating the seriousness of their health condition” (Salway, Platt, Harriss & Chowbey, 2007, p. 924). Receipt of benefits may increase people’s sense of legitimacy. However, the system is considered unpredictable in terms of who would be successful in receiving benefits. Rejection can have a negative impact in terms of confidence in the legitimacy of their claim. Take up of benefit increases with the amount of entitlement (Pudney, Hancock & Sutherland, 2006). This suggests that perceived ‘costs’ of claiming in terms of time, effort, information needs, ‘hassle’ and stigma are weighed up against potential monetary gains.

At 55 pages long, the DLA form is complex to fill in with any impairment but for those with cognitive deficits, such as after ABI, this task would be difficult for many without the assistance of another person. A study examining the experience of applying for DLA in Scotland showed that 97% of 606 respondents found the form difficult to fill in (Banks & Lawrence, 2005). Many turn to those who they know well to help them fill in the form. However, although applying for DLA has been described as complex, no study to date has examined the process of carers assisting care-receivers to fill in this complex form. Thus, little is known about the type of collaboration used by care-givers and care-receivers when applying for DLA. Will collaboration be similar to previously documented tasks? Or will the complexity of the form put the task outwith the ZPD of care-receivers? If the task is too complex, this may affect PwABI’s ability to contribute to the process and the type of assistance that carers provide will be affected also.

Implications of collaboration to complete claim forms go beyond cognition to identity issues

The implications of collaboration on a task such as completing the DLA form go beyond issues of distributed cognition and assistive and augmentative collaboration. There are implications for self-esteem and identity. The DLA form task differs from other tasks which have been reported in the literature. The role of carer assistance often aims to be enabling, assisting care-receivers to complete tasks and increasing feelings of independence and self-esteem (McCluskey, 2000; Gitlin et al., 2002). However, the language of the DLA form is focused on deficit with questions such as ‘Do you often fall or stumble when moving around indoors?’ and ‘Do you usually have difficulty or need help getting out of bed in the morning or getting into bed at night?’ Asking a person to reflect upon their shortcomings and perceived failings could have a negative impact on individuals, especially if they must do this in front of significant others. In order to receive benefits, people are required to go into the details of their disability. Thus, the form encourages disability rather than encouraging people to think about the ways in which they are enabled. The desire to think positively about oneself may lead an individual to try to self-present as more capable than they are (Goffman, 1959). However, due to the low rates of receipt of benefits and when facing financial hardship, people are forced to emphasise any impairments they have in order to increase their chance of receiving benefits. We also know that both family members and PwABI are known to cope via denial of disability (Ponsford et al., 1995). Denial can have benefits for families as it helps to provide an emotional buffer when adapting to changes which have taken place as a result of ABI (Ponsford et al., 1995). The process of addressing disability for the form would undermine this coping strategy.

In this PhD research the process of collaboration between carers and PwABI when completing the DLA form will be observed to examine processes of collaboration and their implications for both cognition and identity. Findings will be presented in chapter seven of the thesis.

The Present Research

In order to study cognitive and practical adaptation following ABI the research will take a sociocultural standpoint which sees cognition as created and distributed within social relations, rather than as an individual phenomenon. Adopting a sociocultural stance has two major implications for the way that adaptation following ABI should be studied. Firstly, this approach means that examination of cognitive and practical adaptation should be at the level of the relationship, thus *dyads* should be studied. Secondly, emphasis is placed on *process* rather than product. In terms of collaboration then the question is not if individuals engage or even when. Instead the question is *how* do people collaborate in order to achieve adaptive end goals? (Rogoff, 1998). Thus, microgenetic processes of collaboration will be studied. This approach can complement more traditional outcome oriented approaches.

The Contribution of the Research

This PhD research will study cognitive and practical adaptation in informal care relationships following ABI by video recording informal care dyads taking part in two joint tasks, (1) planning inviting a friend or relative round for a meal and (2) completing part of the DLA claim form, advancing the field in three ways:

Critique one: Previous research has focused on outcomes and under-emphasised processes

So much research is outcome focused. We know that care relationships improve quality of life for PwABI (Hinckley, 2006; Lyons et al., 1995) but we don't know enough

about how. There is not enough information on the processes by which informal care relationships adapt, both cognitively and practically. Carers are the ultimate assistants for cognition and they are an untapped resource. More information is needed about the strategies used by informal care relationships when engaging in ADLs (O'Neill & Gillespie, 2008). Information on strategies used on both sides of the relationship could benefit relationships currently adapting to cognitive impairment through improvement of information for care-givers and care-receivers. Also information on strategies can be used when designing ATCs which simulate carer input as these devices have the potential to reduce reliance of people with cognitive impairment on their carers, increasing care-receiver independence and simultaneously reducing care-giver burden (O'Neill & Gillespie, 2008; O'Neill et al., 2010). Accordingly, the third research aim is to map collaboration in informal care dyads when engaging in a joint task to answer question 3a: *What strategies do carers and PwABI use in collaboration on a joint task?*

Critique two: The scaffolding metaphor has not been considered for its applicability to atypical adult learners

The child development literature is replete with examples of the ways parents scaffold their children, but not enough attention has been paid to the potential of the scaffolding metaphor to enhance theoretical discussion surrounding informal care in relationships where one person has sustained cognitive impairment. Accordingly, the fourth research aim is to consider the applicability of the scaffolding metaphor for a cognitively impaired adult sample to answer question 3b: *Is the type of input provided by carers on the joint task comparable to scaffolding as described in the child development literature?*

Critique three: Research uses simple, artificial tasks to assess joint activity

PwABI are regularly asked to fill in complex forms in order to secure financial assistance to help with the costs of living with a disability. It has been suggested that the process of filling in such forms is difficult and stressful (Banks & Lawrence, 2005; Salway et al., 2007). It is thought that many people must seek assistance from others to fill in the form due to its complexity but no study to date has examined the process of filling the form in. Accordingly, the fifth research aim is to observe the process informal care dyads go through when filling in the DLA claim form to answer question *4a: What happens when carers and PwABI collaborate to fill in the Disability Living Allowance (DLA) claim form?* When answering this question, analysis revealed a striking number of disagreements in dyads when completing the form. This finding led to a final research question to be addressed, question *4b: Why do carers see more disability than PwABI when filling in the DLA form?*

Chapter Three – Methodology

This thesis comprises four pairs of questions. Questions 1a & 1b and 2a & 2b were presented at the end of chapter one and questions 3a & 3b and 4a & 4b were presented at the end of chapter two. Each of these questions is answered by four mixed methods data sets and analyses which map quantitatively and qualitatively the relational patterns of identity and cognitive/practical adaptation in 28 informal care dyads following ABI. The methods chosen facilitate the examination of *processes* of adaptation.

To answer questions *1a: Are there any disagreements and/or misunderstandings between carers and people with Acquired Brain Injury (PwABI) regarding carer identity?* and *2a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding PwABI identity?* the first data set was created, which comprises numerical ratings given by PwABI and carers relating to the perspectives of both halves of the dyad on their own and their partner's identity alongside their beliefs about the perceptions of their partner. These ratings allowed patterns of agreements/disagreements and understandings/misunderstandings in informal care relationships regarding carer and PwABI identity to be mapped. To answer questions *1b and 2b: How can the pattern of divergences be explained?* a second data set was created. This comprises video recordings of the discussions between researcher and individual participants whilst completing the rating task. The video data set was analysed to locate the sources of the convergences/divergences of perspective mapped in the rating task.

In answering question *3a: What strategies do carers and PwABI use in collaboration on a joint task?* the third data set, video recordings of dyads engaging in a joint task, were analysed to discover what strategies carers and PwABI use during collaboration to complete the inviting a friend of relative for a meal joint task. In

answering question 3b: *Is the type of input provided by carers on the joint task comparable to scaffolding as described in the child development literature?* the video data for the inviting for a meal task was analysed further to see if the interactions met the three major criteria for scaffolding: The type of strategies used, the flexibility of support used, and gradual removal of supports.

In answering question 4a: *What happens when carers and PwABI collaborate to fill in the Disability Living Allowance (DLA) claim form?* the fourth data set, video recordings of dyads working together to fill in part of the DLA form, was analysed. The analysis looked at how dyads answered the form, whether there were disagreements about the answers given, and, if there were disagreements, were these in the direction of carers or PwABI seeing more disability? Question 4b: *Why do carers see more disability than PwABI when filling in the DLA form?* arose from analysis of question 4a. Video recordings of dyads completing the DLA form task were further analysed to find the source of observed disagreements.

Outline of the Chapter

This chapter will describe in detail the methodology used in this PhD research. The chapter will begin with the participants. Participant recruitment methods will be described with attention to issues surrounding ethical approval, recruitment within NHS settings and the problems of recruiting within an ABI population. The chapter will then present demographic information about the 28 informal care dyads who took part in the research. The chapter will next introduce in detail the development of the rating task, designed to answer questions 1a & 1b and 2a & 2b. The selection and use of the two joint tasks to answer questions 3a & 3b and 4a & 4b will then be addressed. Lastly, the research procedure will be described.

Participant Recruitment Methods

56 participants, 28 PwABI who were two or more years post ABI and their 28 closest informal carers were recruited for the research between May 2009 and September 2010. Of the 28 dyads, the first eight were recruited from Headway groups in Scotland, the subsequent 16 dyads were recruited from the Astley Ainslie Hospital in Lothian NHS health board and the final four dyads were recruited from the Community Treatment Centre for Brain Injury in Greater Glasgow and Clyde NHS health board.

Headway groups

Permission was granted by the University of Stirling Psychology Department Ethics Committee for this stage of the research. 11 of the 13 Headway groups in Scotland were approached by email by the researcher to see if it would be possible to recruit from their groups. An information sheet for group leaders about the research was included in the email. Groups in Glasgow, South Lanarkshire, Edinburgh, Perth and Kinross, Fife, Dumfries and Galloway, Ayrshire, and East Lothian all responded. Six of the eight Headway groups who responded invited me to attend one of their group meetings and discuss my research with members. Presentations about the research were given to the groups in Glasgow, South Lanarkshire, Perth and Kinross, and Fife. The groups in East Lothian and Dumfries and Galloway invited me to come to a group session and mingle with members, discussing research participation with individuals. The Ayrshire and Edinburgh groups asked for information packs to be sent to them for distribution within their groups.

Anyone who expressed an interest in taking part in the research was given an information pack. Information packs included an information sheet for PwABI which was tailored for potential participants by including larger text, graphics, and clear, simple language. Information packs also included an information sheet for carers, a pre-paid

return envelope which was pre-addressed to the researcher at the Psychology department at the University of Stirling, and a letter of invitation to take part in the research. If interested in hearing more about the research and to possibly take part, potential participants were asked to fill in their contact details and preferred method of contact (that is, phone, e-mail, mail) on a tear-off strip on the letter of invitation and to post it back to the researcher in the envelope provided. If a tear-off strip was received at the University, potential participants were contacted to organise the first home visit. Eight participants were recruited via this method (two from Edinburgh Headway, two from Perth and Kinross Headway, two from Glasgow Headway and two from South Lanarkshire Headway).

NHS ethics

In order to recruit from NHS sites in Scotland, NHS ethical approval was sought and granted. The NHS Research Ethics number for the research is 09/S0501/26. Research & Development (R&D) approval was sought and granted for three health boards: Lothian, Greater Glasgow and Clyde, and Forth Valley. Although R&D approval was granted for Forth Valley, recruitment did not take place from this health board. Sites which would act as participant identification centres were located in Lothian and Greater Glasgow and Clyde.

Lothian Health Board

The site recruited from in Lothian was the Astley Ainslie Hospital (AAH) in Edinburgh. The AAH specialises in post-acute care and rehabilitation for people after injury, stroke and cardiac disease (National Health Service, Lothian, 2011). The AAH provides both inpatient and outpatient rehabilitation services. Contact was established with the brain injury team within the Clinical Psychology service at the AAH. Dr Andrew Harrison, Consultant Clinical Neuropsychologist, was the primary point of contact. A database of 779 patients with Traumatic Brain Injury, both active and discharged from the

service, who were referred between 1993 and the time of recruitment was used to select potential participants. Participants were selected if they met the following inclusion/exclusion criteria: They were two or more years post injury (with no upper limit on time elapsed since injury); aged between 16 and 70 at the time of recruitment; did not have psychiatric co-morbidity and had no known history of alcohol or substance abuse. Participants were to be excluded from the research if they were medically unstable or unable to consent under the terms of the Adults with Incapacity Act, although this was determined after the participant identification stage, when potential participants were contacted.

Those who met the criteria were mailed an information pack from the hospital. As for Headway participants, information packs included an information sheet for PwABI, an information sheet for an informal carer of the PwABI's choice, a letter of invitation with a tear-off reply strip for potential participants to return to the University and a pre-paid, pre-addressed envelope. Potential participants were asked to contact the researcher if interested in taking part in the research by returning the reply slip with name(s), and contact details. Once a reply slip was received at the University they were contacted by their preferred method of communication to arrange the first research visit at their home. As the research required that PwABI take part with their closest informal carer, at the stage of arranging the first home visit it was ascertained whether there was a close informal carer whom the PwABI saw regularly (a minimum of three hours a week) who was willing to take part with them. Thus, it was the PwABI who defined who their main informal carer was and invited them to participate. This requirement was met for all but one potential PwABI participant, who declined to participate further when it was explained on the phone that an informal carer was required to take part in the research with the PwABI.

There was a 12% response rate from potential participants emailed a research information pack from AAH. Nineteen PwABI responded to the mailing but three did not take subsequent part in the research, one for health reasons, one as mentioned above because he did not wish to take part with an informal carer and one decided he did not wish to take part in the research after hearing more about the format of the research sessions. In total 16 dyads took part in the research from AAH.

Greater Glasgow and Clyde Health Board

The site recruited from in Greater Glasgow and Clyde was the Community Treatment Centre for Brain Injury (CTCBI) in Glasgow. This is a community based rehabilitation service for people who have experienced brain injury through trauma, subarachnoid haemorrhage, anoxic/hypoxic brain damage or encephalitis/meningitis (National Health Service, Greater Glasgow and Clyde, 2011). Contact was established with the centre director Dr Denyse Kersel and a Clinical Neuropsychologist, Dr Nicola Goudie. The same inclusion/exclusion criteria were used as for the Astley Ainslie Hospital. Potential participants were identified by an Assistant Psychologist in the service and information packs sent out. The information packs were the same as for the AAH mailing, but the name of the hospital which was identifying potential participants was changed. As for participants recruited from Headway and the AAH, reply slips were sent directly to the University of Stirling Psychology Department using the pre-paid, pre-addressed envelope provided. Once a reply slip was received, potential participants were contacted and a time organised to meet. However, instead of meeting participants at their home as for participants recruited from Headway groups and the AAH, staff at the CTCBI felt that it was preferable for participants to be invited to the CTCBI to take part in the research. A private consulting room was booked for research sessions.

There was an 8% response rate to the mailing from CTCBI. All four dyads who responded to the letter of invitation took part in the research.

The Realities of Recruitment from a Clinical Population

Before providing further information about the participants who took part in this PhD research it is necessary to address the process of recruitment as this was extremely difficult and lessons can be learned from the researcher's experience. Recruitment was arguably the most challenging aspect of the researcher's PhD experience for two reasons:

Difficulties with the NHS R&D System

The system of applying to the NHS for ethical approval to conduct research with clinical populations is widely regarded as complex and time consuming and it is necessary to factor the time taken to receive ethical approval into research timelines. However, what receives little attention is the process of receiving NHS Research and Development (R&D) approval. When applying for R&D approval from more than one health board, this process is as complex and as time consuming as the process of securing ethical approval.

Each health board has disparate systems for the process. Between the two health boards eventually recruited from, one required that you have written approval from your chosen participant identification centre before R&D approval could be granted, the other required that you have R&D approval in place before you could first approach your chosen participant identification centre. There were also differences in health boards' willingness to provide an honorary contract to researchers working outside the NHS. When issued with an honorary contract this allowed the researcher greater access to the participant identification process. This was not granted by Forth Valley NHS board and the chosen participant identification centre felt that the workload of identifying participants who were

two or more years post injury was too great and so declined to act as a participant identification centre in the research.

As well as being fragmented, the process of applying for R&D approval was not transparent. The application form was the same across health boards but the process was not and there was no detailed information available about what each health board required and how their requirements differed. This only became apparent once the applications had been submitted and contradictory emails were received from those in R&D offices in the different health boards. The system should become standardised with increased transparency for those wishing to recruit from more than one health board, but not Scotland wide, where the national system comes into effect.

Difficulties Recruiting without a Clinical Supervisor

Not only was the process of securing approval to recruit a problem for this research, but recruiting from a clinical population was also difficult. There was no clinical supervisor for this research and this made the process of recruitment more complex. Contacts needed to be established from the ground up, which was time consuming and slow. Contacts were based on goodwill rather than reciprocity as clinicians were required to put time and effort into assisting with the research process without a clear benefit to them, such as inclusion in research outputs.

Rehabilitation centres do not wish for multiple mailings to be sent to the same patients for different studies in a certain time period and many centres had Clinical Psychology doctoral students affiliated to the centres conducting their own research concurrently and their recruitment took precedence. There were also other students in my own department and across Universities looking to recruit from the same or similar samples and this further complicated the process. Therefore, the pool from which to recruit

was narrowed and it was not clear until rehabilitation centres were approached whether the target population was already being studied or had recently been approached by another researcher.

Not having a grounding in the organisation of clinical settings for brain injury rehabilitation was also a barrier to recruitment. The population of those who were two or more years post injury had been selected at the outset of the research. It was only after NHS ethics approval had been granted that it was discovered that rehabilitation centres do not organise their records on the basis of time since injury but on date of referral to the service. This made the process of identifying potential participants more complex. It would be beneficial for research PhD students who are looking to perform research in the clinical domain to be given the opportunity to conduct a short clinical placement or work experience in the beginning stages of their PhD, in order to gain greater insight into the running of and remit of services and build relationships with staff with a view to recruiting from the service at a later stage. Greater links between Clinical Psychology and academia would be beneficial both to academic students conducting research with clinical populations and for clinicians and clinical units looking to increase their research involvement.

Participant Demographic Details

Of the 28 PwABI and their 28 informal carers who took part in the research, mean age of PwABI was 47.21 years, S.D. 10.95, range 19-68. Mean age of carers was 54.59 years, S.D. 11.52, range 32-87.

Mean time since injury was 7.84 years, S.D. 10.40, range 2-45 years. ABI was sustained as a result of traumatic injury in 24 (85.71%) cases. Of the 24 traumatic injuries, 11 were a result of road traffic accidents (RTAs), nine as a result of fall and three as a

result of assault. The reason for one traumatic injury was not recorded by the researcher. Of the four non-traumatic injuries, three were a result of Cardio-Vascular Accident and one was the result of Herpes Simplex Encephalitis (HSE).

In terms of gender, 22 (78.57%) PwABI were male, six (21.43%) were female. Twenty three (82.14%) carers were female, five (17.96%) were male. Fourteen carers were spouses (50%), nine were parents (32.14%), four were siblings (14.28%) and one was a co-habiting friend (3.57%). Nineteen (67.86%) dyads were co-habiting at the time of the research, nine (32.14%) were not.

Twelve (50%) carers were employed at the time of the research. Nineteen (67.86%) PwABI were unemployed at the time of the research and nine (32.14%) were employed. Of the nine PwABI who were employed, one had changed their job as a result of being unable to fulfil the duties of his post after ABI, three were with the same employer but had moved from full to part time hours and five PwABI were in the same job as before their ABI. Only three (10.71%) PwABI were unemployed prior to their ABI.

No participant reported a history of psychiatric diagnoses, alcohol or substance abuse problems.

Outcome Measures

As well as the social history taken during the research sessions, other information was collected related to anxiety, depression, self-awareness and level of current cognitive functioning. Both PwABI and carers completed the Hospital Anxiety and Depression Subscale (HADS) and the Patient Competency Rating Scale (PCRS). The HADS and PCRS were used as they were standardised measures of well-being and awareness of disability and could both provide greater detail on the sample studied and further enhance discussion regarding identity and cognitive/practical adaptation in informal care dyads.

PwABI completed the Addenbrooke's Cognitive Examination Revised, version A (ACE-R) to assess current level of cognitive functioning. This was carried out alongside the Frontal Assessment Battery (FAB) which assesses the presence of dysexecutive syndrome. More information about each test is provided below, followed by mean scores of participants on each scale:

Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond & Snaith, 1983) is a self-report measure of anxiety and depression. It contains 14 questions, seven relating to anxiety and seven relating to depression. The HADS is used to assess both the presence of anxiety and depression and the severity of symptoms. It takes between two and five minutes to complete and is used in both hospital and community settings. People are asked to self-report their experiences based on how they have been feeling in the last week. Each question is answered on a four-point scale (0-3). Anxiety and depression are considered separately. Thus, the minimum score is zero and the maximum score is 21 for each subscale. A score below eight indicates no presence of anxiety or depression. A score between eight and ten suggests the possible presence of anxiety and/or depression and a score of 11+ indicates probable anxiety and/or depressive disorder. A literature review compared 747 studies which had used the HADS until 2000 (Bjelland, Dahl, Haug & Neckelmann, 2002). Factor analyses revealed a two factor structure demonstrating that the depression subscale and the anxiety subscale were measuring different constructs. The authors of the review also found that using a cut-off score of eight to indicate presence of anxiety or depression had provided sufficient sensitivity and specificity in previous studies. The Cronbach's alpha for HADS-A varied from .68 to .93 (mean .83) and for HADS-D from .67 to .90 (mean .82). (Bjelland et al., 2002). In the present research, the correlation between the two

subscales was .598 which is in line with previous studies where correlations ranged from .4 to .74, with a mean of .56 (Bjelland et al., 2002).

Patient Competency Rating Scale (PCRS)

The PCRS (Prigatano & Fordyce, 1986) is a 30 item measure which uses a five point scale: one - can't do; two - very difficult to do; three - can do with some difficulty; four - fairly easy to do; five - can do with ease. The scale is used to assess perception of behavioural competency in four areas. The areas are: physical functioning and self care skill (for example, "how much of a problem do I have in taking care of my personal hygiene?"); emotional control (for example, "how much of a problem do I have in controlling crying"); interpersonal skill (for example, "how much of a problem do I have in participating in group activities"); and cognitive abilities (for example, "how much of a problem do I have in remembering what I had for dinner last night") (Ranseen, Bohaska & Schmitt, 1990). There are three versions of the PCRS: the patient's form, the relative's form and the clinician's form, each containing the same questions. The responses provided by the PwABI are compared to either those of a significant other or a clinician. The scale has a minimum score of 30 and a maximum score of 150. The total score out of 150 can be measured for both the PwABI and the significant other or clinician. A discrepancy where the PwABI rates themselves as more competent than the significant other/clinician does indicates impaired self-awareness. The greater the discrepancy, the greater the impairment in self-awareness. Discrepancy scores can also be computed for each of the 4 competency areas to give a more detailed picture of unawareness. The scale has reported test-retest reliability of $r = 0.97$ for PwABI and $r = 0.92$ for significant others (Prigatano, Altman & O'Brien, 1990) with a tentative suggestion that discrepancy scores correlate significantly with indices of injury severity (Kolakowsky-Hayner, 2010).

Addenbrooke's Cognitive Assessment (ACE-R)

The ACE-R is a cognitive screening tool which provides a global score and sub-scores for five specific domains of cognitive functioning: orientation/attention, memory, verbal fluency, language, and visuo-spatial functioning. The ACE-R takes between 12 and 20 minutes to administer. The total scale is scored out of 100 and there are two cut-offs suggested. A score between 82 and 88 gives 94% sensitivity and 89% specificity for cognitive impairment and a score below 82 gives 84% sensitivity and 100% specificity for a diagnosis of cognitive impairment. The alpha coefficient for the assessment is 0.80 (Mioshi, Dawson, Mitchell, Arnold & Hodges, 2006).

Frontal Assessment Battery (FAB)

The FAB is often administered alongside a wider cognitive assessment to establish whether there is frontal lobe damage and associated dysexecutive syndrome. The scale was originally designed to discriminate between dementia with a frontal lobe phenotype and dementia of AD type. The scale takes up to five minutes to administer and is scored out of 18. A score of 12 or less indicates frontal involvement and dysexecutive disorder. This test was administered in addition to the ACE-R on the advice of Dr Julia Clark, Clinical Neuropsychologist in the Dumbartonshire Community Brain Injury Rehabilitation Team (personal communication).

Mean results for the 28 dyads on the HADS, PCRS, ACE-R and FAB are provided in the table overleaf. Mean HADS scores were higher for anxiety than depression for both PwABI and carers. Mean scores on both subscales of the HADS for both PwABI and carers were below clinical thresholds. Mean scores were higher on the PCRS for PwABI than carers suggesting that PwABI rated their competency as higher than carers, although there was greater variability in carers' ratings. Discrepancy scores indicated overall agreement about capabilities but the variability in scores was large. The mean cognitive

test score was 81.67 indicating that this sample is cognitively impaired. However, based on mean scores, there is an absence of dysexecutive syndrome in the sample as a whole.

Table 3.1

Mean Scores on the Outcome Measures HADS, PCRS, ACE-R and FAB

| | Mean score | S.D. | Range |
|----------------------------------|------------|--------|--------|
| Carer HADS Anxiety (N=28) | 6.86 | 4.062 | 0-15 |
| Carer HADS Depression (N=28) | 3.62 | 3.201 | 0-10 |
| PwABI HADS Anxiety (N=23) | 6.87 | 3.745 | 0-14 |
| PwABI HADS Depression (N=23) | 5.61 | 3.974 | 0-16 |
| Carer rated PCRS (N=27) | 102.11 | 25.239 | 63-148 |
| PwABI rated PCRS (N=20) | 115.55 | 18.942 | 74-147 |
| PCRS discrepancy score (N=22) | 1.68 | 23.11 | -48-44 |
| ACE-R (N=18) | 81.67 | 7.577 | 69-96 |
| FAB (N=17) | 15.35 | 1.801 | 11-17 |

Comparability of carer groups

Table 3.2 on page 100 shows a breakdown of demographic data and mean outcome measure scores for participants according to the type of carer relationship. Levene's test for equality of variance showed a non-normal distribution, thus non-parametric tests were used to compare the different relationship groups. The Kruskal-Wallis test revealed four significant between group differences from the fifteen comparisons. These were PwABI gender, carer age, whether or not dyads were co-habiting and whether the carer was employed. Pairwise comparisons using the Mann-Whitney U Test were carried out to establish where the between group differences lay. On the comparison of romantic partner dyads and parent-child dyads, there was a significant difference between groups in PwABI

gender ($Z=-2.070$, $p=.038$, 2-tailed), carer age ($Z=-2.808$, $p=.005$, 2-tailed) and carer occupation ($Z=-2.523$, $p=.012$, 2-tailed). Co-habitation level was not significant ($Z=-1.057$, $p=.290$, 2-tailed). On the comparison of romantic partner dyads and sibling dyads only levels of co-habitation were significant ($Z=-3.117$, $p=.002$, 2-tailed). There was no significant between groups difference on PwABI gender ($Z=-.535$, $p=.593$, 2-tailed), nor on carer age ($Z=-.625$, $p=.532$, 2-tailed) nor on carer occupation ($Z=-.064$, $p=.949$, 2-tailed). Finally, on the comparison of parent-child dyads and sibling dyads, both carer age ($Z=-2.473$, $p=.013$, 2-tailed) and whether or not dyads were co-habiting ($Z=-2.138$, $p=.033$, 2-tailed) showed significant between group differences. There were no significant between group differences on PwABI gender ($Z=-1.540$, $p=.124$, 2-tailed) or levels of carer employment ($Z=-1.929$, $p=.054$, 2-tailed).

Although Table 3.2 shows some diversity between groups, there is also a lot of commonality. Due to these results and the thesis's focus on processes of caring rather than the relationship per se, the decision has been taken to treat carers as one group.

Table 3.2

Demographic information and outcome measure scores by dyadic relationship type with Kruskal-Wallis test results (based on median values)

| | Romantic partners (n=14) | Parents (n=9) | Siblings (n=4) | Cohabiting friends (n=1) | Chi-Square | Degrees of freedom | Sig. |
|---|-----------------------------|--------------------|--------------------|-----------------------------|------------|-----------------------|------|
| PwABI average age | 51.57 | 38.78 | 49.75 | 52 | 6.046 | 3 | .109 |
| Carer average age | 49.77 | 64.78 | 47.50 | 54 | 10.633 | 3 | .014 |
| Average time since injury | 9.31 years | 6.38 years | 7.33 years | 2 years | 3.506 | 3 | .320 |
| PwABI Gender | 1 female 13 male | 4 female 5 male | 0 female 4 male | 1 female | 8.955 | 3 | .030 |
| Carer Gender | 13 female 1 male | 7 female 2 male | 2 female 2 male | 1 female | 4.096 | 3 | .251 |
| Co-habiting | 12 (85.71%) | 6 (66.6%) | 0 (0%) | 1 (100%) | 10.579 | 3 | .014 |
| PwABI Employed | 5 (35.71%) | 3 (33.3%) | 1 (25%) | 0 (0.00%) | 1.560 | 3 | .668 |
| Carers Employed | 8 (57.14%) | 2 (22.22%) | 3 (75%) | 0 (0.00%) | 9.231 | 3 | .026 |
| PwABI average HADS score - Anxiety | 6.50 (n=12) | 7.71 (n=7) | 5.67 (n=3) | 9 | 1.106 | 3 | .776 |
| PwABI average HADS score - Depression | 4.92 (n=12) | 5.71 (n=7) | 7.33 (n=3) | 8 | 1.676 | 3 | .642 |
| Carers average HADS score - Anxiety | 7.36 | 7.22 | 6.75 | 8 | 2.881 | 3 | .410 |
| Carers average HADS score - Depression | 4.21 | 3.56 | 4.00 | 2 | 1.252 | 3 | .741 |
| PwABI PCRS score | 121.91 (n=11) | 115.00 (n=6) | 95.50 (n=2) | 89 | 4.521 | 3 | .210 |
| Carer PCRS score | 105.85 (n=13) | 101.00 (n=9) | 100.50 | 70 | 2.893 | 3 | .408 |
| Average ACE-R | 80.70 (n=10) | 80.20 (n=5) | 83.00 (n=2) | 96 | 3.383 | 3 | .336 |

Comparability of Headway and Rehabilitation Samples

Independent samples t-tests were conducted on the demographic data to establish whether the Headway sample and the rehabilitation centres sample were comparable. The Headway sample are accessing long-term support services which may assist in the process of adapting to ABI, whereas those recruited from rehabilitation centres may not be receiving such assistance. Independent t-tests showed that there was no significant difference between the means of these two samples on the gender or age of PwABI or carers, time since injury, HADS scores, PCRS individual scores and discrepancy scores and scores on the ACE-R and the FAB. Therefore, the Headway and Rehabilitation samples are comparable and can be treated as one data set.

Method for Answering Questions 1a & 1b and 2a & 2b: Identity Rating Task

Research questions 1a & 1b and 2a & 2b address identity adaptation in informal care dyads following ABI. In order to answer these questions, a suitable method must be designed to facilitate examining the dyad at the relational level, to garner both quantitative and qualitative data and to be accessible to a population with ABI.

The Interpersonal Perception Method

To best answer research question *1a: Are there any disagreements and/or misunderstandings between carers and people with Acquired Brain Injury (PwABI) regarding carer identity?* and question *2a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding PwABI identity?* a methodology which allows simultaneous study of both halves of a dyad is required. A self-report methodology can allow perspective taking on both sides of an informal care relationship following ABI to be systematically examined. Perhaps the most rigorous and theoretically advanced self-report methodology to examine perspective taking in dyads was developed

by Laing et al. (1966; Gillespie & Cornish, 2010). The Interpersonal Perception Method (IPM) was originally developed for use in marriage counselling and family work. It is based upon the idea that not only are our own perspectives important in steering our behaviour, but also what we perceive other peoples' perspectives to be. The original IPM questionnaire asked dyads to answer 12 questions around each of 60 dyadic issues.

The IPM posits that there are three levels of intersubjectivity. Level one is the 'direct perspective' and concerns both self and other's views about a given phenomenon. For example, within the married dyadic relationship there is wife's view of X and husband's view of X.

The second level of intersubjectivity is the 'meta-perspective'. This relates to self and other's ideas about each other's perspectives of a given phenomenon. Here there is wife's view of husband's view of X and husband's view of wife's view of X.

The third and final level of perspective taking revealed by the IPM is 'meta-meta perspectives', which refer to self's perspective of other's perspective of self's perspective on the given phenomenon (and vice versa); for example, wife's view of husband's view of wife's view of X and vice versa.

An example of a question from the original IPM devised by Laing et al. (1966) is as follows. Question 1 relates to direct perspectives, Question 2 relates to meta-perspectives and Question 3 relates to meta-meta perspectives:

- 1) How true do you think the following are?
 - a. She depends on me
 - b. I depend on her
 - c. She depends on herself

- d. I depend on myself
- 2) How would SHE answer the following?
- a. I depend on him
 - b. He depends on me
 - c. I depend on myself
 - d. He depends on himself
- 3) How would SHE think you have answered the following?
- a. She depends on me
 - b. I depend on her
 - c. She depends on herself
 - d. I depend on myself.

Both members of a dyad are asked the same questions and then perspectives of self and other are compared. Comparison of 'direct' perspectives allows the identification of agreement and disagreement, so does one half of the dyad see themselves, others and situations in the same way that the other half of the dyad does. By comparing a 'direct' perspective with a 'meta-perspective' we are able to see patterns of understanding/misunderstanding - so whether one half of a dyad correctly judges how the other half perceives a variety of phenomena. It is possible to have agreement without understanding and understanding without agreement. A third comparison, that between 'meta-perspectives' and 'meta-meta perspectives' allows the examination of realization of understanding and misunderstanding.

Gillespie and Cornish (2010, p. 24) showed the variety of comparisons which are facilitated by the IPM in the following table:

Table 3.3*Actual Intersubjective Relations*

| Comparisons | Intersubjective relations |
|--|--|
| Direct perspective & Direct perspective (S→X & O→X) | Agreement/disagreement |
| Direct perspective & Meta-perspective (S→X & O→S→X) | Understanding/misunderstanding |
| Meta-metaperspective & Meta-perspective (S→O→S→X & O→S→X) | Realisation of understanding/misunderstanding |

S refers to Self, O refers to Other

The major strength of this framework is that it clearly lays out the levels of intersubjective relations in dyads (Gillespie & Cornish, 2010). It has previously been suggested that misunderstandings are more detrimental to relationships than disagreements (Sillars et al., 2005) and this method parses clearly the different relations. By mapping intersubjective relations within married dyads, Laing et al. (1966) believed this information could be used during therapy. That is, if a misunderstanding is found then this could be corrected (Gillespie & Cornish, 2010). For example, a husband and wife could agree in their direct perspectives on physical discipline with their children in that they both agree this is an unacceptable course of action. However, the wife may misunderstand her husband's viewpoint, thinking that he is in favour of such action. By addressing their agreement but misunderstanding in therapy, this could help the dyad to realise that they are in greater alignment in their views on the issue of discipline than the wife believed.

Principles of the IPM were used as the basis of the rating task developed for this research. However, key changes to the presentation were required to overcome criticisms of the IPM and to make the method simple enough for PwABI to effectively engage with it and these will be described below.

Adaptation of the IPM

Removal of meta-meta perspectives

The self-report presentation of the IPM is not without its limitations and a novel presentation is required for this specific population. The third level of intersubjectivity, meta-meta perspectives, was removed from questioning. Meta-meta perspectives are seen regularly in talk, for example when an employee is worried she has created the wrong impression of herself in the mind of her boss, or in an argument when one partner says “you always think I don’t love you”. However, meta-meta perspectives are largely unconscious and thus it can be argued that they are not open to self-report. When asked explicitly, meta-meta perspectives are too complicated to elicit, particularly for those who have experienced cognitive impairment.

Adaptation with Talking Mats

The IPM was further adapted for use with PwABI. This was carried out via the use of Talking Mats (Murphy, 1998b). This is a low tech communication tool which uses an A3-sized mat with a five-point scale running along the top. Items for discussion are presented individually to participants as picture symbols with accompanying verbal explanation. The participant can then place the symbol where they wish along the mat according to the scale. Talking Mats are useful as they allow concepts to be represented using pictures as well as words, thus allowing ideas to be organised clearly and visually. The visual presentation provides a joint marker of the progress of the discussion, thus minimising misunderstandings between PwABI and researcher. This method has been used successfully in research with a variety of participants, such as those with aphasia, dementia, and MND (Murphy, 2000, 2003, 1999). For continuity of presentation, Talking Mats were used with both PwABI and informal carers in the research.

Interview presentation

For research on identity adaptation in relationships affected by ABI, it is important to examine not just the patterns of perspective taking (that is, agreements/disagreements and understandings/misunderstandings in informal care dyads) but also the *sources* of patterns of convergences/divergences of perspectives. To answer questions *1b and 2b: How can the pattern of divergences be explained?* it is necessary to elevate the IPM beyond its quantitative roots. Therefore, questions were not administered in a traditional questionnaire format. Instead, whilst questions were presented verbally using the Talking Mats, the researcher probed further, helping participants to elucidate the thought processes behind the ratings given. The process of completing the rating tasks was video recorded, thus yielding not just quantitative data from ratings themselves but also qualitative data from the talk between researcher and participants which surrounded the task.

Analysing the talk surrounding the rating task allows a dialogical approach to be used in this research. Dialogical analysis takes the communicative relation as the basic unit of analysis and can reveal qualitatively the internal voices of each half of the dyad, yielding further data about how each half feels about themselves and their new identity after ABI (Gillespie & Cornish, 2010).

Developing the Rating Task Items

An interpersonal perception rating task was developed for this research. The identity rating task had 14 items drawn from the literature and from a previous study of perspective taking in informal care dyads after aphasia (Gillespie et al., 2010) in order to map out both key divergences and convergences of perspective. The 14 items chosen were: kind, irritable, lazy, confident, independent, confused, passive, embarrassed, interested, supportive, mature, overprotective, intelligent and self-centred.

The items on which divergence about carers was expected were: ‘overprotective’ (Carnes & Quinn, 2005), taking on previously shared responsibilities alone (renamed the opposite, ‘independent’) (Gosling & Oddy, 1999), ‘embarrassed’ (Pot et al., 1998), loss of interest in hobbies and interests due to carer role captivity (renamed the opposite, ‘interested’) and ‘confident’ (Semple, 1992). The items on which we expected divergence about PwABI were: ‘passive’ (Yeates et al., 2007), ‘self-centred’ (Farmer & Stucky-Ropp, 1996), ‘irritable’ (Kreutzer et al., 1994), displaying child-like qualities (renamed the opposite, ‘mature’) and asponaneous (renamed, ‘lazy’) (Thomsen, 1984), and ‘confused’ (Ponsford et al., 1995). In order to give participants a chance to demonstrate agreement and report positively on one another, the task also included the items, ‘intelligent’, ‘kind’ and ‘supportive’ but did not expect divergences on these items. Each of the 14 identity items was evaluated by participants on a five-point scale ranging from ‘I am’ to ‘I am not’ (or ‘my partner is’ to ‘my partner is not’) and ‘my partner thinks I am’ to ‘my partner thinks I am not’. The rating task was piloted with five PwABI previously known to the researcher from the Head Forward Centre in Manchester to check usability and comprehension of the method and the individual items to be rated.

Managing varied epistemologies within the mixed-methods approach

The research takes a pragmatist approach and thus selects methods based on their utility and evaluates these according to the purpose the knowledge generated serves (Cornish & Gillespie, 2009). As a result both quantitative and qualitative data was derived from the IPM approach as each type of data showed something different and interesting in relation to adaptation to ABI. However, it should be acknowledged that the varied epistemologies within this mixed-methods approach are in tension with one another. Radical constructionist perspectives would argue that the use of quantitative data is naïve and that there is an inability to generalise in any substantive way from the data generated.

Qualitative theorists could argue that the researcher selection and thus imposition of items to be rated on the IPM on the basis of literature does not allow participants the freedom to explore and utilise their own ideas, language and priorities in relation to their own and their partners' identities and leads participants towards discussion in certain pre-determined directions in the talk surrounding the rating task. Conversely, supporters of a pure quantitative approach would argue that the IPM data is limited due to the small number of participants and lack of statistical power, again affecting generalisability.

Method for Answering Questions 3a & 3b and 4a & 4b: Two Joint Tasks

How to Study Distributed Cognition in Informal Care Partnerships after ABI?

Although previous research has assessed cognitive and practical adaptation to ABI (Thomsen, 1984; Uzzell & Stonnington, 1996), this research has often not come from a sociocultural standpoint which sees cognition as created and distributed within social relations, rather than as an individual phenomenon. Adopting a relational, sociocultural stance has two major implications for the way that cognitive and practical adaptation after brain injury should be studied. Firstly, this approach means that *dyads* must be studied, and thus research and analysis must occur at the relationship level. Secondly, emphasis is placed on *process* rather than product. In terms of collaboration, the question is not if individuals engage or even when. Instead the question is *how* do people collaborate in order to achieve adaptive end goals? (Rogoff, 1998). Thus, microgenetic processes of collaboration should be studied to examine how cognition is distributed within the social relationship and what impact this has on functioning.

In order to answer question 3a: *What strategies do carers and PwABI use in collaboration on a joint task?* and question 3b: *Is the type of input provided by carers on the joint task comparable to scaffolding as described in the child development literature?*, observation of dyads engaging in some meaningful way is required. Collaboration between

care partners is occurring constantly as carers assist those they care for to achieve everyday tasks, so for this research, an everyday task which facilitates the examination of strategies that carers use and the contributions that the cared for make in collaboration is needed.

Joint Activity and the Selection of a Suitable Task

The previous literature on joint activity is diverse. There is a great deal of work within Psycholinguistics which examines dyads engaging in a variety of tasks. Some involve a referential communication task where one half of the dyad describes ambiguous objects for the other member to identify. Participants are seen to use increasingly short descriptors as the director/matcher relationship becomes established and the relevant information in common ground increases (Clark & Wilkes-Gibbs, 1990). Such collaborative learning is a pervasive effect which takes place even in ambiguous object description tasks with participants who have hippocampal amnesia (Duff, Hengst, Tranel & Cohen, 2005). This work has been extended using communication conflict tasks where different maps are introduced on late trials to directors and followers to assess the impact of this conflicting information on intersubjective coordination (Gillespie & Richardson, 2011). Although these tasks assess process in-depth and provide rich data on collaboration, the tasks used are too artificial to use to examine the *everyday* strategies employed in collaboration in care relationships.

Joint activity research within the child development literature is also plentiful. Researchers have studied spontaneous mother-child interactions, with the suggestion that joint activity helps to foster cohesive relationships (Gardner, 1994). More structured interactions have also been studied in mother-child dyads. These are often highly structured tasks which are age appropriate to the children, such as Piagetian conservation

tasks and matching tasks (Stright et al., 2009) which do not reflect the type of collaboration engaged in by informal care dyads.

The planning inviting a friend or relative round for a meal task

The task chosen to answer questions 3a & 3b is planning inviting a friend or relative round for a meal (see Appendix A for the task sheet). Planning meal times is something which families engage in on a daily basis and when participation outside the house is difficult after ABI, a common way to introduce more social interaction is to have people come to the house. This task has recently been shown to yield rich data on strategy use in a sample with aphasia (Gillespie et al., in prep.). The task requests that dyads work together in any way they wish to simulate the everyday decisions that would be made when planning a social dinner. Participants are asked nine questions which reflect each aspect of the planning process. The questions are asked via written questions on one sheet of A4 paper with an accompanying written explanation of the task (see Appendix A). To provide rich data, interactions are video recorded in order to capture nonverbal and verbal aspects of communication which are intertwined in interactions (Stone, 1998).

Although the task chosen taps into an everyday process, planning is just one stage which is involved in having someone round for dinner. Beyond planning, the actual process of completing the tasks required to host a friend or relative was not assessed in this research. Also, whether this is truly a 'joint' task can be called into question. Carers often take over household domestic tasks after ABI and so they may plan having someone round for dinner without any input from the PwABI. Also it is a task with little real-world consequence and so the type of interaction may be artificial and not reflect the reality of such a task. To compensate for these limitations a second task was selected to be completed immediately after the first task which had greater real world significance.

The Disability Living Allowance claim form task

To answer research question 4a: *What happens when carers and PwABI collaborate to fill in the Disability Living Allowance (DLA) claim form?* the second task is for dyads to work together to fill in part of the DLA claim form (see Appendix C for the task sheet). DLA is a benefit designed to assist with the costs of living with a disability. The benefit is available to anyone aged under 65 who has a mental or physical disability which is severe enough to require assistance with care needs and/or with walking. The benefit has both a care and mobility component and those on the highest rate for both components can expect to receive £125 per week (rates recorded January 2012). The current process requires that applicants complete a 55 page claim form which covers a variety of aspects of disability and its impact on participation in activities of daily living. The completed claim form is used as the basis for assessment of eligibility for receipt of the benefit and, if eligible, the level of benefit required. Access to finances after ABI has been documented in the literature as a source of great stress for families (Verhaeghe et al, 2005), thus access to DLA benefit is very important for families after ABI and is a form which many have filled in before. Due to the complexity of the form, PwABI often require help from informal carers to complete the form.

By choosing the DLA form this task is both real-world, as it has often been filled in before, and is related to an area of stress and burden for relationships. Although the DLA is expected to be filled in by PwABI alone, this is often not possible and so is likely to be carried out as a joint task in informal care relationships.

Section two of the DLA form: “Help with your care needs during the day” was filled in by dyads in this study. Questions pertaining to personal care and financial information were removed as these were deemed too personal. The remainder of this

section of the form asks nine questions about engagement in social activities, mobility inside and outside, adherence to medication, and meal preparation. Eight of the nine questions had follow-up sub-questions if the initial question was given a 'yes' answer by the respondent. An answer of 'yes' indicated that the PwABI had difficulty in that particular area of functioning and that help was needed to participate. An answer of 'no' indicated that there was no problem in that area of functioning. As in the inviting a friend or relative around for a meal task, the process of completing part two of the DLA form was video-recorded. These two naturalistic joint tasks should yield the type of quantitative and qualitative data on strategies employed by both parties during collaboration that has been called for.

Procedure

For participants recruited from Headway groups and the Astley Ainslie there were three home visits. Visit one was a chance for both potential participants (PwABI and informal carer) to meet the researcher and hear more about the research. During the first session, the research was explained in more detail, including the rationale for conducting the research and what it would mean for participants if they decided to take part. Potential participants were shown the equipment which would be used, such as the video recorder and Talking Mats and the researcher answered any questions potential participants had. If participants were still interested in taking part in the research, they were each given a consent form and asked to complete this at their leisure. Participants read through the consent form during the first visit in case they had any questions. Informed consent was gained from all 58 participants. The second research visit was then arranged for a time that suited all parties.

The rating tasks and joint tasks were completed during the second and third visits. The rating tasks were completed in one session and the joint tasks in the other session. The order in which participants completed the sessions varied. They were given a choice at the start of the second research visit as to whether they wished to do the joint tasks or the individual rating tasks to give participants flexibility.

The identity rating task entailed filling in three Talking Mats per participant. Accordingly all dyads completed six rating tasks. The rating tasks were carried out in the following order for all participants: (1) direct perspective – views on their own identity, (2) direct perspective – views on their partner’s identity, (3) meta-perspective – estimate of their partner’s views on their own identity. All ratings were made without the presence of the partner so that participants felt free to explore their perspectives. Whilst one half of the dyad completed the rating task, the other half of the dyad was asked to fill in the HADS and the PCRS. The ACE-R and the FAB were completed with the PwABI upon completion of the identity rating task, before the carer was brought back into the room. PwABI took an average of 33.30 minutes to complete the rating task, S.D. 15.74 minutes, Range 19.14 minutes to 88.46 minutes. Carers took an average of 35.78 minutes to complete the rating task, S.D. 13.97 minutes, Range 15.41 minutes to 67.13 minutes.

The joint tasks session involved the completion of both joint tasks. The DLA claim form task was completed first by all dyads, followed immediately by the meal task. Participants were first presented with one copy of the DLA claim form section two and asked to work together, however they wished, to fill in the form. Two pens were provided and the task sheet was placed in front of the pair. The mean time to complete the DLA form task was 15.64 minutes, S.D. 10.01 minutes, Range 4.05 minutes to 40.43 minutes. As the joint task session was conducted in the homes of participants, it was felt that it

would be intrusive to request to sit in another part of the house whilst the dyads completed the tasks. As a result, the researcher remained in the room whilst dyads worked together and was therefore available if dyads had any questions about the task or the form itself. Whilst dyads completed the form, the researcher engaged in alternative tasks, such as reading, with the aim that participants did not feel as though they were being overtly observed. Once the claim form was completed, this was collected from dyads and the meal task sheet was placed in front of them. Dyads were asked to complete this task in exactly the same way as in the claim form task, to work together as before, in any way they wished to go through the process of planning inviting someone for a meal. Once this task was completed, the task sheet was collected from the participants. The mean time to complete the meal task was 6.86 minutes, S.D. 4.50 minutes, Range 2.5 minutes to 20.36 minutes.

After both the rating tasks and the joint tasks were completed, participants were then debriefed. Participants were told that the research acknowledged that brain injury does not just affect individuals but it affects everyone in the family and that the research was looking at the ways in which relationships adapt in more detail. It was explained to participants that because brain injury can change the way people see themselves and each other, the rating task was exploring how much people agreed and understood one another. In terms of the joint tasks, it was explained that when people know each other well they communicate in complex and subtle ways and this is also the case when one person has a brain injury. What hadn't been studied was *how* this subtle and complex communication works and that was why this research was observing dyads working together on tasks.

The procedure differed for the four dyads who were recruited from the CTCBI. These dyads were seen only once by the researcher and this was at the CTCBI. During the one research session, the research was explained to participants and informed consent was

established. Participants then took part in the rating tasks only, not the joint tasks. Whilst one half of the dyad completed the rating task, the other waited in the centre's waiting room and completed the HADS and PCRS. The ACE-R and FAB were conducted with the PwABI at the end of the rating task. The joint tasks testing session was not conducted with these four dyads as the researcher felt that saturation had been reached within this data set.

The Role of the Researcher

The role that the researcher plays is central to the research process and must be acknowledged. When engaging in research, participants are always reporting *to* another, the researcher, and the nature of these exchanges can affect the outcomes of research. Throughout the thesis the researcher's voice is present, particularly within the rating task data. Where a participant's words are in response to the researcher, the researcher's voice has been included in the data extract to provide context regarding the voice their comment is responding to.

It was important to build trust within research encounters. The researcher's previous experience with individuals with brain injury was as a volunteer and support worker, a different role to that of researcher where the researcher grew to know individuals over months. Trust and rapport had to be built during a short time during research. The first research session was designed not just to explain more about the research but also as a chance to get to know the participants and for them to get to know a little about the researcher and her motivations. During research encounters efforts were made to minimise the unequal power relation between researcher and participant. The researcher was always honest in explaining to participants that she had no personal experience of brain injury or informal care. The researcher emphasised that the research was exploratory and that she felt it was the participants who were the experts in adapting to brain injury and that the

researcher simply wished to hear about their experiences and learn from them. However, it must be acknowledged that a power differential will always be present in research.

Correspondence Between Data Sets and Thesis Data Chapters

Information on the participants contributing to each data set are given below alongside information on which thesis chapters will address the analysis of each data set:

The first data set comprises the numerical ratings given by PwABI and carers. All 28 dyads took part in the rating task section of the research. The second data set comprises the videos of participants completing the rating task and discussing their ratings with the researcher. Videos were created for all 28 dyads. The analyses arising from data sets one and two will be presented in chapters four (carer identity) and five (PwABI identity) of the thesis.

The third data set comprises videos of carers and PwABI engaging in a joint task: planning inviting a friend or relative round for a meal. 23 dyads completed this joint task. Dyads 25-28 who were recruited from the CTCBI did not take part in either joint task. Dyad 22 also did not take part in the joint task session of the research due to leaving for a trip before the final session could take place. The analyses arising from data set three will be presented in chapter six of the thesis.

The fourth data set comprises videos of carers and PwABI filling in part of the DLA claim form: "Help with your care needs during the day". 22 dyads completed the DLA joint task. As with the meal task, Dyads 22 and 25-28 did not take part in the DLA task. The data from Dyad seven was removed as they completed the DLA form on the basis of the non-ABI partner. The analyses arising from data set four will be presented in chapter seven of the thesis.

Chapter Four – Invisible Care and Carers’ Struggle for Recognition

Acquired disability resulting in an informal care relationship causes role changes. For family and friends, this may mean becoming care-givers, a role which most have not experienced before (Emslie et al., 2009) and which can be demanding and stressful (Simon et al., 2009). Adaptation to these role changes is complex, with carers at risk of physical and mental health problems (Braun et al., 2009; Greenwood et al., 2009). Beyond individual outcomes, relationships can become fractured, with each side experiencing divergent practical, social and emotional demands which lead to divergent perspectives on a range of issues. Disagreements about care-givers have focused on their overprotectiveness (Ridley, 1989; Larson, 1998; Croteau & Le Dorze, 2006), embarrassment (Pot et al., 1998), independence (Gosling & Oddy, 1999), and confidence (Semple, 1992). What none of these studies has done is to systematically assess both sides of the care relationship simultaneously to ask: *1a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding carer identity?* This chapter will address this question and will then go beyond the divergences themselves to locate their source. Thus, this chapter will also answer the question: *1b: How can the pattern of divergences be explained?*

How the Data Set was Analysed

To answer question *1a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding carer identity?*, disagreement and misunderstanding were calculated on an item-by-item basis. Disagreement was considered the difference between the ratings care-givers gave themselves and the ratings their partners with ABI gave them for the 14 identity items. Misunderstanding was operationalised as the difference between care-givers’ estimates of the rating their partner would give them and the actual rating the partner gave them. Wilcoxon matched-pairs signed-ranks tests, with

two tailed significance, were used to test (1) whether care-givers and PwABI agree in their views about care-givers and (2) whether care-givers understand the views that their partner with ABI has about them.

To answer question *1b: How can the pattern of divergences be explained?*, videos of participants completing the rating task and discussing their ratings with the researcher were analysed. Using Nvivo nine software, potential sources of disagreement and misunderstanding were coded. Strategies carers use to deal with the new unequal role dynamics within the care-giver/care-receiver relationship were uncovered and these strategies raised issues for carer recognition. Accordingly, a dialogical analysis was carried out to explore the types of recognition that care-givers experience. A dialogical analysis entails coding when participants quote (either directly or indirectly) the voices of others (Gillespie & Cornish, 2010). Whenever an individual speaks, they do not simply speak their own words, but the words of other people and institutions (Wertsch, 1991). This relates to the notion of “ventriloquation”, which Bakhtin (1973) defines as “the process in which one voice speaks through another voice” (p. 78). In this analysis, frequency of direct quoting was examined to identify who the carers’ significant others are, and to explore the content of direct quotations to reveal the type of recognition care-givers experience. Finally, to complete the picture on the source of divergences, a possible source of recognition beyond significant others was considered, namely recognition from the Bakhtinian ‘superaddressee’ for fulfilling societal expectations of the ‘ideal carer’.

Question 1a: Are There any Disagreements and/or Misunderstandings Between Carers and PwABI Regarding Carer Identity?

Table 4.1 presents the median ratings of (1) care-givers on themselves, (2) PwABI on care-givers, and (3) care-givers estimates of the views of the PwABI on the topic of care-giver identity.

Table 4.1
Disagreements and Misunderstandings About Care-Givers

| | View of CG on self | View of PwABI on CG | Do participants disagree in their views on the care-giver? | | CGs estimate of view of PwAB | Do the care-givers misunderstand the views of PwABI? | |
|--------------------------|--------------------------|---------------------------|--|-------|---------------------------------|--|-------|
| | Median (range) | Median (range) | Z | Sig. | Median (range) | Z | Sig. |
| Positive Identity | | | | | | | |
| Kind | 4 () | 4 () | -1.265 | .206 | 4 () | -1.291 | .197 |
| Interested | 4 () | 4 (0-4) | -1.485 | .138 | 4 (1-4) | -2.140 | .032* |
| Intelligent | 3 () | 4 () | -3.136 | .002* | 4 () | -1.913 | .056 |
| Supportive | 4 () | 4 () | -.577 | .564 | 4 () | -1.725 | .084 |
| Confident | 3 () | 4 () | -2.190 | .029* | 3 () | -.299 | .765 |
| Mature | 4 () | 4 () | -1.513 | .130 | 4 () | -.758 | .449 |
| Independent | 4 (1-4) | 4 (0-4) | -2.178 | .029* | 4 () | 1.603 | .109 |
| Negative Identity | | | | | | | |
| Lazy | 0 () | 0 () | -.647 | .518 | 0 () | -.355 | .722 |
| Irritable | 2 () | 1 () | -1.766 | .077 | 2 () | -2.610 | .009* |
| Self-centred | 0 () | 0 () | -.097 | .923 | 0 () | -1.087 | .277 |
| Embarrassed | 2 () | 0.5 () | -2.738 | .006* | 0 () | -.918 | .359 |
| Passive | 2 () | 2 () | -.323 | .746 | 2 () | -1.115 | .265 |
| Overprotective | 3 () | 2 () | -2.005 | .045* | 3 () | -1.681 | .093 |
| Confused | 0 () | 0 () | -.350 | .726 | 0 () | -.461 | .645 |

Asterisk (*) indicates statistically significant disagreement ($p < .05$)

The analyses are uncorrected for multiple comparisons, and if Bonferroni corrections were applied, a significance level of 0.002 would be required. This would result in one significant disagreement about the identity of the carer, on the item intelligent. There would be no significant misunderstandings about the identity of the carer.

There were five significant disagreements: carers tended to rate themselves as less confident (median 3 vs. 4) and less intelligent (median 3 vs. 4) than the PwABI rated them to be. Conversely, carers rated themselves as more embarrassed (median 2 vs. 0.5), more independent (median 4 (1-4) vs. 4 (0-4)) and more overprotective (median 3 vs. 2) than the PwABI rated them to be. Carers also rated themselves as more irritable (median 2 vs. 1) than their partners rated them to be, however, this final disagreement just failed to reach significance ($p = .077$). These disagreements suggest that carers are judging themselves negatively compared to their partner's view of them. They feel they are overprotective, stifling their partners and getting irritable with them. They lack confidence in their abilities, feel they are taking on a lot of responsibility and they feel lacking in intelligence and embarrassed.

There were only two misunderstandings: carers think their partners will rate them to be more irritable (median 2 vs. 1) and more interested in the world (median 4 (1-4) vs. 4 (0-4)) than their partners actually rated them to be. Although there was significant disagreement about carer embarrassment, overprotectiveness, intelligence, independence and confidence, there were no significant misunderstandings on these items. Thus, there was no statistically significant misunderstanding on any of the items on which there was significant disagreement.

Discussion and Emergent Questions

The results from the first analysis show that there are a number of disagreements between care-givers and their partners regarding the care-giver's identity. However, despite there being disagreement between PwABI and care-givers about levels of care-giver confidence, embarrassment, intelligence, independence and over-protectiveness, there was no corresponding misunderstanding. Misunderstandings surrounded two different items, irritability and interest in the world. Therefore, care-givers understand that they often disagree with their care-receivers. They are aware that their partners will rate them more positively on a number of identity dimensions. However, carers disagree with their partners' appraisals, and see themselves more negatively than their partners see them.

People, especially in Europe and North America, tend to view themselves more positively than observers (Kashima & Triandis, 1986). Yet the care-givers in this study view themselves more negatively than PwABI. This leads us to *question 1b: How can the pattern of divergences be explained?* Based on the quantitative findings to question 1a, specifically why do carers tend to view themselves negatively relative to the PwABI's view of them without misunderstanding PwABI's viewpoint?

Question 1b: How can the Pattern of Divergences be Explained? What are the Sources of the Disagreement without Misunderstanding?

Could it be that carers are simply being modest in their responses to the questions about themselves? For example, when asked how intelligent they think they are, carers may not wish to place the symbol at four (very like me) as they may feel this is boasting, even if it reflects their feelings about themselves. This could explain carers' lower ratings of self compared to the ratings of PwABI. However, when examining the pattern of disagreements, there are other positive items such as kind, supportive and mature which do have the highest rating (very like me) as the median for carers' self-reports and there is no disagreement between PwABI and care-givers on these items. Therefore, the modesty explanation alone cannot account for the disagreements without misunderstanding in this sample.

To answer question 1b, it is necessary to go beyond the quantitative data to the video data. Possible sources of divergences were coded in the video data of care-givers completing the rating task and discussing their ratings with the researcher. Care-givers discussed with the researcher the fact that they conceal the burden of care from both their partner with ABI and more widely from friends and family. This concealment has the potential to explain the pattern of divergences observed when answering question 1a.

Concealing Care from PwABI

There is a shared goal within the care relationship for the PwABI to be independent and maintain self-esteem and a positive identity. However, the reality is that for many with ABI, and by definition anyone with a care-giver, some level of assistance with activities of daily living is required. To be seen to receive care undermines this sense of independence. Thus PwABI are caught between needing care and not wanting to receive care (Power, 2008). Care-givers often work to ease this bind by concealing their care provision (Thomas

et al., 2002) and distress (Farmer & Stucky-Ropp, 1996). Thus, care-givers try to give their partners the benefits of care without the identity cost. But this means that they are engineering a divergence of perspective between themselves and PwABI, as illustrated in the following exchange with Vicky:

Researcher: Do you think Chris would say that you are too protective?

Carer [Vicky]: No, I don't think he probably would. Erm, I don't think he realises how much chasing up I do behind him *[pause]* er, looking after him.

Researcher: Behind the scenes?

Carer: Behind the scenes, yes. I try to. I have to re-wash the dishes [...] Chris does the ironing, which is very nice. Except I did this morning because some of the shirts were *[whispers]* not well ironed [...] So, erm to protect his feelings. And I'm making decisions [...]

Researcher: That must be quite difficult to be doing these things but not appearing to be doing them, a juggling act.

Carer: Well I try to encourage his independence.

[Dyad 15: Chris (68) PwABI and Vicky (65) carer. Married, four years post TBI]

This excerpt shows the work that Vicky is doing behind the scenes to support Chris. Her priority is to “encourage his independence” but Chris now struggles to successfully complete tasks independently. Thus, to encourage independence Vicky must support Chris without Chris being aware of this support. Her care must be invisible.

Concealing Care from Public Gaze

Supporting the feeling of independence often leads care-givers to not only conceal their effort from the PwABI, but also from friends and family. Central to feeling independent is the successful public performance of independence (Krefting, 1990).

Consider the following excerpt from Rachel:

Researcher: Would you say you were a lazy person?

Carer [Rachel]: No. Erm, no [*places symbol at 'not like me'*]. Again I'd like to be but I'm not. Never get a chance.

Researcher: Sounds like you have quite full days.

Carer: Oh yes, yeah there's quite a lot of [...] well there's a lot of support needed for Fran to look as though she doesn't need support.

[Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE]

Care-givers work back-stage to protect the identity of the PwABI, cleaning up after them, doing their laundry, ensuring that they arrive to meetings on time, appropriately equipped. Front-stage, care-givers help their partner with ABI to communicate, interact, and behave appropriately. Successful performance results in an impression of independence. Our analysis thus supports previous research finding that care-givers conceal care-provision from care-receivers (Power, 2008; Gillespie et al., 2010) and friends and family (Krefting, 1990).

A difficulty with the concept of concealment is that it is impossible to measure the precise prevalence with which this occurs due to the fact that it is likely to be concealed

from the research process. However, the concept has both a theoretical logic and has been demonstrated in the talk of care-givers during this research and published research (Gillespie et al., 2010; Power, 2008). Given the nature of the phenomenon, and that carers would likely conceal the burden of care from researchers, we can speculate that the phenomenon is more widespread than reported.

How Concealment can Explain the Divergences of Perspective Mapped in the Analysis to Question 1a

Concealment can help to explain the disagreements about carer identity from the point of view of PwABI. Hiding the volume and burden of care work would lead PwABI to underestimate the impact of the caring role on their partners, both physically and emotionally. This leads to PwABI's estimations of carers as more confident and intelligent and less overprotective, embarrassed and independent than carers judge themselves to be. There is disagreement without misunderstanding on these items because the disagreement is engineered by care-givers. Care-givers hide their lack of confidence, feelings of embarrassment and their inability to share the workload in the household, from their partner with ABI.

However... Carers Need Recognition for a Challenging Role

This widely observed phenomenon, of concealing the burden of care, has an unfortunate unintended consequence. It creates an identity problem for carers. They are denied recognition for their efforts as others are unaware of the extent of their efforts. That carers want to be recognised for their efforts is evident in their responses to one of the identity rating task questions: do you think your partner thinks you are supportive? In response to this question the following comments were received:

“She’d bloody better” [*Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE*]; “Yeah, I bloody hope so!” [*Dyad 11: Bill (34)*]

PwABI and Nena (32) carer. Married, three years post TBI after an RTA]; and “She’d better” [Dyad 20: Emma (29) PwABI and Angela (49) carer. Daughter and mother, four years post TBI after an RTA]. Carers do not want to be taken for granted, and they want their efforts to be recognised, but, this desire is undermined by concealing the burden of care.

Why is Recognition Important?

It is widely recognised that one’s sense of self is derived from and through our interactions with others (Mead, 1934). Recognition from others in our interactions and relationships is essential for the development of a positive view of Self (Maslow, 1943) and our sense of well-being (Laing, 1960). However, if the carer is concealing the burden of their caring role then they are denied recognition for all that goes into being a carer: the physical work of caring, the effort expended in concealing this work and also the emotional work that goes into caring for a loved one who is not the person they were before (Lezak, 1988). So what recognition do carers actually receive from significant others around them for the care that they provide?

What Recognition do Care-Givers Experience?

Table 4.2 reports the dialogical analysis of the videos of the 28 care-givers in this study completing the rating task. The table maps who the significant others are for care-givers, how many direct quotations of these significant others there were, the number of these quotations which provide positive or negative recognition and the number of quotations which are neutral in terms of recognition.

Table 4.2*Voices of Significant Others in the Carer: Do They Provide Recognition?*

| Significant Other | No. of Direct Quotes | Positive Recognition | | Negative Recognition | | No. of Neutral Quotes |
|-------------------|----------------------|----------------------|--|----------------------|---|-----------------------|
| | | No. | Description of recognition | No. | Description of Recognition | |
| PwABI | 58 | 6 | Acknowledging support (3) Accepting of situation (1) Encouraging (1) Kind (1) | 45 | Critical (9) Defiant (9) Demanding (9) Pessimistic (6) Disinterested (5) Irritable (4) Confused (3) | 7 |
| Family | 12 | 1 | Helping carer to support (1) | 7 | Critical (3) Patronizing (2) Uncomprehending (2) | 4 |
| Friends | 17 | 10 | Supportive of carer (6) Helpful (4) | 7 | Patronizing (3) Avoiding (3) Judgemental (1) | 0 |
| General public | 11 | 0 | | 11 | Stigmatising (7) Patronising (3) Uncomprehending(1) | 0 |
| Health services | 22 | 5 | Helpful (3) Supportive (1) Understanding (1) | 12 | Disinterested (8) Confrontational (2) Discouraging (2) | 5 |
| Total | 120 | 22 | | 82 | | 16 |

Care-givers quoted significant others 120 times, receiving almost four times as much negative recognition (82) as positive recognition (22). The voices in each category of significant other will now be discussed in turn to further understand voices within the carer and the recognition they provide or fail to provide to carers.

Voice of PwABI

Care-givers directly quoted the PwABI 58 times, with only 10% providing positive recognition for the care-givers' efforts and 78% providing negative recognition. The voice of PwABI refracted through care-givers was demanding or pestering (16%), critical (16%), defiant (16%), pessimistic (10%), disinterested despite attempts to enthuse them (9%), irritable (7%), and confused (5%).

Below is an excerpt which demonstrates the demanding or pestering nature of the PwABI voice, one of the most frequent voices found refracted through care-givers:

Carer [Maureen]: It doesn't matter what else you were doing. "I have to be at such and such a place at such and such a time". "Remember that, you must remember that" - because he writes in his diary, the wee soul. He tries hard to do things for himself. Erm like tonight he's meeting, I'm putting him on the half five train for James. Five o'clock he'll start. "Have you remembered, have you remembered, have you remembered?" And if the windows blew in I would still have to have him on the half five train. So, but it's not his fault, it's just what's happened.

[Dyad 23: Mark (60) PwABI and Maureen (56) carer. Married, five years post TBI after a fall]

When Mark is quoted, his voice is seen to be repetitive and pestering and highlights how for carers, the needs of the PwABI must come first. There is a sense that Maureen feels guilty about the pestering image of the PwABI she is communicating, when she says "he tries hard" and ends by saying, "but it's not his fault". There is also a sense of pity when Maureen refers to her husband as a "wee soul". The sense of pity and guilt suggests that she doesn't see their husband-wife relationship in the same way as before the injury, as a relationship of equals, balance and reciprocity.

The voice of the PwABI shows that it is not just the burden of care that carers cannot get recognition for from their partners. Due to the cognitive effects of the injury, carers feel that their partners have changed. The relationship has become unbalanced, and instead of being a relationship between husband and wife, parent and child, brother and sister relationships are now characterized by "health and disability, giving and taking, powerful and powerless" (Krefting, 1990, p. 861). This has been widely discussed as a negative relationship change for the powerless individual, that is, the person with ABI.

However, this new inequality is also profoundly negative for the carer as they are lacking the emotional recognition and support which they feel they used to get from their partner in a reciprocal relationship. Carers often described caring for the PwABI as “looking after a child” and the voice of the partner often comes through the carer as childlike. The childlike voice of the PwABI can be seen in the following excerpt, coded as defiant:

Carer [Rachel]: She's really like a truculent three year old kind of thing because she's not the terrible two's toddler, she doesn't have temper tantrums. She's more at the kind of dangerous stage where you know, "I can do it all by my own self" *[imitates PwABI, takes on a childlike, defiant tone]* and then ch, chaos ensues, you know, yeah.

[Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE]

Significant others use of language relating to childhood naivety has been seen in previous research of accounts of disability from ABI survivors and their relatives (Yeates et al., 2007). To conceptualise their partner as childlike was necessary for carers to be able to “explain the unusual and sometimes hurtful actions of the survivor” (Bowen et al., 2010, p. 130). Caring for a partner with ABI has been described as returning to early parenting (Ponsford et al., 1995) and the childlike voice of the PwABI in the care-giver serves to reinforce the notion that both relationship and roles are not just altered but now unbalanced, with the carer unable to receive the emotional recognition that they may have received from their “partner” prior to the injury.

However, the lack of recognition for the caring role is to be expected from PwABI as carers are deliberately concealing the burden of their caring role from their partners. Carers will have to look further for the recognition they require.

Voice of family members

Care-givers directly quoted family members 12 times, and only 8% of quotations provided positive recognition for the care-giver's efforts, with 58% providing negative recognition. The voice of family members refracted through care-givers was critical (25%), patronising (17%) and uncomprehending of the reality of the situation (17%). The following excerpt demonstrates the critical nature of the voice of family members, the most frequent type of voice:

Researcher: Finally, would you say you were too protective?

Carer [Rachel]: No, I don't think I am, erm [*pause*]. Somebody said something the other day you know, "well you know if you just let Fran do this". It was one of her family 'cos they really just don't understand what it's like, you know 24/7. "If you just let her do something".

[Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE]

This excerpt demonstrates a disagreement between Rachel and the PwABI's family where the PwABI's family were critical of the support given to the PwABI by Rachel. It has previously been suggested that disagreements which question the competence of the care-giver are likely to be "reflected in negative self-evaluations and feelings of failure" (Semple, 1992, p. 653). As critical responses are the most common from family members, these are likely to hamper the development of a positive sense of self as competent care-giver.

As well as being critical, family members could patronise the PwABI, and this was a source of frustration for the carers in the study. The patronising voice of family members can be seen in the following excerpt:

Researcher: Would you say it's true that people treat Emma differently since her injury?

Carer [Angela]: Sometimes. I don't like that. I just don't like. I don't mind...I hate when people treat her like something, like she's not right, you know "Hi hen, how?" [*Raises voice and slows speech*]. What are you doing? Don't you dare. You say "Hi Emma, how are you?" You know elderly people tend to do it. Like my mum does it sometimes you know and Peter's mum. They're like "Oh hen, oh watch now hen" you know as if she's made out of egg shells or like she's five.

Researcher: Fragile.

Carer: Aye, now that bugs me.

[Dyad 20: Emma (29) PwABI and Angela (49) carer. Daughter and mother, four years post TBI after an RTA]

The preceding quote highlights another tension within care-givers. Carers feel they lack recognition from family members: that family members do not understand what the carer is experiencing. In previous research on paradoxical communication, arguments have been described as arising as a result of family members seeing the PwABI as more capable than they are and thus viewing the carer as mollycoddling them (Krefting, 1990). However, as the last quote demonstrates, carers become equally frustrated when family members treat the PwABI as cognitively impaired and patronise them by speaking slowly and over-emphasising their words.

The powerful impact of family members on the primary caregiver's sense of identity and self-esteem has been demonstrated in a previous study of the family situation in dementia care (Semple, 1992). Family members were seen to clash frequently about support needs and Semple describes how conflict among family members regarding the appropriate type and amount of support can arouse care-giver anger and undermine their sense of competence, contributing to a negative viewpoint on the Self.

Lack of recognition is expected from family. As we saw in the earlier analysis of concealment, care-givers conceal not just from the PwABI, but incorporate family members into the cycle of presenting greater independence and ability in PwABI.

Voice of friends

Care-givers directly quote friends 17 times, with 59% providing positive recognition for the care-giver's efforts and 41% providing negative recognition. When negative, the voice of friends was avoiding (18%), patronising (12%) and judgmental (6%). When positive, the voice of friends refracted through care-givers was supportive (35%) and helpful (24%).

Friends provide the greatest source of positive recognition for care-givers of any significant others. The following excerpt demonstrates the support provided to care-givers, and how valuable this support is felt to be:

Carer [Wayne]: But more friends and people who we knew erm, socially, and er you know people at our golf club. Other members and so on, just came along and put out a hand and said you know "take it easy" you know. Made a hell of a difference really. It really did.

[Dyad six: Catherine (46) PwABI and Wayne (70) carer. Daughter and father, three years post stroke]

Although support from friends is vital, the opportunities for the receipt of support diminish after ABI. Social isolation is a common sequelae of brain injury for both care-givers and care-receivers. The number of friendships and as such, sources of positive recognition lessens as time passes post injury (Kozloff, 1987). As a result, there is a perception of abandonment in carers, and this is shown through the “avoiding” voice of friends as the following quote demonstrates:

Carer [Elizabeth]: People [...] that we'll maybe just see now and again and say "oh hi" and you know stop and speak to you and that. Now they'll sort of avoid you and I've seen that.

[Dyad eight: Derek (56) PwABI and Elizabeth (52) carer. Married, three years post stroke]

Patronising responses to the PwABI were seen from friends as well as from family members. In the following excerpt we see a patronising response to the care dyad, as a friend of Maureen and Mark is perceived to treat them as a charity case:

Carer [Maureen]: I've actually heard people say "We need to take Mark and Maureen out again".

[Dyad 23: Mark (60) PwABI and Maureen (56) carer. Married, five years post TBI after a fall]

Friends are a powerful source of recognition for carers, providing emotional support and practical help. However, they are guilty of patronising the PwABI as family

members do and they can ‘drop off the radar’, avoiding interacting with the PwABI and carer, and thus narrowing sources of interaction and positive recognition for care-givers.

Voice of the public

Care-givers directly quoted the general public 11 times, with 100% of these voices providing negative recognition. The voice of the general public refracted through care-givers was stigmatising (64%), patronising (27%) and uncomprehending (9%). The stigmatising voice of the public can be seen in the following excerpt:

Carer [Beth]: I think a lot as well, like Michael. You look at Michael and you wouldn't be able. If he was walking around with a big scar from there to there [*points at her head*] or whatever, people would say "Oh there's something" but because it's not visible, well obviously like his arm and his leg but people don't understand...and I do believe there's certain people who think "oh, he's at it, he's kidding on" because they don't under[*stand*], and they cannae see anything, a physical thing and whatever so it is, quite hard aye.

[Dyad 26: Michael (48) PwABI and Beth (38) carer. Married, four years post TBI after a fall]

In chapter one, the impact of having a hidden disability on identity was discussed. This quotation from Beth suggests the tendency by the public, without a visible cue to disability, to make negative assumptions about the nature of the behaviour of PwABI. This can be frustrating and embarrassing for care-givers and is felt to be “quite hard” to deal with.

As well as stigmatising dyads, the voice of the public is refracted through the carer as patronising. The public is perceived to patronise the PwABI in particular, in the same way as by family and friends, such as by overemphasising words or speaking very slowly.

A societal viewpoint is ventriloquated by carers throughout the rating task. This is the notion of being 'so lucky' and this viewpoint lacks recognition of the daily struggle care-givers face. The notion of luckiness can relate to other families who have been through brain injury, can relate to the prognosis for recovery, or other aspects of life, such as to have each other or to have been able to keep their home or their jobs. Some carers feel they absolutely are lucky and they cling on to this feeling of being lucky and how it could have been so much worse. But for others, this idea of luckiness only adds to their woes, as they feel anything but lucky despite everyone telling them that this is the case. There is a tension here as they are trapped between being grateful for still having their partner and resentment for their partner being a changed person (Perlesz et al., 1999; Landau & Hissett, 2008). For those who do not feel lucky, this leads to feelings of guilt as society doesn't recognise the ambiguous loss and resultant grief that is associated with a person still being physically present but radically altered (Landau & Hissett, 2008; Lezak, 1978). Although several carers talk about the notion of luckiness, there was one direct quotation relating to 'luckiness' and this is presented below:

Carer [Maureen]: I mean anybody else, he only fell from there. He was outside on that roof and that was all the distance he fell. And any normal person would have broken their leg but no, no, he had to go the whole hog and yeah it was awful. But people don't know. "You're lucky". "Right, you know, ok". "You're lucky". And I know, I know that. Ian could have been in a home and he could have had no

life at all. But no lucky, not that word. But it's just, it's dead sad, because he was a nice man *[stares off into the distance]*.

[Dyad 23: Mark (60) PwABI and Maureen (56) carer. Married, five years post TBI after a fall]

In this excerpt, the voice of the public is refracted through Maureen. They believe her to be lucky as her husband didn't die and the quote of "you're lucky" highlights that the situation could have been worse. However, this viewpoint ignores the burden Maureen faces and more importantly the changed relationship between Maureen and her husband. When Maureen says "he was a nice man", this hints at the negative personality changes that Mark has undergone, transforming him into a different person to the one Maureen married. When Maureen says "people don't know" this highlights her isolation in the realities of her changed role and relationship.

Voice of health services

Care-givers quoted people working in the health services, (that is, acute hospital services, rehabilitation and transitional services and general practice) 22 times, with only 23% providing positive recognition for the care-giver's efforts and 55% providing negative recognition. The voice of health services refracted through care-givers was disinterested (36%), confrontational (9%) and discouraging (9%).

Communication with the care receiver is not the only issue for carers. Communication with health services is also difficult as carers feel they have a sense of poor communication with professionals (Ridley, 1989). Misunderstandings between health services and carers are frequently described by carers and are perceived as frustrating and demonstrating insensitivity on the part of health professionals (Larson, 1998).

The following excerpt demonstrates what one care-giver felt her GP was thinking, and demonstrates the disinterested voice of health services which is most frequently refracted through carers:

Carer [Leanne]: *[discussing the family GP]* I think she should have known you know, a bit more. I don't know, I think she was just trying to, it felt like "I don't know what to do with you so just go away and get someone else to look at you".

[Dyad 14: Peter (46) PwABI and Leanne (44) carer. Married, time since TBI after fall unrecorded]

In terms of carer recognition, failure of services to follow up on them was a source of anguish for many carers. Carers often feel they have been left by services, feeling that services only recognise the acute and transitional phases but don't acknowledge that for carers of those with brain injury, the support is only just beginning when the PwABI leaves acute or transitional services. Carers thus feel invisible to health services in the long term. In the following excerpt, John is expressing his frustration that he felt long term care was left in his hands when he felt that it was the responsibility of health services to assist with this process. The voice of health services refracted through the carer is imagined and relates to how he would *like* health services to respond:

Carer [John]: They're *[rehab. professionals]* not actually turning round, putting the phone down and saying "We're coming down to see you. See how you're getting on. We're not leaving it to you, we're coming down to see you".

[Dyad 18: Grant (59) PwABI and John (54) carer. Siblings, three years post stroke]

Regardless of the reality of follow-up from hospital and/or rehabilitation settings, the carers in this study feel as though they have been left to carry on alone. This impacts on recognition for care-givers as they feel that the protocol for treating patients ends when they come home, which makes carers feel as though health services view the PwABI as ‘better’ and not in need of further input. This undermines the significant work which care-givers put in to assist PwABI to engage in daily life and the burden this places on carers.

How Lack of Recognition can add to the Explanation of Divergences of Perspective about Carer Identity

The analysis of voices of significant others in the carer reveals a lack of recognition from all angles. The lack of recognition that carers receive from a variety of significant others contributes to the explanation of the pattern of disagreements we saw, with carers viewing themselves negatively compared to PwABI’s viewpoint. Carer’s perceive the voice of others to be negative, denying them recognition for all they do as carers and this lack of recognition from others has impacted negatively upon the way carers view themselves. Recognition from others for what we do is essential for a sense of well-being (Laing, 1960) and the voice of others refracted through care-givers lacks acknowledgement of the carer in their caring role, thus they cannot derive self-esteem and build a positive sense of Self from their caring role.

Beyond Significant Others to the Generalised Other: Striving Towards an Impossible Ideal

Significant others, such as friends and family are not the only possible sources of recognition for carers, this can come in the abstract from the generalised other.

Cultural Representations of What it Means to be a Carer

Mead’s (1934) notion of the generalised other relates to the understanding we have of the commonly held expectations that others have relating to roles, actions and thoughts.

Representations of ‘carer’, portrayed via cultural mediums such as through the media, guide thinking as to what is required of carers even if one has never actually been in this position. Cultural representations of carers include the notion of selflessness, with the prioritisation of the care-receiver’s identity and protection of the care-receiver’s self-esteem over their own. The ideal care-giver is depicted in figures such as Florence Nightingale or Mother Teresa, a person who is ever kind, ever patient and provides just the right level of input to support whilst at the same time promoting independence. Cultural representations will be internalised and carers will try to live up to the template they have of the ideal care-giver.

If carers feel they are living up to the cultural ideal of ‘carer’ and meeting the expectations of the generalised other, then they may receive recognition in the abstract – from a wider audience, described by Bakhtin as the “superaddressee”:

“Each dialogue takes place against the background of the responsive understanding of an invisibly present third party who stands above all the participants in the dialogue” (Bakhtin, 1986, p. 126).

The superaddressee is a higher addressee, an authoritative third party, whose “sanction is decisive for the acceptance or non-acceptance of the text’s words as legitimately expressing the world of the narrative” (Mey, 2000, p. 283). A speaker addresses the superaddressee in speech in addition to their direct audience. The superaddressee varies and may be God, absolute truth, the people or any other expression of a higher addressee (Bakhtin, 1986). However, the superaddressee is not a “metaphysical” or “mystical” being but is instead a metalinguistic fact, or “constitutive aspect of the whole utterance” (Bakhtin, 1986, p.126) which is often hidden within an utterance and can only be revealed through deeper analysis (Mey, 2000).

If recognition is received from the superaddressee for meeting the expectations of the generalised other, it may help to counteract the lack of recognition that carers received from significant others in the study. So are carers able to meet the expectations of the generalised other and receive recognition from the superaddressee?

Trying to ‘Fit the Mould’ of the Ideal Carer

Care-givers are actively trying to reconstruct their identity in order to fit cultural representations of carers and become good carers. However, this is not an easy process. Fitting the template of carer requires the care-giver to be selfless and almost saintly, thus the expectations are unrealistic. Also, as the move to a new role, that of care-giver, takes place, other previously held roles and social positions associated with ‘normal work’ and ‘normal relationships’ are not forgotten. There is no simple ‘change’ in identity as traces of previous social positions remain. Instead there is a layering of different identities which are in tension. The following excerpt demonstrates the tensions inherent in the identity of a person who is trying to fit the cultural mould of the selfless, nurturing carer:

Researcher: Would you see yourself as a supportive person?

Carer [Laura]: [*Places symbol at ‘quite like me’*], [*pause*] I have to be. There’s no other alternative with an eyesight problem as well. You have to be there to guide her through different things, if you are going on buses or trains you have to tell her which bus she is going on because she can’t see the numbers[...] so somebody has to be with her and it’s generally me.

Researcher: Have you found it easy to?

Carer: No, very difficult, verrry difficult because I am not the most easy going of persons. I have kind of had to learn to adapt very rapidly, had to learn to keep my temper, such like her father doesn't [...]

Researcher: Do you feel like it's something you are there with now, or?

Carer: Sometimes. And other times I could just argh [*flings arms above her head*] but I walk away and go outside and have a walk round about and come back and I'm fine.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

We can see from the answer to this question that Laura knows that as a carer she should be supportive and she has actively learnt to fulfil the supportive role. However, as the discourse progresses we see a tension within Laura as being supportive does not come naturally to her. A tension remains between her past self who had a short fuse and the new supportive identity that she has carved out for herself. This can be seen in the last response where the voice of Laura's old self ("argh") is juxtaposed against her new self, the Laura who has a strategy to maintain the new supportive identity by getting some breathing space and having a timeout. The difficult process of reconstructing her identity to fit the carer role is expressed in the dialogue by the repetition of the idea of 'having to adapt'. Even when she does meet the expectations of carer by being supportive, there remains a tension which prevents her from exclusively taking on the new role of carer.

The Ideal Carer's Mantra: "You Just Have to Accept the Hand you've Been Dealt and Move On"

One cultural representation of care-givers involves the ability to accept adversity, to work through it and adapt in positive ways. This acceptance and working through is one

of the goals of rehabilitation of the PwABI (Bowen et al., 2010) and is as much an ideal for carers. 'To accept the hand you have been dealt and move on' is a mantra which is echoed by the carers in this study. This parroting of the expectations of the generalised other has an impact on carers in one of two ways. For some it is a useful mantra and a good guide to follow, but for the majority of carers this discourse is hollow. Some carers find it difficult to accept what has happened to their partners and as a result themselves, but feel they should be able to achieve acceptance. This leaves them feeling inadequate when they can't live up to the mantra of 'getting on with the hand you have been dealt'. Thus, they have failed at living up to the cultural template of carer and this may affect the recognition they can receive from the superaddressee. The following excerpt expresses both the mantra of the 'ideal carer' and the difficulties that Laura has in accepting the way things are:

Researcher: Ok, so now we are going to talk about the same things again but it's how you see Sarah rather than how you see yourself.

Carer [Laura]: Lovely person, lovely natured, very emotional...Now I love her to bits but 18 hours out of 24 I hate her. You know it's just the total effects of the accident. I'm 67 years of age and I did not expect to go back to looking after a child at my age because basically she is a child. In her outlook and everything else she tends to be quite childish. Because of her head injury again is very childish words in conversation and that can be quite embarrassing as well. But she gets on with life and you've just got to accept what you've, the hand you've been dealt.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

In this excerpt we see Laura's struggles with becoming a carer. She feels she is getting older and does not wish to "go back to looking after a child". Fitting the template of the ideal carer is difficult, as Laura finds Sarah's child-like nature after ABI embarrassing and hard to deal with. Laura ends the excerpt by saying, "you've just got to accept what you've, the hand you've been dealt", yet this feels hollow as her description of life with the PwABI up to this point has suggested that she finds it very difficult to accept what has happened.

Anxiety: Not Living up to an 'Ought Ideal'

Higgins (1987) has highlighted that discrepancies between self-concept and the "ought self", that is, your "representations of the attributes that someone believes you should or ought to possess (i.e., a representation of someone's sense of your duty, obligations or responsibilities)" (p. 321) leads to emotional vulnerabilities related to anxiety. 44.8% of carers in this study scored eight or more on the anxiety subscale on the HADS, the lower diagnostic threshold for the scale (Bjelland et al., 2002). 24.1% scored between eight and ten which indicates possible anxiety disorder and 20.6% scored above 11 on the scale, indicating probable anxiety disorder. This compared to 17.3% of carers scoring within the clinical range for depression (a score between eight and 20) on the depression subscale of the HADS. These percentages link to previous findings on anxiety scores (Greenwood et al., 2009) which highlighted the overemphasis in the literature on caregiver depression and the corresponding under-emphasis on caregiver anxiety. Carers feel they ought to be able to meet the demands of being a perfect carer as it is their responsibility to be able to do this for the PwABI (Higgins, 1987). Not fulfilling the expectations of the generalised other leaves care-givers feeling anxious and as a result negative about themselves and their ability to provide an appropriate standard of care to their loved ones.

In summary, in their words and descriptions of caring, care-givers are not just addressing their direct audience, but the superaddressee. If they can feel they are fitting the cultural template of what it means to be a carer then they may be able to feel recognised for their role in the abstract, from a higher authority. However, the reality of fitting the cultural mould of the ideal carer is impossible, as the mould requires almost saintly patience and selflessness. Cultural ideals suggest that carers should be able to accept the situation and move forward with positivity, yet this is difficult in reality as past roles, relationships and experiences which were more 'normal' and 'better' still remain, in tension with the new role and identity of care-giver. Being unable to live up to the template of the ideal carer leaves carers feeling anxious and lacking recognition from all angles.

Discussion

Summary

In answer to question *1a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding carer identity?* divergences of perspective are common between carers and those they care for regarding the carer's identity. Disagreements are the most common type of divergence. Carers see themselves as less confident, less intelligent, more embarrassed, more over-protective and more independent than their partners with ABI rate them to be. However, these disagreements do not translate into misunderstandings. The two misunderstandings found did not relate to the items on which there was disagreement. Ultimately, carers did not misunderstand their partners' view of them so much as they disagreed with it on the basis of this study using the rating task methodology. Carers saw themselves negatively, feeling that they are overprotective, stifling their partners and getting irritable with them. They lack confidence in their abilities, feel they are taking on a lot of responsibility, and feel embarrassed and unintelligent.

The second analysis attempted to answer question *1b: How can the pattern of divergences be explained?* Carers have deliberately created a divergence of perspective between themselves and the PwABI. Carers conceal the care work that they do so that they can help maintain their partner's sense of self-esteem and independence whilst providing necessary care. However, this leaves carers in a difficult position. They have invested a great deal in their role as carer, struggling to mould their identity and meet societal expectations of the ideal carer. They want recognition for this role and feel frustrated that they don't get it. The lack of recognition they receive for their role, both from significant others and from the superaddressee, leaves them anxious, lacking in self-esteem and viewing themselves negatively.

Recognition from Partners?

What is to be done? Current suggestions are that disagreements and contesting viewpoints within family systems are a problem for the relationship and should be addressed, perhaps through bringing "all aggrieved groups to the table to talk about what they each see as different in themselves and each other" (Bowen et al., 2010, p.134) or externalising the problem to confront it as a united pair (Yeates et al., 2007).

Attempting to resolve this divergence of perspective between carers and PwABI is not advocated here as it has been manufactured by carers and is adaptive for both PwABI and the relationship. To attempt to discuss the differing viewpoints would undermine the work that carers have done to create the misunderstanding and protect their partner. Also, previous studies have shown that care-receivers believe they discuss problems and are more in alignment with carers than carers do. Thus, care-receivers may not be aware of a discrepancy in accounts (Walls et al., 1977). However, as we have seen, carers require recognition for the carer role as their identity and self-esteem is negatively affected by

concealment of the care work that they do. Yet it is not desirable for this recognition to come from the PwABI, because it would come at the expense of threatening PwABI identity. Instead, this recognition needs to come from an alternative source outwith the primary dyad.

Recognition from Family and Friends?

Analyses of the significant others within the carer's discourse, namely the PwABI, family and friends, society and health services all revealed a lack of recognition of the carer. In the same way that carers cannot expect to receive recognition from the PwABI due to the concealment of the burden of care, the same is true of family and friends. To reveal the extent of their burden would be to put the PwABI at risk of stigma, marginalisation and loss of self-esteem.

Recognition from Health Services?

One unproblematic source of recognition is from Health Services due to their unique insight into the prognosis of those with brain injury and the reality of the support that carers are likely to provide. Moreover, revealing the burden of care to health professionals does not risk stigmatising the PwABI. However, carers felt that interactions with health services were problematic, as health services were disinterested, confrontational and discouraging. Perceived failure of health services to follow up on families in the long term was a source of stress for carers, denying them recognition of the daily effort required to assist PwABI to participate. Scottish Intercollegiate Guidelines Network (SIGN) clinical guidelines on early management of patients with a head injury highlight that follow-up is beneficial for patients and families, particularly when this includes education, advice and reassurance, and this follow-up can be by telephone or in person where severe and persistent problems are identified (SIGN, 2009). Follow-up has demonstrated positive benefits for patients (for example, Wade, King, Wenden, Crawford

& Caldwell, 1998). Recommendations have also been made for open-ended offers of support for carers (Royal College of Physicians and British Society of Rehabilitation Medicine, 2003). The findings of the present study need to be replicated, however, they provide preliminary evidence that as part of the recommended follow-up and open-ended support opportunities it would be beneficial to include opportunities for recognition of carers. As the dyads in this study were a mean of 7.84 years post ABI, it suggests that recognition of carers is required in the long term.

Recognition Through Local Support Groups?

In addition, detailed and up to date advice should be given to carers regarding local carer support groups during follow-up. Guidelines have recommended early referral to self-help groups for carers (Royal College of Physicians and British Society of Rehabilitation Medicine, 2003). Support groups have been shown to be beneficial for carer well-being (Foster, 2011). They provide a unique space which allows for ‘camaraderie and comparison’ (Locock & Brown, 2010). In terms of camaraderie, being with other people who are ‘in the same boat’ allows for “connecting through shared experience” (Foster, 2011, p. 59), including the sharing of practical advice and coping strategies (Butow et al., 2007; Benbow, Lock Ong, Black & Garner, 2009; Locock & Brown, 2010). This ‘experiential’ knowledge is regarded as particularly beneficial for carers as it is a qualitatively different type of knowledge than that which can be offered by professionals or lay people (Munn-Giddings & McVicar, 2006). Support group members state that one of the main benefits of attendance of groups is that they could “meet others who could do more than sympathise with their situation” and instead provide genuine empathy (Munn-Giddings & McVicar, 2006, p. 29). Carers groups also provide the opportunity for carers to share negative emotions, such as anger, fear and guilt which can provide reassurance to the group that it is not only acceptable to have negative emotions but that others share

them (Locock & Brown, 2010). Carers struggle to fit the cultural notions of the ideal carer, as these are unrealistic. To be able to see that other care-givers experience the same difficulties and that others struggle to fit the 'ought' ideal, may help carers to feel better about not being the perfect carer.

From a dialogical theoretical perspective, carers groups may do more than help carers feel better about not being the perfect carer. They may reduce the impact of lack of recognition from the superaddressee by replacing this, even temporarily, with a more salient and grounded positive interpersonal recognition from other carers as a group. Recognition from fellow carers can be provided on issues which are difficult to discuss as they may hurt the PwABI or significant others and which may, in another setting, leave carers vulnerable to stigmatising valuations from others who do not comprehend the realities of the care-giving role (Goffman, 1963). In addition, engaging with other carers regularly over time may help to internalise 'other carers' as a significant other with a voice within the dialogical selves of carers. This voice has the potential to be more positive, helping to balance the more negative voices of other types of significant others in contexts outwith the support group itself.

However, recognition has not been explicitly discussed in the literature on support groups and support groups were not discussed directly during the rating task. It cannot be inferred from this study what longer term impact receiving recognition from fellow carers may have or for how long the superaddressee may be absent from the room. In addition, the make-up of support groups may be extremely relevant. The process of articulating and inviting recognition for the aspects of care-giving which are more difficult to speak about may vary between different types of carers. It has been suggested that in carer support groups, partners may find it easier to engage in honest talk surrounding their role at first

than other types of significant others (Yeates, personal communication). More research is required to explore processes of recognition in carer support groups from a dialogical theoretical perspective. However, the safe space provided for carers to express difficult emotions and have others respond to them with empathy and experiential understanding may be key to providing the source of recognition that carers may be lacking.

A caution arising from the heterogeneity of the sample

Several different types of relationship have been subsumed under the 'carer' label and it must be acknowledged that the amalgamation of findings may have led to subtle differences between relationships being missed. Although there was evidence of concealment, lack of recognition and negative feelings about self across carer relationship types, the way in which this manifested may vary. When examining the dialogical self of carers, the PwABI voice was found to be defiant, demanding, pessimistic, disinterested, irritable and confused and these quotations came from the spectrum of carer relationships. However, in the cases where the voice of the PwABI was found to be critical, the majority were direct quotes from the dialogical selves of romantic partners, rather than familial relationships. It may be that romantic partners see more criticism of their efforts as there is a greater rupture in the relationship, a more marked relational change and a greater need for adjustment. A relationship previously characterised by equality and a meeting of minds is replaced by an unfamiliar and unequal relationship which must be negotiated. Although not reported in this chapter, during analysis direct quotations of the carer's own voice were examined and there were examples of the carer's voice being highly protective and an emotion regulator for the PwABI. These quotations came almost exclusively from family relationships (siblings and parents) and perhaps indicate that parents and siblings may return to previously held roles of protector and nurturer which were in place at an earlier stage in life pre-ABI, roles which romantic relationships have never held with one

another and may be more difficult to manufacture. It is therefore acknowledged that subtle nuances within different carer categories may be lost by categorising all types of significant others as 'carers'.

Limitations of the study

The realities of the recruitment process have meant that the IPM data is based on a small number of participants and statistical power is lacking in the study. Ideally, a sample of between 50 and 60 dyads should have been included in the research. As well as smaller than desired participant numbers, there is a risk of Type I error in the data. The quantitative data was uncorrected for multiple comparisons. If Bonferroni corrections had been applied, there would have been only one significant disagreement, on the item intelligent and no significant misunderstandings about the identity of care-givers.

Conclusion

Care-givers struggle to live up to the ideal of being a perfect carer, of being selfless, and providing care without getting frustrated or wanting to share that frustration. Yet, care-givers are doing something which is not in the ideal image of the carer, but which is actually much more selfless; they are working to protect the identity of their partner at the expense of their own identity. Care-givers are successfully concealing the burden of care, successfully making their partners feel more independent than they are, and successfully making friends and family overestimate the abilities of their partner. The cost is that carers feel misunderstood by their partner, their friends and family. Indeed rather than receiving recognition for their tremendous and often selfless efforts, they feel that they are rewarded with being taken for granted by their partners and criticised by significant others.

Chapter Five – Convergences of Perspective about PwABI Identity: Taking a Relational Approach Reveals Intersubjective Alignment

ABI produces a complex mix of cognitive, behavioural, communicative and psychological problems and the onset of disability causes role changes. PwABI can become care-receivers, struggling for independence (Newsom & Schultz, 1998), and at risk of stigmatisation (Goffman, 1963). Divergences of perspective about PwABI are commonly reported within informal care relationships, and are particularly focused on changes in PwABI personality and behaviour (Ponsford et al., 1995). It has been suggested that PwABI are often unable to recognise and process changes they experience due to deficits in self-awareness (Prigatano & Fordyce, 1986; Prigatano & Altman, 1990), and as such self-awareness deficits are considered a major barrier to psychosocial and relationship adjustment after injury (Ponsford et al., 1995; Prigatano & Fordyce, 1986). However, there is a great deal of uncertainty surrounding how common impaired self-awareness is and how it should be assessed. In addition, the term self-awareness is too broad in itself and it may be better to think of awareness in terms of the various domains of functioning after ABI. Indeed, awareness of deficits has been shown to vary across domains. People with TBI have been shown to exhibit greater awareness deficits in the domains of behavioural and affective functioning than sensory and motor functioning (Hart, Seignourel & Sherer, 2009). What no previous study in the ABI literature has done is to systematically assess both sides of the care relationship simultaneously to ask: *2a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding PwABI identity?* This chapter will address this question and will then go beyond the divergences themselves to locate their source. Thus, this chapter will also answer the question: *2b: How can the pattern of divergences be explained?*

How the Data Set was Analysed

To answer question *2a: Are there any disagreements and/or misunderstandings between carers and PwABI regarding PwABI identity?* disagreement and misunderstanding were calculated on an item-by-item basis. Disagreement was considered the difference between the ratings PwABI gave themselves and the ratings their care-givers gave them for the identity items. Misunderstanding was operationalised as the difference between PwABI's estimates of the rating their partner would give them and the actual rating the care-giver gave them. Wilcoxon Matched-Pairs Signed-Ranks tests, with two tailed significance, were used to test (1) whether care-givers and PwABI agree in their views about PwABI and (2) whether PwABI understand the views that their care-giver has about them.

To answer question *2b: How can the patterns of divergences be explained?* the issue of self-awareness is pinpointed. The PCRS, a standard discrepancy measure of self-awareness was completed by 22 of the 28 dyads in the study. Discrepancy scores on the PCRS are used to categorise PwABI into two groups, a group with small discrepancy scores (who would be classified as self-aware on the basis of this measure) (N=15) and a group with large positive discrepancy scores (who would be classified as lacking self-awareness on the basis of this measure) (N=7). These groups were compared using Independent Samples T-Tests. The means of the two groups were compared on levels of cognitive impairment, HADS scores for both carer and PwABI, and carer and PwABI ratings on the PCRS. Differences between conceptualisations and methodologies between the rating task used in this research and the PCRS scale were considered. Video recordings were analysed of the seven PwABI in the large discrepancy score group completing the rating task and discussing their ratings with the researcher. Using NVivo nine software,

perspectives of PwABI were explored in talk, regarding their deficits, functional consequences of deficits and their relationship with their informal carer.

Question 2a: Are there any Disagreements and/or Misunderstandings between Carers and PwABI Regarding PwABI Identity?

Table 5.1 presents the median ratings of (1) PwABI on themselves, (2) care-givers on PwABI, and (3) PwABI’s estimates of the views of care-givers on the topic of PwABI identity.

Table 5.1
Disagreements and Misunderstandings About PwABI

| | View of PwABI on self | View of CG on PwABI | Do participants disagree in their views on the care-giver? | | PwABI’s estimate of view of CG | Do PwABI misunderstand the views of CGs? | |
|--------------------------|-----------------------|---------------------|--|--------------|--------------------------------|--|--------------|
| | Median (range) | Median (range) | Z | Sig. | Median (range) | Z | Sig. |
| Positive Identity | | | | | | | |
| Kind | 4 () | 4 () | -.577 | .564 | 4 () | -1.299 | .194 |
| Interested | 4 () | 4 () | -1.786 | .074 | 4 () | -1.915 | .056 |
| Intelligent | 3 () | 4 () | -.423 | .673 | 3 () | -.192 | .848 |
| Supportive | 4 () | 4 () | -.872 | .383 | 4 () | -1.459 | .145 |
| Confident | 3 () | 2 () | -.497 | .620 | 3 () | -1.753 | .080 |
| Mature | 4 () | 3.5 () | -1.283 | .200 | 4 () | -1.476 | .140 |
| Independent | 3 () | 3 () | -1.006 | .314 | 3 () | -.264 | .792 |
| Negative Identity | | | | | | | |
| Lazy | 0 () | 0 () | -.221 | .825 | 0.5 () | -.213 | .831 |
| Irritable | 2 () | 1 () | -1.182 | .237 | 2 () | -1.589 | .112 |
| Self-centred | 1 () | 2 () | -2.381 | .017* | 0.5 () | -2.134 | .033* |
| Embarrassed | 1.5 () | 1 () | -.945 | .344 | 2 () | -.979 | .328 |
| Passive | 2 () | 3 () | -.132 | .895 | 2 () | -.646 | .518 |
| Overprotective | 2 () | 2 () | -.165 | .869 | 2 () | -.302 | .763 |
| Confused | 2 () | 3 () | -1.230 | .219 | 3 () | -.399 | .690 |

Asterisk (*) indicates statistically significant disagreement ($p < .05$)

The analyses are uncorrected for multiple comparisons, and if Bonferroni corrections were applied, a significance level of 0.002 would be required. This would result in no significant disagreements and misunderstandings about the identity of the PwABI.

There is one significant disagreement and one significant misunderstanding between PwABI and their care-givers regarding the identity of the PwABI. This corresponding disagreement and misunderstanding is on the item self-centred. PwABI think they are less self-centred than their carers judge them to be (median 1 vs. 2). In

addition PwABI think that their carers will judge them to be less self-centred (median 0.5 vs. 2) than their care-givers actually do. Due to there being only one significant disagreement and misunderstanding out of 14 items in the rating task, it would seem that there is alignment between the ratings given by the 28 PwABI and their carers in this study regarding the identity of the PwABI.

Discussion and Emergent Questions

The lack of divergences found in this study is unexpected on the basis of the literature

The finding of convergences of perspective between carers and PwABI on all items but self-centred is unexpected, as the literature suggests that there are lots of divergences of perspective regarding PwABI. For example, divergent perspectives have previously been found on issues surrounding the disability (Horowitz et al., 2004), risk (Heyman & Huckle, 1993), and the requirements of the care-receiver (Walters et al., 2000). When divergences were found previously in the literature, what was the explanation for them?

Previous divergences centred around personality change

Personality changes, the prevalence of which varies between samples but which have been described as “a most consistent feature after closed head injury” (Jennett, 1972, as cited in Brooks, 1984, p. 124), can cause long-term problems for family and friends (Perlesz et al., 1999), and are a significant source of divergences. Care-givers have previously been shown to characterize their care-receivers with ABI as hostile (Kreutzer et al., 1994), angry (Farmer & Stucky-Ropp, 1996), disinhibited (Brooks, 1984), child-like (Thomsen, 1974), irritable (Thomsen, 1984), self-centred (Farmer & Stucky-Ropp, 1996), passive (Yeates et al., 2007), and dependent (Ridley, 1989); all negative characterizations that PwABI are likely to reject. These aspects of personality on which there are

divergences are incorporated in the rating task so we would expect to see disagreements and misunderstandings on these items.

Cognitive and communicative impairments impair perspective taking ability

The cognitive and communicative impairments experienced by PwABI can often compound problems. These impairments have been described as prohibiting the ability of PwABI to relate to others in an appropriate and meaningful way (Trudel et al., 1998; Verhaeghe et al., 2005; Wood & McMillan, 2001). Both the recognition and processing of perspectives on self and other may be reduced leading to inter-personal misunderstanding (Yeates et al., 2008). In addition, lack of expression is common in people with cognitive impairment and this can interrupt patterns of interaction and perspective taking (Gosling & Oddy, 1999).

Self-awareness deficits prevent PwABI seeing changes in themselves and understanding the viewpoint of others

One of the most common reasons cited for there being divergent perspectives surrounding the PwABI is self-awareness deficits after injury. The general prevalence of self-awareness impairments is unknown but problems in self-awareness are considered common after TBI, particularly after severe injury (Prigatano, 1991; Sherer, Bergloff, Boake, High Jr & Levin, 1998). To be unable to recognise changes in oneself after ABI will affect the ability to reflect on self and to take the perspective of the other on issues of self and disability, and this can contribute to negative outcomes, such as “conflict with family members, who may be seen by the injured individual as overly protective or negative” (Ponsford et al., 1995, p. 236). Inability to pinpoint negative changes can also lead PwABI to make unrealistic life decisions.

Current conceptualisations of self-awareness deficits see the problem as lying ‘within’ the PwABI and are traditionally thought to have a neurocognitive and/or denial

driven basis (Ponsford et al., 1995; Bond, 1984), with increasing recognition of the influence of social factors on expressions of awareness (Clare, 2004; Bowen et al., 2010). Patients with self-awareness deficits frequently maintain that they are normal in their higher cerebral functions whilst at the same time acknowledging that there is some change within themselves which they are unable to pinpoint (Prigatano & Altman, 1990). Difficulty in identifying deficits is shown both in patients' self-reports and also their artistic expressions (Prigatano & Altman, 1990). Change is particularly difficult to pinpoint in the domains of affective and behavioural functioning (Hart et al., 2009). An inability to identify areas of change, which are apparent to the care-giver, are likely to result in divergences of perspective between PwABI and care-givers. It should be noted here, however, that some studies have found divergences in the opposite direction. For example, Pagulayan, Temkin, Machamer and Dikmen (2007) found that an in-patient sample of those with TBI reported *more* difficulties than their carers up to one year post injury.

Emergent Question: Why has this study revealed a lack of divergences?

Although the situation is not clear cut, the literature contains many cases of divergences of perspective between care-givers and PwABI, which are likely to be exacerbated by the cognitive and communicative deficits PwABI experience, particularly deficits in self-awareness. However, the 28 PwABI in this study show alignment with care-givers in their perspectives about PwABI identity. Why has this study revealed a lack of divergences of perspective between PwABI and their care-givers about PwABI identity when the majority of other studies suggest significant disagreements and misunderstandings?

Question 2b: How can the Pattern of Divergences be Explained? Why is there a Lack of Divergences of Perspective Regarding PwABI Identity in this Study?

Lack of Divergences is Due to the Relational Method Used in this Research

It is proposed that the finding of a lack of divergences regarding PwABI identity in this research may be due to the fundamental differences between conceptualisations and measurement methods in this study compared with others. This research has taken a relational approach which has systematically measured both sides of informal care dyads simultaneously, has separated out different levels of perspective taking and does not privilege the care-giver's viewpoint over that of the PwABI. In addition, the use of dual analysis techniques, incorporating both quantitative mapping of perspectives alongside qualitative exploration of the talk surrounding ratings, has led to rich data on perspectives and convergences/divergences.

The remainder of the chapter will turn to the concept of self-awareness to explore the possible explanation for the finding of convergences in the present study as being a result of the rating task methodology. Self-awareness can be measured in a variety of ways but this chapter will focus on one commonly used method, namely that of self-report discrepancy rating scales using significant other ratings. Discrepancy rating scales measure perspectives of both halves of a dyad as the present research does, and assesses convergence/divergence as the present research does. However, the critiques below will argue that self-report discrepancy rating scales study relationships at the individual level, do not treat the viewpoint of care-givers and care-receivers as equal, and confuse disagreement with misunderstanding.

Are Few Divergences in the Rating Task Simply a Result of the Sample?

Before continuing it is necessary to rule out differences between my sample and samples which have previously been studied using traditional discrepancy rating measures.

Does my sample show any divergences on a traditional self-awareness measure?

Alongside the rating task, the sample carried out the PCRS, a self-report discrepancy rating scale which is frequently used in research and clinical settings to measure self-awareness in PwABI. The scale purports to measure self-awareness by measuring the discrepancy between the ratings given by PwABI regarding their capabilities and the ratings given by a relative or clinician on the same items. A discrepancy where the PwABI rates themselves as more competent than the significant other/clinician, is suggested to indicate impaired self-awareness. The greater the discrepancy, the greater the impairment in self-awareness.

Of the 28 dyads who took part in the research, 22 pairs completed the PCRS. Six PwABI were unable to complete the measure due to it being too complex. Of the 22 pairs who did complete the PCRS, seven PwABI (32%) had a positive discrepancy score (a discrepancy score greater than zero) *and* six of the seven also had a higher number of items where they rated themselves as more competent than their carer rated them than the number of items on which carers and PwABI agree and where carers rated the PwABI as more competent than the PwABI rated themselves. This indicates deficits in self-awareness according to two types of PCRS scoring criteria (Fleming et al. 1996).

Table 5.2*PCRS Results for the Seven Dyads with an Indication of Low Self-Awareness*

| Dyad | PwABI name | Carer name | Discrepancy score | Number of items rated higher by PwABI | Number of items rated same | Number of items rated lower by PwABI |
|------|------------|------------|-------------------|---------------------------------------|----------------------------|--------------------------------------|
| 3 | Sarah | Laura | 37 | 18/30 | 10/30 | 2/30 |
| 5 | Fran | Rachel | 19 | 17/30 | 10/30 | 3/30 |
| 11 | Bill | Nena | 16 | 13/30 | 16/30 | 1/30 |
| 15 | Chris | Vicky | 43 | 21/30 | 9/30 | 0/30 |
| 17 | Richard | Carolyn | 24 | 18/30 | 8/30 | 4/30 |
| 19 | Hugo | Jocelyn | 44 | 25/30 | 3/30 | 2/30 |
| 23 | Mark | Maureen | 25 | 20/30 | 10/30 | 0/30 |

The data set of the 22 dyads who completed the PCRS was split into two, dyads with either a negative discrepancy score or no discrepancy between ratings, where the PwABI would be classified as self-aware on the basis of PCRS discrepancy scores (N=15) and dyads with positive discrepancy scores (N=7), that is a divergence exists between carers and PwABI regarding PwABI capabilities where PwABI rate themselves as more capable. PwABI would be classified as lacking self-awareness on the basis of large positive PCRS discrepancy scores. The two groups were subsequently compared. Independent Sample T-Tests showed that the two groups were significantly different in mean discrepancy scores ($t=-6.637$, $p=.000$) so it is appropriate to consider these two groups separately. Due to 32% of the 22 dyads completing the measure having large positive discrepancy scores, the differences between this study and others which only use PCRS ratings is not due to the sample in this study having uniform small or negative discrepancy scores.

It is the Conceptualisation of Divergences of Perspectives and the Method of Exploring Relationships Which Differ Between this Study and Others

If the sample is not the reason for the lack of divergences, then we can continue with the explanation that differences in conceptualisation and measurement of relationships are responsible for the difference between this study which finds few

divergences of perspective and previous studies which suggest divergences. The remainder of this chapter argues via four critiques that traditional conceptualisations and self-report patient/carer discrepancy measurements of self-awareness are flawed, creating an individualised and false impression of relational phenomenon by (1) treating disagreement as misunderstanding, (2) measuring a relationship but privileging the viewpoint of one half of that relationship, (3) only using quantitative ‘scores’ to explain complex and fluctuating relations, and (4) failing to account for the co-construction of reality within relationships. It is argued that the rating task used in this research overcomes the flaws by taking a relational approach which measures both halves of a dyad simultaneously; measuring both agreement and understanding and exploring perspectives and the relation between them quantitatively and qualitatively without privileging any viewpoint. The relational approach used in the current study has the potential to explain the lack of divergences observed when answering question 2a.

Critique One: The Concept of Self-Awareness Suggests Understanding but Discrepancy Scales Measure Disagreements

Mixing up disagreement and misunderstanding: The concept indicates understanding

There are various definitions of self-awareness but all share the idea that to be self-aware an individual must be able to see themselves objectively and understand that they have deficits in certain areas. One such definition from Clare et al. (2008) defines self-awareness as “an accurate appraisal of a given aspect of one’s situation, functioning or performance, or of the resulting implications” (p. 2367). This conceptualisation suggests that *understanding* is required to be self-aware. Theorists such as Mead suggest that consciousness of our Self is largely a reflection of others’ attitudes towards us. So for consciousness and a sense of self to develop one must “become other”, and thus be able to take the stance of other towards oneself (Mead, 1934; Gillespie, 2005). As a result, what

we think others think about us can have a strong impact on the way we not only perceive ourselves but ultimately how we behave (Whittaker, 2008). So from a social psychological viewpoint, to be self-aware, we must be able to *understand* the way others see us.

But the measurement measures agreement

The measurement of self-awareness via self-report discrepancy rating scales involves asking PwABI to judge their competency on a range of behaviours. Simultaneously the method asks a significant other to judge the PwABI's competency on the same range of behaviours. This method asks for a direct perspective on competency from the PwABI and then a direct perspective on the PwABI from the significant other and compares the two. Thus, the measure is one of agreement, not one of understanding. If there is a discrepancy between the scores of PwABI and significant other then all this can show is a difference of opinion, a disagreement. At no point is the PwABI asked how they think others outside see them, a meta-perspective and a measure of understanding more closely related to the concept.

Awareness of how other people see the PwABI (meta-perspective)

The rating scale used in this study replicates discrepancy rating scales as it asks each half of the dyad how they see one another, a measure of agreement/disagreement. However, the rating task also asks participants to estimate how they think their partner sees them, a measure of understanding/misunderstanding. To be able to assess the concept of self-awareness, it is the level of understanding which is relevant. The rating task allows the teasing apart of agreements/disagreements and understandings/misunderstandings and allows for these to be measured separately.

The rating task also allows a further level of analysis to explore the lack of divergences in more depth. Due to the presentation of the rating task, videos were created

of the PwABI completing the task and discussing their ratings with the researcher. This facilitates the analysis of talk to assess how PwABI think their significant others see them and the brain injury. Thus, the rating task framework can also be used as a coding template for qualitative data, to analyse meta-perspectives in talk (Gillespie & Cornish, 2010) to see whether PwABI understand and are aware of how others view them.

The videos of the seven PwABI who were placed in the large discrepancy score group due to their PCRS discrepancy scores, were analysed to assess whether PwABI show understanding of how other people see them, a different level of perspective taking to agreement. Evidence of inter-personal understanding was found in the talk of these seven PwABI, complementing the quantitative data on understanding found in the analysis to answer question 2a. The first excerpt comes from Sarah when talking about the perceived perspective of her care-giver:

Researcher: Do you think your mum thinks you are irritable?

PwABI [Sarah]: [...] I'm generally with my mum 24/7 so sometimes my mum needs a break cos I've got a problem or something or I'm talk, talk, talking or doing du de du do you know what I mean, my mum just needs, "go away Sarah, I need space for myself".

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

In this excerpt, Sarah shows awareness that she can try the patience of her carer. Sarah knows that she talks a lot when she has a problem and can see her mother's perspective that Sarah is too much to handle at times. Sarah understands that her mother needs a break. The next excerpt is from Fran. Here she is talking about her carer:

PwABI [Fran]: I'm now just someone who needs a lot of help and support and probably more than I recognise because I'm not aware sometimes of all the scaffolding, if you like that she [carer] puts in, in order that you know, I can manage, it's that. So, so I think that's very hard and she's having to do all that kind of unsupported.

[Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE]

In the excerpt above we see great insight from Fran about her partner's perspective. Fran is aware that Rachel is toiling to help support her and she also picks up on the help which she doesn't see, the help that Rachel is providing behind the scenes. In addition to recognising the work that her carer does, Fran is also aware of the strain which this puts on Rachel.

Understanding of the difference between disagreement and misunderstanding

In addition to showing understanding of their partner's perspective on the PwABI, there are moments of insight captured within the talk of the seven PwABI, where they highlight the difference between disagreement and misunderstanding. In talk these PwABI acknowledge that they understand their partner's point of view but they disagree with it. For example, the next excerpt comes again from Sarah at the beginning of the first rating task, in which I will ask Sarah for her ratings on her own identity. I have explained that her mother will also be answering these questions about how she sees Sarah:

PwABI [Sarah]: And I know for a fact before I even start this, this will not be the same as my Mum's actually answered.

Researcher: What makes you say that?

PwABI: Erm, cos I heard a phonecall I wasn't meant to hear about three weeks ago. And then the truth came out in the phonecall, you know. But then three days later I told her, "see that phonecall". I told her and she went "well now you know" [*shrugs*], which is fair enough.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

In the first line of this extract, we can see that Sarah is aware that her mother sees things differently from her. Sarah understands that her own and her mother's perspectives are not in alignment, but she disagrees with her mother's perspective, hence her saying that the answers will be different. This awareness would not be captured by the PCRS as this scale only measures agreement/disagreement. Yet we see here that Sarah is aware of her mother's position, but she disagrees with it. Another example of a PwABI who demonstrates awareness of the difference between disagreement and misunderstanding is Bill in the following extract:

Researcher: Do you think Nena thinks that you're an intelligent person?

PwABI [Bill]: I think in many ways I'm more intelligent than I was, what would she think? Just the same as what I was.

[Dyad 11: Bill (34) PwABI and Nena (32) carer. Married, three years post TBI after an RTA]

Here we see that Bill is aware of his wife's perspective on his level of intelligence but he disagrees with this as he feels that he is more intelligent since his injury. Thus, there is understanding but not agreement and the difference between the two is explicated by Bill.

Despite the demonstration by the seven PwABI with high discrepancy scores of an understanding of the difference between disagreement and misunderstanding, these PwABI are still demonstrating, both in their talk and their PCRS scores, a discrepancy in perspectives with their partners. This may be problematic for relationships as it indicates a lack of relational alignment. The use of the IPM and the different ways in which data may be gathered from the method facilitates the exploration of where discrepancies exist.

The rating task is a way forward as it considers different levels of perspective taking

There is a difference between agreement and understanding which is not addressed in current discrepancy measures of self-awareness. The concept of self-awareness suggests understanding but the discrepancy measurements used to test the phenomenon only measure levels of agreement/disagreement and use these to contribute to classification of PwABI as aware or unaware. The rating task used in the present study avoids the confusion between the two levels. It measures both agreement and understanding, clearly and separately and the presentation of the rating task, which video records discussions, allows us to examine the talk of PwABI whilst completing the rating task. As a result we see that disagreement within dyads should not be used to categorise PwABI as lacking self-awareness, as they frequently understand their partner's viewpoint. This finding explains the lack of misunderstandings within the data set used to answer question 2a.

Critique Two: Measures Disagreement but Treats One Viewpoint as More Accurate

The next critique follows on from the first. We saw that self-awareness discrepancy rating scales measure disagreement not misunderstanding. However, these scales go further than this. Not only do they measure the relationship between two different viewpoints to assess disagreement, but they treat one viewpoint as "true" or more accurate and this leads to the implicit assumption that the other viewpoint is "false" if it deviates

from the “true” viewpoint. The carer’s rating is taken as the benchmark and the deviation of the PwABI’s score is measured from this baseline. To measure a relationship between two viewpoints and consider one viewpoint “true” when neither are based on objectivity is worrying at best. The privileging of the viewpoint of the significant other over the PwABI serves to marginalise the PwABI’s viewpoint. Most importantly, it individualises a shared problem. Shakespeare and Clare (2005), discuss the “power of problematizing the mundane” (p. 328) where previously mundane and unremarkable features of everyday existence suddenly become a matter for intense scrutiny after a diagnosis of cognitive impairment. Minor mistakes such as forgetting the name of someone you met recently, which in a normal population would be quickly fixed or forgotten, become pathological, cause for grave concern or evidence of progressing illness. Any two people are likely to disagree in their viewpoints, however, when one of those people has an ABI, their perspective is considered valid only if it is in line with the viewpoint of the carer on the basis of discrepancy measures which use significant other ratings, otherwise this is something pathological and is evidence of deficit.

The carer’s ratings are treated as a benchmark from which to measure PwABI’s ratings. Due to their cognitive and communicative deficits it is assumed that it is PwABI who are the cause of communication breakdown, and will thus be the cause of disagreements. This is in line with the individual approach to deficits after ABI that is dominant in the clinical literature (Ylvisaker, 2003). However, to take a relational approach means to examine how both sides of the relationship interact to produce patterns of communication (Yeates et al., 2007). Indeed, interactional problems do not just lie with PwABI. Interruptions in the pragmatics of conversation also come from carers. Carers have been shown to withhold feedback and miss opportunities for repair which leads to misunderstandings in conversation (Friedland & Miller, 1998). Significant others may also

marginalise prior and important facets of the care-receiver's self whilst engaged in interaction which can cause anguish for the care-receiver (Sabat & Harré, 1992).

Significant others are also more likely to dismiss their partner's communicative efforts.

Thus, communicative problems may be distributed within the relationship.

Treating carer as a 'reliable' witness is a bad idea

The PCRS has a relative and clinician version but often in research, it is only a significant other who provides the competency rating on the PwABI. Family members have also been through a trauma when their loved one experienced a brain injury. Brain injury can have as devastating an impact on family members as the PwABI (Ponsford et al., 1995). Relatives will experience grief (Landau & Hissett, 2008) and will also need to come to terms with their radically altered roles, increased responsibility and the PwABI becoming dependent on them. As Bond (1984) states "insight usually alternates with periods of denial of disability in many patients – a process which is often shared with their relatives" (p. 159). Ponsford et al. (1995) note that family members may find it difficult to pinpoint or acknowledge that there are changes in their loved one and what these changes may be. Coming to terms for relatives is exacerbated by the frequent presence of depression and anxiety, along with high subjective burden (Perlesz et al., 1999). This may lead to significant others feeling swamped by their caring role and could lead to inaccuracies in their reporting of deficits in the PwABI. To interpret discrepancy rating scales of awareness the rating given by the significant other must be considered a more accurate rating, a baseline from which to measure deviations by the PwABI (Kolakowsky-Hayner, 2010). This cannot be the case and has previously been cautioned against (Cavallo, Kay & Ezrachi, 1992). However, the caution that has been suggested in interpreting the ratings of relatives has focused on the short term after ABI (Fleming et al. 1996), yet difficulties with relative ratings may extend into the long term post injury.

Comparison of means of small discrepancy scores group and large positive discrepancy scores group

To explore why some dyads would have a PwABI classified as low in self-awareness and others high, Independent Samples T-Tests were carried out on the data once the two groups had been separated out into the small discrepancy score group (N=7) and the large positive discrepancy score group (N=15) on the basis of PCRS scores. Groups were compared on HADS scores of carer and PwABI, carer and PwABI PCRS scores and cognitive test scores. The t-tests showed one significant finding. The means of the two groups were significantly different ($t=2.095$, $p=0.05$) on carer's PCRS ratings. The mean PCRS rating made by carers was 106.43 out of a possible 150 in the aware group and just 89.43 in the low awareness group, a 17 point difference. However, there was no significant difference in the mean PCRS scores as rated by PwABI between the two groups ($t=-.612$, $p=.548$). In the high self-awareness group the mean was 113.62 and in the low self-awareness group it was 119.14. Therefore, it is carers' ratings which differ between the two groups, not PwABI's ratings. If PwABI are "lacking self-awareness" then it would be assumed that it would be their ratings which would differ from other PwABI's self-ratings of competency. We would expect these to be significantly higher, if the competency level of the two groups is comparable. Therefore, we must probe the issue of competency further.

Are the PwABI in the large discrepancy score group more cognitively impaired?

Are the carers in the large discrepancy score group providing lower ratings of their partner's competency because of greater impairment in these PwABI? The two groups, those with large discrepancy scores and small discrepancy scores did not differ significantly in levels of cognitive impairment ($t=.923$, $p=.369$). The mean for the large discrepancy score group on the ACE-R was 82.58 and the mean for the small discrepancy

score group was 79.29, both indicating cognitive impairment. Therefore, it is not the case that the PwABI in the large discrepancy scores sample are significantly more cognitively impaired than the small discrepancy scores group. Thus, cognitive impairment cannot explain the lower PCRS scores given by carers in the large discrepancy scores sample. Unfortunately, an objective measure of independence in ADLs was not available for participants and this would be useful in providing a more complete picture of the competency level of groups.

The role of anxiety and depression

There were no significant differences in the mean HADS subscale scores for either PwABI or carers in either group. However, the mean carer anxiety score in the large discrepancy scores group was 8.14 (N=7), whereas for the small discrepancy scores group the mean carer anxiety score was 6.43 (N=21). Although there was not a significant difference in the mean of the two groups, the mean anxiety score for the carers in the large discrepancy scores group is above eight, which indicates possible anxiety disorder (Bjelland et al., 2002).

Based on the findings above, it would appear that it is not a lack of self-awareness in PwABI which explains the high positive discrepancy scores in the large discrepancy scores group of seven dyads. Instead it is carer's low capability ratings that led to the discrepancy. These ratings were not on the basis of greater cognitive impairment in PwABI but there was some anecdotal evidence that the carer's in the large discrepancy scores group were experiencing greater anxiety than carers in the small discrepancy scores group.

It is necessary not to assume that PwABI are responsible for relational problems. As we have seen above both sides of the relationship are adapting to the changes that ABI

brings and this is difficult for both. To measure two sides of a relationship and consider the outcome as indicative of deficits within one half of the relationship is dangerous. Both halves of a dyad may have differing opinions, but who is to say which is “correct” or “right”? It is assumed that carers provide a more accurate rating of PwABI, which may be the case, but we must always bear in mind the difficulties that carers also face in adapting to having a partner with ABI and be aware of the resulting biases they may bring to their partner ratings.

The rating task is a way forward as it avoids privileging either viewpoint.

The rating task used in this research shows promise in overcoming the criticism of discrepancy rating scales prioritising the carer’s viewpoint. The rating task treats both viewpoints as equal. The rating task can chart patterns of relational convergences and divergences of perspective and in the case of this study we see good alignment between the 28 dyads who took part regarding the identity of PwABI, as there was only one disagreement and corresponding misunderstanding. There may be greater intersubjective alignment in informal care relationships indicated in this study because the divergences reported about PwABI previously have come from reports by carers alone, not PwABI and we have seen in the T-Test results reported above that carers are sometimes the source of divergences of perspective. When assessing both halves of the dyad simultaneously we get a more balanced viewpoint and as such see fewer divergences.

Critique Three: When Only Using ‘Scores’ to Classify, the Unique Perspectives of PwABI are Ignored

Taking PCRS scores alone ignores the dialogue PwABI and carers have with the disability and their unique perspectives surrounding their relationship and the injury. What the rating task used in this research affords is to both map perspectives quantitatively and then explore patterns of convergences and divergences qualitatively via analysis of the

discussions which surround PwABI and carers choosing how to rate themselves and their partners. This can further avoid the privileging of perspective and assuming that divergences are reflective of self-awareness deficits in PwABI. Videos of the seven PwABI with large positive PCRS discrepancy scores completing the rating task and discussing their ratings with the researcher were analysed and coded for PwABI's perspectives on their deficits and the functional implications of these deficits. When talk during the task is analysed, we gain rich data on the perspectives of PwABI.

Talk surrounding the task shows perspectives of PwABI on their deficits

PCRS discrepancy scores produce a number which indicates the presence and magnitude of self-awareness problems in PwABI. However, in as far as we can talk about awareness, it is always about domains, degrees and fluctuations over time. People with self-awareness deficits have been shown to demonstrate insight in talk but not on standardised measures, and can demonstrate varying levels of awareness at different times (Clare, 2004; Clare et al., 2008). Thus, a number alone is not enough to describe complex and shifting phenomena. The presentation of the rating task in the present research allows us to uncover perspectives PwABI have about their brain injury in talk and explore these with them in greater depth, providing richer insights into perspectives and viewpoints of PwABI. In the following extract Sarah is talking about her deficits post ABI:

PwABI [Sarah]: What's really been affected for me...is my speech. My speech. My brain and my mouth don't communicate.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

In this excerpt, Sarah acknowledges that she has speech problems post ABI and that these cause communication difficulties. The next extract comes from Fran, talking about whether she experiences confusion:

Researcher: And finally do you see yourself as a confused person?

PwABI [Fran]: yep, right up there [*places symbol at 'very like me'*]. Yes, yep.

[*Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE*]

In this excerpt, Fran admits to problems with confusion since her encephalitis. She speaks without any attempt at denial or self-presentation about her deficit in this area and places the symbol at the highest level on the scale, 'very like me'. The next extract comes from Mark, when answering about perceived intelligence:

Researcher: Do you see yourself as an intelligent person?

PwABI [Mark]: I guess about there [*places symbol at three - 'a bit like me'*]. I think probably if you'd asked me this before my injury it would have been there-ish [*points at four - 'very like me'*].

Researcher: A bit higher up?

PwABI: But probably just now. I mean I've had to learn to read and write and they've come back well. But there's times, good days and bad days I think probably about there [*points at three - 'a bit like me'*].

[*Dyad 23: Mark (60) PwABI and Maureen (56) carer. Married, five years post TBI after a fall*]

In the conversational excerpt above, Mark says that he feels his intellectual capacity has been negatively impacted by the injury and that he has been forced to learn the basic skills of reading and writing again. He acknowledges that this is an ongoing battle, with good days and bad days.

When examining talk of the PwABI in the large discrepancy scores group, we gain a richer insight into their perspectives on their deficits at the time of research.

PwABI explore through talk their perspectives on the functional outcomes of their deficits

Exploring talk does not just provide insights into PwABI views on their deficits, but also the functional outcomes of these. The first excerpt comes from Bill, when he is discussing his independence with the researcher:

Researcher: And finally would you describe yourself as an independent person?

PwABI [Bill]: Erm, I do need help to do certain things so I'd say I'd like to be independent and I like to do as much as I can myself so. I'd say in the middle. I'd like to be more, but obviously I can't now, so.

[Dyad 11: Bill (34) PwABI and Nena (32) carer. Married, three years post TBI after an RTA]

In this excerpt we see that Bill is aware that the deficits resulting from his brain injury have led him to lose some of his independence as he relies on others, particularly his wife Nena to assist him with ADLs. In the next excerpt we return to Fran, also discussing her independence:

Researcher: Do you see yourself as an independent person?

PwABI [Fran]: No, I've lost a lot of that as well [...] I try to be sometimes but I'm very dependent, and mostly on Rachel [*carer*]. Erm because I just don't get things right or I can't do stuff.

[Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE]

In this extract Fran discusses the functional implications of her injury. She is unable to be as independent as she would like to be and relies on her care-giver to assist her. The next extract is from Richard, discussing his hobbies:

Researcher: Would you say that you have hobbies? Would it be true to say that?

PwABI [Richard]: [*shakes head*]

Researcher: Is that something that's changed?

PwABI: Aye.

Researcher: What hobbies did you used to have?

PwABI: Football, golf, just played sports and that basically, aye.

Researcher: Is that something you'd like to get back?

PwABI: Back to aye, but it's impossible.

[Dyad 17: Richard (40) PwABI and Carolyn (67) carer. Son and mother, four years post TBI after assault]

In the excerpt above we can see that Richard is desperate to return to his former hobbies but knows that due to his deficits he is unable to recapture his prior way of life, which was active and filled with sporting activities.

As well as exploring the perception of their deficits, the method of eliciting ratings through talk allows us to explore the perspectives of PwABI on the ways in which their deficits have impacted upon their ability to participate in daily life. If the discrepancy scores on the PCRS were the only information we had on these seven PwABI, the ways in which they think about their deficits and the functional outcomes of these may be missed. Exploring these in talk can help us to better understand their perspectives and why there may be convergences or divergences of perspectives within relationships.

Critique Four: Improvements Seen in Self-Awareness Over Time: Improvement or Development of a Shared Reality?

Improvements over time: Just an improvement in co-ordination?

Another reason for fewer divergences in this study compared to previous ones may be that the relational nature of the rating task taps into shared meaning making and thus convergence of perspectives. In the case of a trauma like ABI, PwABI rely on their relationships with significant others to help them re-establish a sense of self post injury (Nochi, 1998, 2000). Thus, informal care relationships adapt together.

There is evidence of improvements in self awareness over time as measured by PwABI's self ratings moving closer to others ratings of them over time, particularly beyond one year post injury (Ponsford et al., 1995). However, this may not be indicative of improvements in individual PwABI self-awareness but adaptation at the relational level. As relationships adapt to brain injury and family members adjust to day to day life it is likely that intersubjective co-ordination will improve. Families will come up against difficult situations, for example how to deal with a situation such as if the PwABI is no

longer able to brush their teeth unassisted. At first it is likely that it will take time to work out how best to go about dealing with the situation, especially if communication is difficult. PwABI and significant others will need to decide if physical assistance is required to brush teeth or whether merely prompts are required. If just prompts are required, then which are most effective? Which do not lead to ill feeling as the PwABI may be sensitive to the fact that they are no longer able to do this seemingly innocuous task? Over time a pattern of communication and co-ordinated action will emerge which allows the PwABI to have clean teeth in minimum time and with a relationship still in relative harmony. Partnerships will find new ways to communicate if old methods fail and these are likely to be idiosyncratic. Over the course of laboratory communication tasks such as map tasks and tangram descriptor tasks, partnerships learn to describe and identify routes and tangrams in decreasing amounts of time and number of words due to the building up of shared referential knowledge and meanings (Clark & Wilkes-Gibbs, 1990). The same is true in relationships post ABI, albeit at a much more complex level and presumably a slower pace.

Or developing a shared reality?

Or is the situation even more complex than improving communication and co-ordination? Are families creating an entirely new reality? Nochi (1998, 2000) suggests that re-negotiation within relationships, of roles and shared intersubjective meaning, is what allows PwABI to recapture their sense of self, thus “sense making resources are embedded within social relationships” (Yeates et al., 2007, p. 153). Each family unit will utilise different and often unique sources of meaning in order to make sense of their situation and begin to adapt and rebuild (Yeates et al., 2007). Larson (1998) has shown that relatives of PwABI feel that there is a lack of available information about brain injury and the deficits and outcomes that are likely to be faced. With a lack of information, family members will

turn to idiosyncratic sources of meaning in their sense making (Mwaria, 1990; Yeates et al., 2007). This suggests that families will over time develop their own unique, shared reality which allows them to cope with changes and navigate daily life. However, this shared reality may be more or less related to “objective truth”. The notion of self-awareness focuses on “a person’s ability to consciously process information related to themselves while maintaining a relatively *objective* view” (Carroll & Coetzer, 2011, p. 292). However, the joint sense making within families may be anything but objective. For example, families may deliberately avoid the truth and engage in promotion of denial of deficits. Hutchinson et al. (1997) have shown that family members coping with a diagnosis of dementia deliberately conceal aspects of knowledge from the person with dementia. Concealment helped families navigate the difficulties that a diagnosis and the symptoms of dementia caused for family relationships. In the previous chapter of this thesis we saw how carers were engaged in active concealment of the care work that they were providing in the hope that this would help PwABI to have more confidence in their abilities and a greater sense of independence. Thus, one half of the relationship works to conceal from the other and actually serves to limit the ability of the PwABI to have full awareness of their deficits. However, this concealment is beneficial as it helps families to navigate daily life and it provides intersubjective alignment within dyads and this is revealed as a lack of divergences in the rating task.

The rating task used in this study maps out perspectives within relationships about who people ‘are’. As there is a shared reality created, it is understandable that there is alignment of perspectives within informal care relationships. The rating task asks for people’s perceptions on how they see themselves and their partners and how they perceive their partner sees them. This does not need to relate to ‘objective truth’. This differs to the

sort of questions that are asked by a measure such as the PCRS which is assessing competency and is aiming to tap into the realities of what a person can and cannot 'do'.

Discussion

Summary

In answer to question 2a: *Are there any disagreements and/or misunderstandings between carers and PwABI regarding carer identity?*, divergences of perspective are uncommon between carers and those they care for regarding the PwABI's identity. There was only one disagreement and corresponding misunderstanding and this was on the identity item self-centred. PwABI perceived themselves to be less self-centred than their carers thought they were and they thought their carers would rate them as less self-centred than they did. The overall lack of divergences of perspectives suggests that PwABI and care-givers are in alignment in their perspectives regarding the PwABI's identity.

The second analysis attempted to answer question 2b: *How can the pattern of divergences be explained?* It was hypothesised that the lack of divergences in the present study was due to the relational approach used to assess perspective taking. Discrepancy rating methods, and thus some of the research which used such scales, measured a relationship but operationalised measurement at the individual level and confused disagreements and misunderstandings. By considering disagreements as misunderstandings, this may have overinflated the pervasiveness of self-awareness problems and misunderstandings in relationships. Considering misunderstandings by measuring what PwABI perceive their partners think about them and what care-givers actually think showed less divergences of perspective than expected.

However, divergences of perspectives have been found using relational methodologies. For example, Yeates et al.'s (2007) study of awareness in the family

context studied both sides of relationships and did not privilege either viewpoint. The study employed qualitative methods so elicited rich perspectives from both sides of the dyad. Thus Yeates et al.'s study found divergences about PwABI whilst avoiding the criticisms that are suggested to be inherent in self-report discrepancy rating scales. Yeates et al.'s study recruited participants for whom self-awareness may have been a specific difficulty which the present study did not but it would certainly be necessary to replicate the current study with different and larger samples before drawing firm conclusions about the convergences of perspectives in this research. It may be that convergences are actually reflective of the particular sample or are an artefact of methodology used in this research.

The relational method used is only one explanation for the alignment found on the rating task versus disagreements in PCRS discrepancy ratings. Another explanation is the different domains which the two methods tap into. Awareness tends to vary depending on the domains of functioning explored (Hart et al., 2009). The PCRS covers items relating to physical functioning, activities of daily living, behavioural and emotional function and cognitive abilities (Kolakowsky-Haynor, 2010) and PwABI may have particular difficulties in awareness in some of these domains. The rating task used in this research covers identity. It may be that the identity items used on this task, which tap into the core of who a person 'is' rather than what a person 'can do' are easier for survivors and significant others to own a shared viewpoint on.

Although the relational rating method used in this research has the potential to overcome some of the problems inherent in discrepancy rating scales, it must be acknowledged that the rating method used in this research may have limitations which have produced a false impression of alignment in relationships. The rating task methodology is a relatively new method which is unstandardised, artificial and abstract. It

can be argued that complex issues surrounding identity cannot be explored through self-report and that there may be a lack of convergence between ratings and talk. In addition, there may be problems with the items used to elicit ratings. These limitations will be discussed in greater depth in chapter eight but it is acknowledged here that the finding of intersubjective alignment in informal care dyads may have been a result of a lack of sensitivity in the methodology.

A caution regarding the heterogeneity of the sample

As in chapter four, the IPM data and subsequent qualitative analysis of the talk of the seven PwABI with high discrepancy scores when compared to their partners' ratings on the PCRS has considered all carers as one group rather than separating out the different types of dyadic relationships. It is acknowledged that this approach may have missed important differences between groups. On the IPM, dyads may rate themselves differently depending on their relationship and the points of reference that this creates. For example, the issue of the point in time that partners were rating the PwABI on the identity items was a salient issue. Carers often asked for clarification about which 'version' of the PwABI they were making a rating on, be this a pre-injury identity, post-injury identity or the identity that they wished for in the future. As has been discussed elsewhere in this thesis, perspectives on another's identity are formed through a layering of knowledge about people in the past, present and an imagined future. This may have lead to differences in ratings across relationships and even within relationships. Some of the romantic relationships were formed post ABI, thus the carer would not have a pre-injury identity on which to draw, others had been formed shortly before the injury and others had been together for many years before the injury. For parents who had watched their child grow through various stages of life to date, pre-injury identity may be important and parents may return to viewing their child in terms of the identity they had when they were much

younger and more dependent. In addition, the facets of identity which are salient for one type of relationship may be different to another. For example, for a romantic partnership items on the IPM which are most important or may seem to have changed the most since injury may be different to those which would be deemed important by a parent or a sibling and ratings may vary accordingly. In addition, there were four romantic relationships, two parent-child relationships and one friendship within the seven dyads with high discrepancy scores. It was a limitation of this research that discrepancies were not explored in light of the different relationships. However, the purpose of this chapter is to explore the potential of the rating task as way to explore identity in relationships after ABI.

Limitations of the study

As for ratings on carer identity, the IPM data for PwABI identity is based on a small number of participants and statistical power is lacking in the study. Ideally, a sample of between 50 and 60 dyads should have been included in the research. As well as smaller than desired participant numbers, there is a risk of Type I error in the data. The quantitative data was uncorrected for multiple comparisons. If Bonferroni corrections had been applied, there would have been no significant disagreements or misunderstandings about the identity of PwABI.

The ACE-R was used to establish level of cognitive impairment in the sample and this tool does not represent fully all of the domains of disability that may affect PwABI. Thus, the analysis which ruled out greater cognitive impairment in the seven PwABI with high discrepancy scores on the PCRS may be misleading. As a result, the seven PwABI may have more severe cognitive impairment than the rest of the sample and it is not possible to establish this hypothesis from the data available.

Conclusion

Despite potential limitations, the relational rating task method shows promise for future use in relationship study. Using a rating task such as this places focus not on individual care-receivers and care-givers, but the relationship. The method allows us to separate disagreements and misunderstandings. The method of systematically measuring both halves of a dyad simultaneously, not prioritising any viewpoint, and exploring the talk surrounding ratings leads to new insights into perspectives on identity and relationships as dyads adapt to ABI. In this study, using the relational rating method, convergence in perspectives regarding PwABI identity was found. However, caution must be taken in interpreting the findings of this study. Findings need to be replicated and potential limitations with the rating method must be addressed before drawing solid conclusions about divergences in perspectives regarding PwABI identity.

Chapter Six – Collaboration between Carers and PwABI: Strategies and Scaffolding in Completion of the Inviting for a Meal Joint Task

Participation in activities of daily living can be difficult for PwABI due to deficits in cognition and communication (Evans, 2003). Close informal care relationships are shown to improve outcomes for PwABI (Lyons et al., 1995), yet the processes by which care-givers assist those they care for remain poorly understood. Accordingly, there have been calls for more research into the precise strategies used in collaboration between care-givers and care-receivers (O'Neill & Gillespie, 2008). Observations of care-givers and care-receivers working together on joint tasks, suggest that care-givers provide subtle, tailored support to assist care-receivers to participate in daily life (Gillespie et al., in prep; Shakespeare & Clare, 2005) but this has never been assessed in a brain injured sample. This chapter asks question *3a: What strategies do carers and PwABI use in collaboration on a joint task?* This chapter will also go beyond the strategies used in collaboration to discuss the implications of care-giver/care-receiver collaboration for the scaffolding metaphor. The scaffolding literature is replete with studies examining the ways in which adults scaffold children, however, the picture regarding scaffolding of those with cognitive impairment remains comparatively vague (Stone, 2002). Thus, this chapter also explores question *3b: Is the type of input provided by carers on the joint task comparable to scaffolding as described in the child development literature?*

How the Data Set was Analysed

To answer question *3a: What strategies do carers and PwABI use in collaboration on a joint task*, videos of care-givers and care-receivers collaborating on a joint task, 'inviting a friend or relative round for a meal', were analysed using NVivo nine software (see appendix A for task sheet). The strategies in the coding frame were chosen on the basis of the scaffolding literature and a previous study of strategies used in the same

‘inviting a friend or relative for a meal’ joint task with participants with aphasia (Gillespie et al., in prep.). The coding frame used is presented in Table 6.1 below. The coding frame presents the 23 strategies which were coded for in the data and defines these as they were coded in this task. There were two levels of coding. Two of the 23 strategies were coded at task level, writing and initiating. When one partner wrote, this was found to continue throughout the task. Initiation of the task only occurred once for each dyad so was also coded at task level. The other 21 strategies were coded at the level of the sentence. (Examples of each strategy as coded in the data can be found in Appendix B). Coding was not mutually exclusive and the same sentence could be coded at different strategy nodes. Coding was conservative, that is, a strategy was only coded if it was clearly occurring within the data.

Wilcoxon Signed-Rank tests with two tailed significance were carried out on the data to establish whether there were significant differences in the number of times each strategy was used by care-givers and PwABI. A significant result ($p \leq .05$) in the test means that there was a significant difference between the number of times that strategy was used by care-givers and PwABI.

To answer question 3b: *Is the type of input provided by carers on the joint task comparable to scaffolding as described in the child development literature?*, the videos of PwABI and care-givers collaborating to complete the inviting a friend or relative for a meal task were assessed alongside the strategies analysis, to see whether collaboration on the joint task demonstrates the three major features of scaffolding outlined in the child development literature. These are: 1) the strategies used; 2) flexibility in level of input and strategies used based on difficulty and skill level; and 3) gradual removal of supports.

Table 6.1*Coding Frame for the Strategies Used in the Inviting a Friend or Relative for a Meal Task*

| Strategy | Definition | Coding level |
|-----------------------------------|---|----------------------------|
| Writing | Who writes answers on the answer sheet | Task level (percentage) |
| Initiating exchange | Who speaks first in an attempt to engage with the task | Task level (percentage) |
| Question | Asks partner a question and leaves a pause | Sentence level |
| Checking agreement | Making sure that the partner is in agreement about a suggestion or answer | Sentence level |
| Steering | Steering the direction of the conversation within the task | Sentence level |
| Speaking for | Speaking for the partner | Sentence level |
| Rephrasing | Phrasing a question or statement in an alternative way | Sentence level |
| Suggest alternative | Making alternative suggestions to the partner, either in response to the partner's or one's own suggestion/answer | Sentence level |
| Offering options | Offering more than one option for the partner to consider | Sentence level |
| Prompting | Saying something to persuade, encourage, or remind the partner to do or say something. | Sentence level |
| Chunking | Grouping information into smaller units | Sentence level |
| Gesturing | Using non-verbal signals | Sentence level |
| Making decision | Coming to a final decision about an answer to a question posed on the task sheet | Sentence level |
| Judging response adequacy | Judging whether a response given by the partner is appropriate and fulfils perceived task requirements | Sentence level |
| Judging completion | Judging when a question is answered completely and the dyad is able to move onto the next question | Sentence level |
| Correcting | Partner overtly corrects the other - either something they have said or written | Sentence level |
| Setting limits | Placing parameters around the task – judging what is relevant and appropriate to discussion | Sentence level |
| Using assistive technology | Using an assistive device to aid completion of the task | Incidence level |
| Requesting help (from partner) | Asking task partner for assistance with any aspect of the task | Sentence level |
| Requesting help (from researcher) | Asking researcher for assistance with any aspect of the task | Sentence level |
| Joking | Making a joke during completion of the task. (Laughter on its own was not considered use of a joke) | Sentence level |
| Repeating | Repeating a word, phrase or sentence exactly as it was said in the person's own last conversational turn | Sentence level |

Question 3a: What Strategies do Carers and PwABI Use in Collaboration on a Joint Task?

Table 6.2

Mean Number of Times Each Strategy was used by Carers and PwABI During the Joint Task, with Standard Deviations and Wilcoxon Signed-Ranks Test Significance Values (based on median values)

| Strategy | Carer (Mean) | S.D. | PwABI (Mean) | S.D. | Sig. |
|----------------------------|--------------|-------|--------------|-------|------|
| Reading Aloud | 7.046 | 5.385 | 2.546 | 2.972 | .024 |
| Questioning | 12.727 | 7.959 | 5.591 | 4.697 | .005 |
| Steering | 2.409 | 2.649 | 0.091 | 0.294 | .001 |
| Judging Response Adequacy | 5.136 | 3.642 | 0.409 | 0.796 | .000 |
| Judging Question Complete | 5.591 | 3.621 | 2.227 | 3.038 | .022 |
| Rephrasing | 1.136 | 1.246 | 0.000 | 0.000 | .001 |
| Suggesting Alternatives | 1.091 | 1.269 | 0.546 | 1.101 | .040 |
| Presenting Options | 1.591 | 3.081 | 0.273 | 0.703 | .027 |
| Prompting | 1.500 | 1.946 | 0.000 | 0.000 | .002 |
| Chunking | 0.546 | 1.011 | 0.456 | 0.213 | .040 |
| Correcting | 1.409 | 1.843 | 0.046 | 0.213 | .003 |
| Setting Limits | 1.500 | 1.870 | 0.136 | 0.351 | .003 |
| Repeating | 1.500 | 2.177 | 0.364 | 0.658 | .009 |
| Asking Researcher for Help | 0.364 | 0.581 | 0.000 | 0.000 | .011 |
| Making Final Decisions | 3.727 | 2.164 | 6.955 | 3.848 | .008 |
| Asking Partner for Help | .000 | 0.000 | 0.682 | 1.249 | .010 |
| Checking Agreement | 1.591 | 2.130 | 1.227 | 1.602 | .400 |
| Speaking for | 0.046 | 0.213 | 0.000 | 0.000 | .317 |
| Gesturing | 0.546 | 1.336 | 0.682 | 2.167 | .671 |
| Using Assistive Technology | 0.091 | 0.426 | 0.046 | 0.213 | .317 |
| Joking | 0.409 | 0.734 | 0.909 | 1.716 | .185 |

Table 6.2 above shows mean values for the number of times each assistive strategy was used by carers and PwABI during the task, and standard deviations. In addition to the 21 strategies in the table, the two further strategies of writing and initiating the task were coded at task level. Percentages of carers and PwABI who engaged in these strategies were calculated. Writing was performed equally by carers and PwABI as 50% of carers and 50% of PwABI wrote answers. More than two thirds, 68.18% of carers initiated the task whereas 31.82% of PwABI initiated the task.

Care-Givers Use a Toolbox of Strategies

The strategies highlighted in red are those used significantly more by carers than PwABI in the process of carrying out the task. The majority, 15 of the 23 strategies were used significantly more by carers than by PwABI. This suggests that carers employ a number of different strategies to complete the task and facilitate PwABI's involvement.

The primary strategy that carers use to move the task forward is questioning. Questioning was the strategy used most often by both carers and PwABI but was used more than double the amount of times by carers. Questioning has been discussed by Shakespeare and Clare (2005) as a major 'vehicle' for moving talk between care-givers and care-receivers forward. Direct questioning draws the PwABI into the task, facilitating their involvement and focusing their thinking, whilst still allowing the carer directive control, as they are choosing what questions to ask. The following excerpt shows a carer using the strategy of questioning:

Carer [Wendy]: *[Reads aloud]* How would you invite them? *[pause]* Would you just ask them or send them an invitation or?

PwABI [Keith]: I'd just ask them.

Carer: Ask them *[Carer writes this answer]*.

Carer: And when would you like to have the meal? At the weekend or during the week or Saturday, Sunday?

PwABI: Saturday.

[Dyad four: Keith (51) PwABI and Wendy (61) carer. Son-in-law and mother-in-law, 27 years post TBI after an RTA]

In this excerpt, the carer Wendy is in charge of reading and writing, so uses questions to draw Keith into the task and facilitate his involvement. Wendy uses questioning to present suitable options for Keith to pick between when answering the wider task questions. Wendy uses Keith's answers to her questions to complete the task sheet.

Once questions have been posed to the PwABI, care-givers assist PwABI to provide appropriate input to the task and answer the questions posed to them by employing a broad range of strategies in the care-giver's toolbox. The strategies in the toolbox are repeating, rephrasing, suggesting alternatives, providing options, prompting, chunking and correcting. Each strategy will be described in turn. The first strategy is repeating a question asked or a suggestion made. The following excerpt shows this strategy in action:

Carer [Elizabeth]: Erm, what food will we have? What kind of food do you want?

PwABI [Derek]: That's you aye [*points to a different question on the task sheet*].

Carer: Um, what kind of food do you want?

PwABI: Um I don't know

Carer: Roast beef?

[Dyad eight: Derek (56) PwABI and Elizabeth (52) carer. Married, three years post stroke]

In this excerpt, Elizabeth asks Derek what kind of food he wants but Derek responds to a different question on the task sheet. To reorient Derek and bring him back to the question at hand Elizabeth uses the strategy of repeating her previous question verbatim.

Carers may also rephrase a question or statement as shown in the following excerpt:

Carer [Julia]: *[Reads aloud]* When would you have the meal? What time would you normally expect to have a meal?

PwABI [Jack]: About six or seven.

[Dyad 24: Jack (19) PwABI and Julia (59) carer. Son and mother, four years post TBI after a fall]

Here, the carer rephrases the question asked on the task sheet. The rephrased question narrows the answers the PwABI can give, reducing cognitive load. It also assists the PwABI to give an appropriate answer to the question as it focuses thinking towards the time meals normally take place.

Carers use the strategy of suggesting alternatives if the response of the PwABI to their questions is not adequate or sufficient, as shown in the following excerpt:

PwABI [Lewis]: *[Discussing what to do if the food is spilled on the floor]* Shall I put spaghetti bolognese?

Carer [Hannah]: Stir fry? It's quicker, yeah? *[PwABI writes stir fry].*

[Dyad 12: Lewis (53) PwABI and Hannah (53) carer. Married, four years post TBI after an RTA]

In this exchange the pair are discussing a quick alternative if the food is spilled shortly before the guest's arrival. Lewis suggests a spaghetti bolognese but Hannah

suggests an alternative as they will need to create a new dish quickly if the guests are due to arrive shortly.

Another strategy in the care-giver's toolbox is to present possible options to the PwABI. The following excerpt demonstrates this strategy:

Carer [Wendy]: Who would you like to invite for a meal Keith? [...] Mary and John, Jean and Andy, Margaret and Jim or Malcolm or Liza and Suzanne?

[Dyad four: Keith (51) PwABI and Wendy (61) carer. Son-in-law and mother-in-law, 27 years post TBI after an RTA]

In this excerpt Wendy offers a variety of options to the PwABI about who to invite. Presenting options reduces the cognitive load on the person with cognitive impairment and provides sensible suggestions for an answer to the question, meaning that the PwABI will give an answer which suits the carer but still hands over final decision making to the PwABI.

Carers may also prompt their partner as the following excerpt demonstrates:

PwABI [Grant]: *[Discussing with John about the final question – what to do if the food is spilled just prior to the guest's arrival]* Go to the chippy *[laughs]*

Carer [John]: Well looking at the timing of it, what have you, yeah what would you do?

PwABI: Go to the chippy.

Carer: You can't go to the chippy, the chippy's shut.

PwABI: Oh right.

[Dyad 18: Grant (59) PwABI and John (54) carer. Siblings, three years post stroke]

In this exchange, the carer tries to prompt his brother to consider his answer to the question in more detail when he says “well looking at the time of it...what would you do?” It would seem from first reading that John knows that the chip shop will be closed at the time the PwABI has organised the meal but wants Grant to come to this realisation himself. Grant remains with his original response and John has to explain explicitly that the answer Grant has provided is not an option. However, due to the long opening hours of chip shops, this excerpt can be interpreted as John trying to get a different answer from Grant, as John feels the answer given is too short. Thus, John is not exerting a knowledge control, but normative control regarding what he thinks is a good answer.

Infrequently, carers were seen to use the strategy of chunking information to make it easier for the PwABI to digest. This was most commonly seen on the question of what food to eat. Carers frequently broke this question down into three chunks, starter, main and desert.

The final strategy in the carer’s toolbox is correcting their partner during the task. The following excerpt shows one way in which carers corrected their partners in this task, spelling:

Carer [Randal]: *[Discussing the final question – what to do when the food is spilled prior to the guest’s arrival]. Yep and then improvise [PwABI writes this and spells improvise wrong] P-R-O [PwABI hovers, Carer takes the pen and writes the word]*

PwABI [Thomas]: Oh yeah.

[Dyad nine: Thomas (54) PwABI and Randal (87) carer. Son and father, two years post TBI after being involved as a pedestrian in an RTA]

Carers primarily involve PwABI in the task by asking questions and then use a toolbox of strategies to assist PwABI to engage with those questions. Once this process is complete and the PwABI has provided input into the task, carers then use further strategies to deal with the responses provided. These strategies are judging a response's adequacy, and if responses were deemed inadequate, steering the PwABI in another direction, setting limits on talk to ensure that it is task oriented and judging when a question is complete and it is appropriate to move on to the next section of the task. An example of the carer dealing with a PwABI's response comes from Maureen and Mark who are discussing the starter for their meal:

Carer [Maureen]: What food will you make? Well you think what you fancy for Jan and Jim this Saturday night, what would you fancy?

PwABI [Mark]: Well for me it would be pâté

Carer: Jim doesn't like it

PwABI: No, so who

Carer: Two starts

PwABI: Two starters yeah

Carer: What would be good for me and Jim? You and Jan could have the pâté.

PwABI: Soup?

Carer: Soup's too heavy, having soup for a starter I cannae eat my dinner.

PwABI: Probably do a mushroom thing. [*Carer writes*] Ok. Mains?

[*Dyad 23: Mark (60) PwABI and Maureen (56) carer. Married, five years post TBI after a fall*]

In this excerpt the carer poses questions to the PwABI and then judges the adequacy of his responses. The PwABI's initial responses are deemed inadequate and more strategies are introduced, such as further questioning, steering the PwABI's thinking and making suggestions to help the PwABI reach a response that the carer deems acceptable. The carer then decides when it is time to move on.

Summary of Care-Giver Strategy Use

Carers utilise more strategies than PwABI during collaboration on the task. Their primary strategy is to ask the PwABI questions. Once questions are asked, carers use a range of strategies in their toolbox to assist PwABI to answer the questions they have posed. Once responses to the questions are elicited from the PwABI, carers judge the adequacy of the answers, set limits on talk and steer the PwABI towards answers which carers judge more adequate. Carers are also responsible for establishing when a question is complete and it is appropriate for the dyad to move on to another aspect of the task.

PwABI Use Strategies Also

Although carers use the most strategies during interaction, PwABI have their own strategies which they use during the task. The strategies used principally by PwABI are highlighted in green in Table 6.2. PwABI were seen to make focal task decisions significantly more than carers, 6.955 times on average during the task. So although carers are in control of meta-cognition within the task, it is PwABI who have responsibility for making final decisions within the task about aspects of the meal, such as who to invite, what to eat and when to organise it for. For example:

Carer [Laura]: Who would you invite?

PwABI [Sarah]: Who would I invite? Erm, who would I invite for dinner, erm let me think. Who would I invite? I would invite Helen

Carer: *[writes Helen].*

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

PwABI were also seen to seek assistance from their carers when they were unsure during the task. An example of seeking assistance comes from Hugo (PwABI) and Jocelyn (carer):

PwABI [Hugo]: Shall we say Graeme and Joan? *[To invite to dinner].*

Carer [Jocelyn]: And will we include Campbell and Jill as well?

PwABI: *[Hovers with pen over task sheet].* So put?

Carer: Just put first name only.

PwABI: Just here? *[Points]*

Carer: Yeah, just put

PwABI: Or under?

Carer: Yeah, just put Graeme and Joan.

[Dyad 19: Hugo (53) PwABI and Jocelyn (47) carer. Co-habiting partners, four years post TBI after a fall]

In this excerpt, we can see that Hugo is unsure about filling in the task sheet and he asks his carer for advice several times regarding where to fill in the answer they have discussed. Requesting help from a caregiver is a strategy which was previously seen in a coping study by Oyeboode et al. (2009). In this study, participants with AD often turned to their care-givers, requesting help and seeking clarification from them whilst carrying out memory tasks. The fact that PwABI turn to care-givers when the cognitive load is too great suggests that care-givers are perceived as a useful resource with an assistive function when PwABI become troubled by an aspect of a task.

Joint Strategies

There were also two strategies which were used equally by both carers and PwABI in this study. The jointly used strategy of checking agreement, coded at sentence level, is highlighted blue in Table 6.2. In addition to checking agreement, responsibility for writing was distributed equally among the 22 dyads taking part in the study. 50% of carers were in charge of writing and 50% of PwABI wrote the answers during the task. An example of the joint strategy of checking agreement is given below:

Carer [Julia]: And then what do you think we would do? I think we would ring up for a takeaway don't you?

PwABI [Jack]: Yes.

[Dyad 24: Jack (19) PwABI and Julia (59) carer. Son and mother, four years post TBI after a fall]

Checking agreement makes sure that care-givers and care-receivers are in alignment in their views and provides a marker of where partners are in a conversation. Such positive communication strategies are an important precursor to effective enablement

of everyday tasks (Simmons-Mackie & Kagan, 1999). In summary, the type of strategies used by carers and PwABI are not mutually exclusive and there are some strategies which are equally useful for both the 'expert' and the 'novice' in interaction.

Completing the Task is a Collaborative Process

Previous research on interactions between expert and novice whilst completing a task has traditionally focused on the input of the expert rather than that of the novice, with the novice's contribution reduced to whether or not they reacted appropriately to the expert's input (Rogoff, 1998). Theorists have argued that for a relational approach, there must be greater recognition of the active role of the novice in shared activity between novice and expert (Vygotsky and Luria, 1994) and acknowledgement that the novice is involved in the "continuing cycle of communicational tension and resolution" (Stone, 1998, p. 354). Accordingly, in the inviting for a meal task analysis, the strategies used by both care-givers and PwABI have been considered. Although carers used more strategies than PwABI overall, PwABI had distinct strategies which they used significantly more than their carers. PwABI also used the strategy of checking agreement as often as their carers and were regularly in charge of writing answers on the task sheet. Interactions surrounding the meal task, therefore, bear the hallmarks of collaboration as both PwABI and carers were involved in distinct ways in completing the task successfully.

Consideration will now be given to how the overall strategies used by PwABI and care-givers are organised to facilitate collaboration and completion of the task.

Domains of Responsibility Established During Collaboration: Carers in Charge of Background, PwABI in Charge of Foreground

Collaboration works in this task by portioning domains of responsibility. It seems that carers and PwABI are each responsible for different domains of the task, which can be termed background and foreground. Carers are responsible for the background of the task.

Shakespeare and Clare (2005) described carers as taking on a directive role in joint activity and this directive role is present in this data also. Carers employ a range of strategies to direct the task and the PwABI's role within it. Directive strategies used more by carers are initiating the task, taking the lead in reading aloud, steering talk towards areas that carers judge appropriate according to their perception of the task and setting limits on talk which is task relevant. Carers are also seen to take on the role of judging whether responses are adequate and they judge whether questions have been answered comprehensively enough to move on to the next question.

The foreground of the task, the final decision making regarding what ultimately is the plan for inviting someone round for dinner is the PwABI's domain. Carers assist PwABI in reaching these focal task decisions through their primary strategy of questioning, which focuses PwABI's attention on the relevant issues to think about when making decisions.

This finding that carers provide much background work on this joint task to facilitate PwABI involvement is in line with the finding in chapter four that carers do a lot of background work more widely, in daily life. Carers work backstage, facilitating PwABI's involvement front stage to foster PwABI identity and self-esteem.

But Carers Influence the Foreground: PwABI's Strategy of Making Focal Task Decisions is Carer Orchestrated

Although PwABI are responsible for making task decisions, in most cases the carer either *allows* PwABI to make decisions or *pushes* them to do so, rather than this being the independent assertion of the PwABI. The following extract shows one carer employing a range of strategies to push the PwABI to make a decision about who to invite:

Carer [Wendy]: Right, who would you like to invite for a meal Keith? Is there anybody in particular you would like? If you were going to have anybody who would you like? Would it be like Mary and John, Jean and Andy, Margaret and Jim or Malcolm or Liza and Suzanne? Who would you like? Or your Mum? Out of that lot who would you like to invite?

PwABI [Keith]: I don't know.

Carer: Well think about it. Who do you think?

PwABI: *[pause]* But they all like different things.

Carer: I know but we'll come to that, we'll come to that. But who, who out of that, that's roughly a guide, would you ask to come for a meal?

PwABI: We'll say Jim and Margaret.

Carer: Jim and Margaret *[carer writes this answer]*.

[Dyad four: Keith (51) PwABI and Wendy (61) carer. Son-in-law and mother-in-law, 27 years post TBI after an RTA]

In this extract, we see the carer employing the strategies of questioning, offering options, repeating, rephrasing and prompting to push the PwABI to make a decision. Although the PwABI makes the final decision, the process is heavily orchestrated by the carer and is not organic. The excerpt feels more like an interrogation than a discussion, with Keith forced to make a decision.

PwABI's decisions are only accepted if they are deemed appropriate by the carer

Even though carers pushed PwABI to make task decisions, decisions were only accepted if they were deemed appropriate by carers. Carers were seen to read aloud more than PwABI. However, carers did not simply read out the questions on the task sheet and assist PwABI to answer those exact questions. Instead, carers were seen to interpret the questions within the task and had clear ideas of how those questions should be answered. Carers interpreted task questions in idiosyncratic ways, thus the reading of the task varied between dyads. So although the process of directing was similar between dyads, the content within the direction carers provided differed. For example, when asked to choose who to invite, some carers read the question literally and when asked "Who will you invite? (First name only)", carers deemed that only one person could be invited. Others interpreted the question as requiring the planning of a dinner party where inviting only one guest would be inappropriate. However, despite differing conceptualisations of the questions, in each case PwABI were required to answer according to their carer's perception of the task. PwABI would often give an answer to a question which made sense, but was judged to be inappropriate either for completing the task itself or for the situation described in the task, having someone round for a meal.

The following excerpt shows a carer judging the response of the PwABI as inadequate for completion of the research task:

Carer [Laura]: *[Reads out last section]* [...] there is food all over the table and the floor. With your guest arriving in ten minutes what on earth are you going to do?

PwABI [Sarah]: Absolutely nothing because that wouldn't actually happen with me.

Carer: Noooo

PwABI: I wouldn't actually put food out until my guests arrived.

Carer: Aha, but this is a scenario.

PwABI: Oh this is a scenario, sorry.

Carer: You want to answer the question. So it's all over the table and Helen's knocking on the front door.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

In this extract, the carer has asked the question specified in the task sheet which is what would happen if the food was spilled prior to the guest's arrival. The PwABI's response here is plausible in response to the question asked. The question suggests that food has been placed out and knocked over before the arrival of the guest. However, the PwABI states that putting out food is not something she would do prior to a dinner guest arriving. The carer does not judge this to be an appropriate response for the research task and steers the PwABI towards focusing on the scenario in the task rather than a real life situation.

In the following excerpt, it is the response not within the parameters of the task but within the parameters of having someone round for dinner which the carer judges to be inappropriate:

Carer [Julia]: And are we gonna give them something for pudding?

PwABI [Jack]: Obviously chocolate and that's it.

Carer: Oh. Just chocolate. I think you'd give them more than that. Shall we not give them some ice cream or something?

[Dyad 24: Jack (19) PwABI and Julia (59) carer. Son and mother, four years post TBI after a fall]

The PwABI's answer here regarding what to have for dessert is adequate in the sense that he has chosen something sweet. However, the carer deems this an inappropriate dessert when entertaining guests and the PwABI is encouraged to consider a different option.

These excerpts demonstrate the fact that it is the carer who defines the task in their own terms. At the beginning of the task participants were told to work together in whatever way they wanted. They were told that the answers they gave would not be analysed but that it was the way they worked together that was of interest to the researcher. Despite knowing that the actual answers dyads gave were not of importance, carers still defined the responses as important. Although PwABI made final task decisions, they were only accepted if they were appropriate to the carer's interpretation of the task.

If a decision made by the PwABI is not in line with the carer's expectations then the carer often rejects this decision. However, carers still push PwABI to make the final decision as the foreground is the PwABI's domain. Therefore, in the case of unacceptable answers, further questioning ensues which refocuses the PwABI's thinking, with the aim of the PwABI making different and more appropriate decisions:

Carer [Jocelyn]: Ok, let's have somebody round for tea. Who will we, who will be the person we invite round?

PwABI [Hugo]: Just any bunch of friends.

Carer: No, particularly who it is. This is as though it's life. As though

PwABI: It's actually happening.

Carer: As though we decided, you and I, that it's about time

PwABI: We had them round

Carer: We had somebody round. So who?

PwABI: Shall we say Graeme and Joan?

[Dyad 19: Hugo (53) PwABI and Jocelyn (47) carer. Co-habiting partners, four years post TBI after a fall]

In the extract above we see the carer asking the PwABI who he would like to invite. The PwABI gives an answer which is too vague; the carer deems the decision unacceptable and rejects this. Through a process of explanation and further questioning by the carer, the PwABI makes a decision which is more acceptable to the carer. Although PwABI still make decisions, it is on the carer's terms and only when a decision is acceptable to the carer will it be included on the task sheet.

Why Let PwABI Make Decisions? Collaboration is a Positive Experience for PwABI

The analysis so far has shown that carers are in charge of directing the interaction, and are particularly responsible for controlling the background of the task. However, we have seen that carers also influence the PwABI's foreground domain, steering PwABI in certain directions. If the carer is in charge and will decide whether a decision is acceptable, why allow the PwABI to make focal task decisions at all? Completing a task successfully is only one aim of collaboration between carers and PwABI. As we saw in chapter four, a major aim for carers in daily life is fostering a sense of confidence and independence in

their partner and maintaining PwABI self-esteem. Facilitating PwABI to make task decisions will contribute to the PwABI's sense of involvement in the collaborative process, increasing their confidence in their ability to contribute to the task and as a result their self-esteem. Thus, the aims of carers in the task are multi-faceted. They wish to complete the task successfully, but also wish to boost PwABI self-esteem.

In their discussion of occasioned talk, Shakespeare and Clare (2005) suggested that carers of those with dementia made efforts in interaction to position the person with dementia as a competent conversational partner through the strategies they chose and this may help to maintain self-esteem in those with dementia. In the present study, having responsibility for making final decisions positions the PwABI as a competent contributor to the interaction. This helps to fulfil a carer's major focus within the task, the maintenance of self-esteem in the PwABI.

Excerpts of talk surrounding the task demonstrate attempts by carers to increase self-esteem in PwABI beyond giving over responsibility for making task decisions:

PwABI [Chris]: Who will lay the table? Chris.

Carer [Vicky]: That's you. The other bit was how would you invite them? That's you. Second phone call by Chris or is it third phone call by Chris. [*Carer points to paper and PwABI writes*]. The other bit that's missing, your major role, is who would do the washing up? Chris.

[*Dyad 15: Chris (68) PwABI and Vicky (65) carer. Married, four years post TBI*]

In this extract, Vicky, the carer is drawing attention in the interaction to all the ways in which Chris, the PwABI, contributes to the process of having someone round for a meal. The task does not ask about the washing up process but this is the part of a regular

meal time scenario that the PwABI has responsibility for. By mentioning this, the carer is going beyond boosting self-esteem via facilitating participation in the task, aiming to bolster self-esteem by revealing during the research process what the PwABI can do during meal times.

In summary, carers and PwABI were both shown to use strategies in collaboration to complete the inviting a friend or relative round for a meal task. Carers used most strategies and were responsible for the background of the task. PwABI were responsible for the foreground of the task, making focal task decisions. However, when analysing talk during decision making, carers were seen to lead and sometimes push PwABI to make decisions. Decisions must be deemed adequate by carers before they are accepted. Carers have a dual aim of completing the task adequately and facilitating PwABI involvement and self-esteem.

Question 3b: Is the Type of Input Provided by Carers on the Joint Task Comparable to Scaffolding as Described in the Child Development Literature?

The experts in this task, carers, have been shown to utilise strategies in interactions with PwABI to assist their partner's ability to participate in the task. Can this be termed scaffolding? Despite the concept of scaffolding being introduced originally in relation to those with cognitive impairment (Vygotsky, 1978), this metaphor has been taken up by the child development literature and relatively little attention has subsequently been paid to scaffolding in interactions with those with cognitive impairment, particularly with adults. Shakespeare and Clare (2005) hinted that the strategies carers use to position their partner as a competent conversational partner during tasks involved "scaffolding" (p. 339) but did not discuss further whether the interactions could be considered scaffolding interactions. The remainder of this chapter will consider whether the strategies used in the inviting for a meal task can be considered scaffolding by considering the major features of the metaphor

in the child development literature. Although equivalence between scaffolding of children and atypical adult learners has not been explicitly suggested in the literature, Wood et al. (1976) introduced the scaffolding metaphor to describe “a process that enables a child or novice to solve a problem, carry out a task or achieve a goal which would be beyond his unassisted efforts” (p. 90). Thus, the emphasis is not just on children, but the more general concept of the “novice”. After brain injury, PwABI often become novices when carrying out ADLs and carers become comparative experts. The metaphor has previously been interrogated in atypical child learners (Stone, 1998) and it is a contribution of this thesis to consider the scaffolding metaphor in relation to atypical adult learners. The clearest outline of scaffolding features were presented by Wood et al. (1976) and this has been supplemented by discussion surrounding removal of supports over time (Pea, 2004). These features will be critically interrogated using the inviting for a meal data. The features are 1) the strategies used; 2) differences in level of input and type of strategies used based on difficulty and skill level ; and 3) gradual removal of supports.

1. The Strategies Used

Wood et al. (1976) outlined the key roles that a tutor needs to fulfil in order to scaffold a novice effectively. These are to evoke interest in the task, simplify the task, keep as primary focus the pursuit of the goal, controlling frustration in the novice and drawing attention to differences between the ideal answer and that produced by the novice, where necessary by demonstration of correct execution.

These roles seem to relate more to practical tasks than to conversational planning as used in the present research. However, there is evidence of all these strategies within the data. Carers evoke interest in the task by initiating the exchange and reading aloud, orienting the PwABI to the task. Carers simplify the task using their strategy toolbox.

Questioning, rephrasing, repeating, making suggestions, presenting options and chunking all simplify the task. Carers keep as primary focus the pursuit of the goal throughout the task via their directing role. By setting task parameters and steering the interaction, carers keep PwABI focused on the task. Carers control frustration in PwABIs by steering talk in a different direction when PwABIs become frustrated. Finally, carers draw attention to differences between the ideal answer and that produced by the novice by the strategy of judging responses for their adequacy and if found wanting, correct the PwABI or steer them towards more appropriate answers via more focused questioning, rephrasing and suggesting alternative options. Thus, the strategies used by carers in the inviting for a meal task seem to correspond to the strategies outlined by Wood et al. (1976). Therefore, on this basis the interactions appear to be scaffolding interactions.

2a. Carer Input Does Vary with Difficulty of Question.

A key feature of scaffolding, as defined by the child development literature is that it is flexible and adjustable (Wood et al., 1976). Parents have been seen to adjust their levels of input based on skill level and the amount of input required for the novice to complete a task (Rogoff, 1998). Carers were seen to provide shifting amounts of support in the present study. Carers were seen to provide less input on questions such as “how will you invite them?” which required less cognitive effort for PwABI’s than on questions such as “what food will you make?” and the final question which asks participants to consider what they would do if the food spilled ten minutes before their guest arrives.

As an example of this shifting of support, consider the answers given by the same dyad to the two questions: “How will you invite them?” followed by “What food will you make?”

Carer [Hayley]: How will you invite her? E-mail?

PwABI [Carl]: Phone

Carer: Ok, you'll phone her?

PwABI: Yeah, I've done it before. *[Writes answer and then reads aloud]* When will you have the meal?

[Dyad two: Carl (54) PwABI and Hayley (53) carer. Partners, 46 years post childhood TBI after being involved as a pedestrian in an RTA]

There are four conversational turns to answer this question. The carer reads aloud the question and makes a suggestion about a method to invite the guest. The PwABI rejects the suggestion and decides he will phone their guest. The carer then checks this response and the PwABI confirms that this is the course of action he wishes to take. The interaction is relatively short and contains some input but not a great deal from the carer. The carer uses two strategies in the exchange, she suggests an option and checks an answer. The second question is 'What food will you make?'

PwABI [Carl]: What food will you make? Pasta *[laughs]*

Carer [Hayley]: Erm,

PwABI: As long as

Carer: Do you not want to try something different?

PwABI: Salad, cold meat salad.

Carer: Ok, so do you not want to try something different?

PwABI: Spaghetti Bolognese? Curry? Erm, toastie cheese. Erm what else is there? Scrambled eggs?

Carer: Well there's books full of recipes.

PwABI: Hmm

Carer: Um, you'd better find out if she's vegetarian first.

PwABI: That's right, she's a student.

Carer: Well if you say a salad

PwABI: Salad, yeah.

Carer: Then you can find out if she's vegetarian and you can exclude meat.

PwABI: *[Moves onto next question]*

[Dyad two: Carl (54) PwABI and Hayley (53) carer. Partners, 46 years post childhood TBI after being involved as a pedestrian in an RTA]

This question requires 14 conversational turns to complete. The PwABI makes a suggestion of pasta but the carer deems this unadventurous and suggests that he could try something different. The PwABI suggests another meal he makes regularly which prompts the carer to repeat her question about him making something new. The carer provides more prompts in this exchange as there is more to consider in the food to prepare for someone coming for dinner than there is in the mode of inviting. For example the PwABI has decided to invite the researcher round for a meal and the carer prompts him to find out if the researcher is a vegetarian. The carer uses various strategies in this exchange, such as questioning, repeating, prompting, steering and making alternative suggestions. The second exchange regarding what to eat is more than three times the length of the first, with the carer providing greater input and utilising a wider range of strategies to assist the

PwABI to consider what food he wishes to serve his guest. This increase of carer input on more difficult questions is in line with the flexibility of input component of the scaffolding metaphor and suggests that the inviting for a meal data comprises scaffolding.

2b. Different Impairments Need Different Strategies

As well as being flexible in terms of input based on the difficulty of the task, scaffolding is also considered to be flexible and adaptable in terms of the *type* of strategies used. The three strategies of gesturing, using assistive technology and speaking for your partner were not used by either carers or PwABI in this study. However, these strategies were used in another study using the same task but with an aphasia sample (Gillespie et al., in prep.) The three strategies would be expected in a sample where there is a dominant communication impairment. However, the fact that these strategies were not used in the present sample of ABI dyads suggests that strategies to assist and augment cognition are selected which are tailored to the individual with whom another individual is interacting and are appropriate to their pattern of deficits. This suggests that the package of support provided by carers may be tailored and is thus in line with the flexible and adaptive nature of scaffolding. However, there was no evidence of tailoring within the inviting for a meal task data in the present study in terms of level of cognitive impairment and the input provided by carers, so we cannot assume that this scaffolding assumption has been met in this task.

3. Can Carers Remove Supports?

A final feature of scaffolding is that the novice should demonstrate increasing mastery of a task over time. As a result, experts should be able to remove the scaffolding once the novice has learnt how to fulfil the task requirements alone (Pea, 2004). As this task was not repeated it is difficult to assess whether there was increasing mastery of the task and corresponding removal of supports. However, in a population with severe

cognitive impairment who are two or more years into their recovery, it is unlikely that learning will occur if a task hasn't already been mastered (Luria, 1973). As a result, the removal of supports over time is unlikely. Without learning, scaffolding input would be required each time a person with cognitive impairment attempts a task which is beyond their cognitive capabilities.

Carers experience frustration

The fact that carers have to continually provide input on similar tasks without the opportunity to remove scaffolds over time may lead to frustration in carers. Joking is a common strategy used within scaffolding interactions (Shakespeare & Clare, 2005; Gillespie et al., in prep.). However, joking was almost absent as a strategy in this data set. Upon examination of the videos there was evidence of frustration in carers during the task. Controlling frustration in the novice was a feature of successful scaffolding in Wood et al.'s (1976) data, yet it is frustration of the *expert* which could act as a barrier to scaffolding in this data set. The following three excerpts demonstrate carer frustration regarding the content of the task. In each case the carer shows frustration when the PwABI does not acknowledge the fact that a role within preparing a meal is one the carer always takes on:

Carer [Nicola]: Who will lay the table? That will be me.

PwABI [Ramsey]: Why?

Carer: Well I would probably lay the table

PwABI: You'll just fill it up with stuff.

Carer: I would normally lay the table if we were in

PwABI: *[laughs]*

Carer: *[sounds exasperated]* Well I would, wouldn't I? So I would probably lay the table.

PwABI: Ok, I'll take it off and put it back on

Carer: Ok. *[reads next question out loud]*.

[Dyad one: Ramsey (49) PwABI and Nicola (age not disclosed) carer. Married, 12 years post TBI after an RTA]

Here, the carer proposes that she will lay the table for the meal. The PwABI questions why the carer assumes it will be her who lays the table. The PwABI then makes an inflammatory remark about the carer "just filling it up with stuff", followed by laughter. The fact that the PwABI doesn't acknowledge that laying the table is a job that the carer does irritates the carer, leaving her feeling exasperated. The PwABI continues to antagonise the carer by suggesting that he will remake the table once she has set it. Here the carer controls her frustration and refuses to rise to the last comment of the PwABI, instead moving on to the next question. Another example of frustration is as follows:

PwABI [Bill]: *[who to invite]* For a meal? Shall I just write Lesley?

Carer [Nena]: Put Ian and Jackie cos we do need to invite a couple *[PwABI writes this]*. If we were inviting someone round for a meal it would be muggins who cooks. It would be me that runs about.

PwABI: *[talks over carer and reads aloud]*. How will you invite them? Ask them or send them text.

[Dyad 11: Bill (34) PwABI and Nena (32) carer. Married, three years post TBI after an RTA]

In this excerpt we see the carer's frustration as she states that she would be in charge of everything if someone were invited round for dinner. The PwABI does not acknowledge this but talks over the carer and continues on to the next question. Another excerpt demonstrating frustration is as follows:

Carer [Vicky]: *[Reads out last question regarding what the couple would do if prior to the guest's arrival the food is spilled]*

PwABI [Chris]: Well.

Carer: Curse a bit.

PwABI: Clean it up.

Carer: But what would you put on the table? *[pause]*

PwABI: Yes well that probably wouldn't have happened would it?

Carer: Well at least if we have had it you've not known about it because the cook has been in the kitchen on her own. Ok food all over [...]

[Dyad 15: Chris (68) PwABI and Vicky (65) carer. Married, four years post TBI]

In this extract, we see the PwABI assert that the situation with the food being spilled prior to the guest arriving would not have happened. In the carer's response we get a sense of her frustration that she is the only one who is involved in the preparing of meals. Her choice of pronoun, "the cook" is interesting, depersonalising her and categorising her in terms of a generic role. Her use of "on her own" shows her loneliness in her role as sole

preparer of meals in the household. This excerpt shows the carer's burden at having to deal with a major household activity, the cooking, alone. It suggests she feels that she is considered a menial labourer rather than wife, and is not recognised for the work she does. It is interesting to note that this is the carer we saw earlier bolstering her partner's self-esteem by pointing out all the ways in which he contributes to the task. This shows the tension between the carer wishing to protect the self-esteem of their partner and bolstering their sense of contribution whilst simultaneously feeling frustration and lack of recognition regarding their own role, a daily life situation seen in chapter four.

In the next excerpt is a carer who is frustrated with the process of collaborating on the task itself, rather than the content per se:

[Discussing who to invite. The carer had previously expressed concerns about the PwABI's ability to engage in the task as he has problems dealing with hypothetical situations]

Carer [Hayley]: Well do you want to do it about your Mum?

PwABI [Carl]: Well, we'd have to get her up the stairs first.

Carer: I suppose. Right, ok put Helen *[researcher]* then.

[PwABI suggests inviting someone else he knows with an ABI]

PwABI: [...] I say it would be a bigger challenge you know.

Researcher: It's entirely up to you who you want to invite.

PwABI: But I don't want, 'cos in fact it would cause me more stress because I have the same problems they have.

Carer: *[To researcher, exasperated]* You see this is, this is going to be impossible.

PwABI: Yeah, Ok we'll just put Helen then.

[Dyad two: Carl (54) PwABI and Hayley (53) carer. Partners, 46 years post childhood TBI after being involved as a pedestrian in an RTA]

In this extract the carer becomes exasperated and seems to give up on the task when the PwABI can't decide who to invite. Conversely to the principle of scaffolding of controlling frustration in the novice, here it is the novice who attempts to control frustration in the expert. After becoming exasperated and stating to the researcher that the task is "going to be impossible" the PwABI makes a decision in order to appease the carer.

The frustration expressed by carers in this task may show the pressure which the inability to remove supports places on dyads collaborating although further investigation of this point is required. Carers use a range of strategies, flexibly, to assist PwABI to participate in tasks but become easily frustrated when there is disagreement on the task. Thus, the scaffolding metaphor is appropriate for adults with cognitive impairment in terms of the strategies used and to some extent the flexibility with which support is provided. However, the scaffolding metaphor is not applicable to adults with cognitive impairment in terms of removal of supports once mastery is achieved. Therefore, the use of the scaffolding metaphor is only partially supported for adults with cognitive impairment.

Discussion

Summary

In answer to question 3a: *What strategies do carers and PwABI use in collaboration on a joint task?*, the analysis of dyads participating in a joint task

demonstrates the strategies that carers and PwABI use to complete the task. Completing the task is a collaborative process with carers and PwABI using different strategies in interaction. Carers initiate and direct the task, controlling the background. They steer the task forward principally using the technique of questioning and then use a 'toolbox' of strategies to assist and augment their partner's cognition. Conversely, PwABI are responsible for the foreground of the task, they are actively involved in collaboration by making focal task decisions. However, the collaborative process was dominated by carers. Although responsible for task decisions, it was shown that carers guide PwABI towards specific decisions which are in line with the carer's perspective on the task. In addition, the role of decision maker is granted to PwABI by carers rather than a role that occurs naturally or is actively taken on by the PwABI. Carers give over the foreground of the task to PwABI to position them as contributing members of the interaction with the aim of maintaining their self-esteem.

In answer to question *3b: Is the type of input provided by carers on the joint task comparable to scaffolding as described in the child development literature?*, collaboration between carers and PwABI bears many of the hallmarks of scaffolding. The strategies outlined as scaffolding strategies by Wood et al. (1976) were used, carers were seen to adjust their input based on difficulty and to some extent the strategies used were appropriate for partners with cognitive impairment. However, a key tenet of scaffolding is not met by interactions between carers and PwABI, namely the removal of supports over time as mastery is achieved. It is unlikely in this sample that learning will be possible. This has implications for the nature of discussions within the task. Carers were found to become frustrated. This may be due to the fact that each time an interaction like this occurs, the same level of scaffolding will need to be provided and this places burden on carers. The flexibility and adaptability of the type of support carers provide, alongside the directive

role that all 22 carers adopted within the task suggests that carers scaffold those they care for in this study. However, removal of supports is not possible for many adults with cognitive impairment so the scaffolding carers put in place will need to be present each time a task is carried out, as mastery cannot be achieved.

How Does this Research Fit into the Wider Literature on Strategies?

There have been calls for more research on processes of interaction between care-givers and care-receivers to reveal the strategies used in collaboration (O'Neill & Gillespie, 2008) by both experts and novices (Rogoff, 1998). Accordingly, strategies of both PwABI and care-givers were investigated and different strategies were found to be utilised by care-givers and PwABI. The strategies used by care-givers in this research were comparable to those found in Shakespeare and Clare's (2005) research on a joint task between carers and those with dementia, with the carer taking on a directing role and using strategies to position the person with cognitive impairment as a competent collaborator. This was achieved in the present research by designating final decision making as the domain of PwABI. In terms of care-receiver strategies, as in Oyebode et al.'s (2009) research, carers were seen as a valuable resource by care-receivers, who used the strategy of turning to their carer for assistance where necessary.

This chapter captures at the level of talk, the patterns of interaction between PwABI and care-givers that were described in chapter four of the thesis. When collaborating on the joint task, carers are working hard in the background to assist PwABI to participate in the foreground of the task and to maintain their self-esteem. However, carers can feel frustrated during the task when they feel unrecognised by the PwABI for the work they do, much like they did in respect of care work more widely.

In terms of scaffolding, the aspect of the metaphor which does not appear applicable for adults with cognitive impairment is removal of supports, although more research with longitudinal data is required to explore this possibility in more detail. The lack of opportunity to remove supports has the potential to frustrate carers. In looking for practical solutions to the issue of pressure on carers it is necessary to turn to the assistive technology literature.

Carers are Assistants for Cognition: Data on the Strategies Carers Use can Inform ATC Design

The way carers employed strategies to facilitate the involvement of PwABI in this task puts carer input in line with Alm et al.'s (2004) definition of a cognitive prosthesis. Alm et al. suggest that a cognitive prosthesis should “act as a compensatory strategy for people with deficits in cognitive processing which, when added to the environment of the person, increases their capacity to function in an effective manner” (p. 118). This definition is applied to the categorisation of ATCs but it could be argued on the basis of this study that carers play the role of the ultimate ‘assistive technology’. Their input acts as a compensatory strategy which increases PwABI’s capacity to function. Accordingly, research on the strategies that carers use when scaffolding those with cognitive impairment would be useful in enhancing the design of technologies which simulate the sorts of support that carers provide during tasks.

One such ATC is the GUIDE (O’Neill & Gillespie, 2008) which is a verbal prompt system which guides users through the steps required to successfully complete a task. The development and use of such devices has the potential for dual impact. Such devices have the potential to increase independence in those with cognitive impairment, which would in turn increase self-esteem, a primary goal of carers. But also, such devices would lessen the burden on carers, reducing the frustration that carers feel when continually scaffolding

their partners. Lessening of burden and frustration in carers and increased feelings of independence in those with cognitive impairment may lead to more positive relations between carers and those they care for (Proot et al., 2000). Development of ATCs of this kind can be informed by information on strategies used during joint activity between carers and those with cognitive impairment. More research is needed on the processes which occur between care-givers and care-receivers during joint activity in larger and more diverse samples and on different tasks. Longitudinal data is required to assess the potential for task mastery.

The Inviting for a Meal Task is Artificial

One limitation of this study is that the task used was artificial and only involved discussion of what 'would' be done in the situation of inviting someone round for a meal. The actual process of inviting someone round was not studied. ATCs which simulate carer support would be most successful if linked to everyday tasks with a clear method of action for successful completion, such as brushing teeth or making a sandwich. Future research should employ test situations which are grounded in real everyday activity in order to gain rich data on the processes involved in collaboration on real world tasks. One such approach would involve naturalistic observations of carers and those they care for engaging together in activities of daily living. This type of data would also add to discussions on scaffolding, as the strategies defined by Wood et al. (1976) are better suited to tasks which involve hands-on activity. In order to study the issue of removal of scaffolding supports in more detail future research should repeat a task with care-givers and care-receivers to see if learning can occur in care-receivers on full or part tasks. If mastery is a realistic goal then how does this affect carer input, and how does this input compare to tasks where mastery is impossible?

A caution regarding the heterogeneity of the sample

Different types of care-giver, care-receiver relationships have been subsumed under the 'carer' category and it is important to raise a caution about this when interpreting the results of this chapter. Although strategies to assist partners to engage in a task seem to be used naturally and pervasively across carers, it is acknowledged that the process of assisting and augmenting cognition may come more easily to parent-child relationships post ABI than to romantic relationships as for parent-child relationships there is a resumption of the previously held role of nurturer and to some extent 'educator'. As Proot et al. (2000) explicate, scaffolding type interactions risk positioning care-receivers as dependent and child-like and can be intrusive and embarrassing for PwABI. Scaffolding interactions between romantic relationships which were previously more equal than a parent-child relationship may be particularly susceptible to negative and embarrassing positioning for the PwABI compared to relationships which were already characterised by parent/offspring roles. Proot et al. (2000) also suggested that the process of scaffolding could be frustrating for carers. Each example of carer frustration explored above came from romantic partners, perhaps highlighting the difficulties with establishing a completely new type of interaction within a particular dyad.

Conclusion

Carers and PwABI both use strategies in collaboration on a joint task. Carers are in charge of the background, putting the supports in place to allow PwABI to participate in the foreground of tasks, making focal task decisions, a process which can build their self-esteem. However, the foreground participation of PwABI is often forced and PwABI input is only accepted when judged appropriate by the carer. This rigidity precludes the type of input which could be provided by a full member of the interaction (Shakespeare & Clare, 2005) and may thus serve to reinforce the unequal status of the care-receiver (Sabat &

Harré, 1992). In addition, the complexity of the scaffolds which need to be put in place by carers each time a task is attempted may take their toll on carers, leaving them burdened and frustrated.

Chapter Seven – A Clash of Perspectives: The Problem of Collaborating When Applying for Disability Living Allowance

Three point two million people in the UK are currently in receipt of DLA (Department for Work and Pensions, 2011), a benefit designed to assist with the costs of living with a disability. To access this benefit, people with disability are required to complete a 55 page claim form which assesses the difficulty claimants have in participating in activities of daily living. It is the completed claim form which is used as the basis for assessment of eligibility for receipt of the benefit and if eligible, the level of benefit required. A study examining the experience of applying for DLA in Scotland showed that 97% of 606 respondents found the form difficult to fill in (Banks & Lawrence, 2005). The process of claiming DLA has been described as “time consuming, complex and stressful and in some cases respondents cited the DLA system as a factor exacerbating the seriousness of their health condition” (Salway et al., 2007, p. 924). As a result of the complexity of the DLA claims process, people with a disability often need to turn to others, such as informal carers, to help them complete the form, particularly when they have a cognitive impairment. Despite research indicating the form’s complexity, no study to date has examined the *process* of filling in the DLA claim form. This chapter asks *4a: What happens when carers and PwABI collaborate to fill in the DLA claim form?*

How the Data Set was Analysed

To answer question *4a: What happens when carers and PwABI collaborate to fill in the DLA claim form?*, the answers participants gave to the nine questions of the “your care needs during the day” section of the DLA claim form were analysed alongside video recordings of dyads filling in the form. Frequencies of the number of dyads who gave ‘yes’ and ‘no’ answers to each of the nine questions on the form were calculated. An answer of ‘yes’ indicated that the PwABI had difficulty in that particular area of functioning and that

help was needed to participate in ADLs in that area. An answer of ‘no’ indicated that there was no difficulty in ability to participate in the area of functioning and thus no disability. These frequencies reveal which aspects of the section of the form: ‘your care needs during the day’ are most relevant to dyads living with ABI and pinpoints dyads who answered ‘no’ to all questions, thus for whom the DLA form was not relevant.

Video recordings of dyads filling in the form were then analysed to reveal the total number of questions on which there was disagreement between carers and PwABI in reaching the answers they gave on the form. The directionality of disagreements was also analysed to see whether PwABI or carers believed there was greater difficulty in PwABI participation in ADLs. Analysis of disagreements revealed a high level of contestations in the data and this was almost always in the direction of the carer perceiving greater difficulty in the PwABI’s ability to participate in ADLs than the PwABI perceives.

Due to the high level of disagreements and the almost uniform directionality of these contestations, a second research question has emerged from the data *4b: Why do carers see more disability than the PwABI when filling in the DLA form?* To answer question 4b and further elucidate the processes of collaboration in dyads when completing the form, the video recordings of dyads collaborating to complete the form were analysed using NVivo nine software. Qualitative analysis focused on the video recordings at the point of disagreements within dyads when reaching decisions about what answer to give on the form, in order to establish the reasons why carers see greater disability than PwABI.

Question 4a: What Happens When Carers and PwABI Collaborate to Fill in the DLA Form?

What Answers did Dyads Give on the Form?

As there were 22 dyads, each answering the nine questions included in the task form, this means that a total of 198 questions were answered (see Appendix C for the task

form). Table 7.1 introduces frequencies and the corresponding percentage of dyads answering yes and no to each question.

Table 7.1

Frequencies of Dyads Answering ‘Yes’ or ‘No’ to Each of the Nine Questions Included in the DLA Form Task

| | Number answering ‘yes’ (a difficulty in this area of functioning) | Number answering ‘No’ (no problem in this area of functioning) | Percentage ‘yes’ | Percentage ‘no’ |
|--|---|--|------------------|-----------------|
| Q1 – Difficulty getting out of bed in the morning or into bed at night? | 3 | 19 | 13.63% | 86.37% |
| Q2 – Difficulty moving around indoors? | 8 | 14 | 36.36% | 63.64% |
| Q3 – Fall or stumble because of illness or disabilities? | 11 | 11 | 50% | 50% |
| Q4 - Have difficulty taking medicines or with medical treatment? | 5 | 17 | 22.73% | 77.27% |
| Q5 – Need help from another person to communicate with others? | 14 | 8 | 63.64% | 36.36% |
| Q6 –Need help from another person to actively take part in hobbies, interests, religious or social activities? | 12 | 10 | 54.55% | 45.45% |
| Q7 – How many days a week do you have difficulty or need help with the care needs you have told us about? ^a | 12 | 10 | 54.55% | 45.45% |
| Q8 – Need someone to keep an eye on you? | 7 | 15 | 31.82% | 68.18% |
| Q9 –Difficulty preparing/cooking a main meal for yourself? | 14 | 8 | 63.64% | 36.36% |
| Totals | 86 | 112 | 43.43% | 56.57% |

^a If classified as ‘yes’ this denotes that a number of one or above was given to this question. If classified as ‘no’ this denotes that a number of zero or N/A was given to this question.

The table shows that in total 43.43% of the 198 questions posed were answered in the affirmative by dyads. A greater number of questions were given a ‘no’ answer by the 22 dyads in this study. These figures highlight the complexity of the situation after ABI and are in line with the literature which describes the heterogeneity of deficits experienced after ABI (Bowen et al., 2010; Ponsford et al., 1995). The figures highlighted in red show

the questions to which a majority of the 22 dyads answered ‘yes’, indicating that the PwABI has difficulty in this area of functioning. This suggests that the areas of communication, social participation and meal preparation are particularly relevant to the dyads in this study and that when there is a difficulty which requires assistance from another, it is experienced once or more a week. Question three on the DLA form, which asks whether a disability causes the PwABI to fall or stumble was relevant to half the dyads. It would appear that being unsteady on their feet was a greater problem than general mobility for the sample studied.

Questions which were less relevant for the 22 dyads in the study were ability to get into bed at night and out again in the morning, mobility indoors, compliance with medication and need for supervision. The DLA form is used for all types of illness and disability; be this mental or physical disability; disabilities that are acquired such as brain injury; or that are congenital such as learning disabilities. It is therefore understandable that some of the difficulties assessed by the DLA form section “your care needs during the day” are less relevant to a sample of those with ABI. However, it is important to note that even when a question is not relevant to the majority of the 22 dyads, some of the sample is always affected by difficulties in each of the nine areas of functioning.

Although the picture is not clear cut, it seems that the items related to participation in the social world are most relevant to the experience of disability for the PwABI sample studied. This finding is in line with the literature and highlights the pressure on informal care relationships adapting to ABI. The dyads in this study are all two or more years post injury and although the usual trend is for a slight increase or stability in participation over the long term, difficulties in social participation can in some circumstances increase over time (Brooks, 1984).

Seven of the 22 dyads answered 'no' to all nine questions, indicating that they felt they had no difficulty with their care needs during the day. These seven dyads have not been included in subsequent analysis. A limitation of this research is that it was not established how many of the 15 remaining dyads were actually in receipt of DLA. It must be acknowledged that this task may be loaded for some participants and future research into application for benefits should assess the number of participants currently receiving the benefit and establish participants' histories in terms of successful and unsuccessful claims and appeals.

Dyads Disagree When Filling in the Form

Of the total 135 answers given by the 15 remaining dyads, there were 43 questions on which the answer was contested. This means that dyads disagreed on 31.85% of questions. Of the 15 dyads that said 'yes' to at least one question, all 15 disagreed on the answer to at least one question and the dyad with the highest number of contestations disagreed on eight questions out of nine. The mean number of contestations was 4.78. Disagreements within relationships on issues surrounding the disability (Horowitz et al., 2004), risk (Heyman & Huckle, 1993), and the requirements of the care-receiver (Walters et al., 2000) have been previously reported in the literature, thus the high level of disagreements about the ability of PwABI to participate in ADLs is in line with these previous findings. However, the form taps into activities of daily living and Prigatano, Altman and O'Brien (1990) have found that relatives and patients tended to agree on such items.

Carers See Greater Disability than PwABI

Almost all, 40 of the 43 (93.02%), disagreements about care needs during the day were in the direction of the carer thinking that there is greater difficulty and more help needed to participate in ADLs than the PwABI does.

An example of a disagreement where the carer sees greater difficulty than the PwABI is presented below. The pair speaking is Jack (PwABI) and Julia (carer). They are answering question five: “Do you usually need help from another person to communicate with other people?” The pair have answered ‘yes’ to this question and are now filling in the particular areas of difficulty:

Carer [Julia]: *[Reads aloud] [difficulty] ‘answering or using the phone?’*

PwABI [Jack]: *[Looks at carer but doesn’t speak].*

Carer: Yes.

PwABI: No, no I don’t.

Carer: Oh I think you do. *[Jack reluctantly agrees].*

[Dyad 24: Jack (19) PwABI and Julia (59) carer. Son and mother, four years post TBI after a fall]

In this excerpt we can see that there is a disagreement about Jack’s ability to answer and use the telephone. This disagreement is overt and is in the direction that the carer perceives greater disability.

The remaining three contestations of 43 were in the direction of the PwABI arguing that there is more disability (6.98%). An example of a disagreement where the PwABI sees more disability comes from Fran (PwABI) and Rachel (carer):

PwABI [Fran]: Ok, *[reads aloud]* do you usually have difficulty or do you need help with taking your medicines or with your medical treatment?

[in unison]: Yes

Carer [Rachel]: Uhum.

PwABI: Twi, twice a day. *[carer writes]* Erm how many minutes?

Carer: Ten minutes

PwABI: *[laughs]* Sometimes longer if I haven't

Carer: But then I'll, exactly, I set them out for you. I'll sort them all out, set them out for you, give you some juice, you drink the juice and forget the tablets. *[Carer writes 10 minutes].*

[Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE]

In this excerpt, there is initial agreement that Fran needs help with taking her medication. However, Fran believes she needs assistance for longer than Rachel does.

It is the Carer's Higher Estimate of Disability Which is Included in the Form

When there is a disagreement, whose answer is eventually put in the form? In the three cases where the PwABI perceived a greater care need, the pair went with the PwABI's higher estimate in two of the three cases. On the 40 questions where there was a disagreement in the direction of the carer seeing greater disability, the carers' higher estimates of disability are given in 30 of the 40 questions, 75% of cases. This finding contrasts with findings in chapter six of the thesis where PwABI had control over the answers given. Instead, on the DLA form it is carers who have control over the eventual answer given.

The following excerpt from Catherine (PwABI) and Wayne (carer) shows a situation where the carer's higher estimate of disability is included in the form. The pair

are answering question five: “Do you usually need help from another person to communicate with other people?” The pair have answered ‘yes’ to this question and are now filling in the sub-questions in this section. They are currently talking about Catherine’s communication on the phone:

Carer [Wayne]: Do you have difficulty on the phone?

PwABI [Catherine]: No, no.

Carer: Well, you just don’t answer it! *[laughs and ticks ‘yes’, there is a problem with communicating on the phone]*

[Dyad six: Catherine (46) PwABI and Wayne (70) carer. Daughter and father, three years post stroke]

In this excerpt Catherine asserts that she doesn’t have a problem with communicating on the phone. Wayne disagrees with this as he points out that she avoids using the phone. He considers this avoidance a problem and ticks ‘yes’ there is a difficulty with answering or using the phone.

This excerpt highlights one of the major reasons why the carer is successful in having their higher estimate of disability included in the form in so many cases. Eleven of the 15 (73.33%) carers were in charge of writing during the task. Holding the pen gives the carer greater control and allows them to make the ultimate decision on what to write. Writing something concrete is a common way in which disagreements are ended even if they are not resolved.

Question 4b: Why do Carers See More Disability than PwABI When Filling in the DLA Claim Form?

The fact that carers perceive greater disability in PwABI than PwABI do in 93.02% of cases requires further explanation. The remainder of the chapter will consider qualitatively what happens when carers and PwABI collaborate to fill in the DLA form in order to further elucidate the patterns of collaboration which lead to disagreements where carers see greater levels of disability.

It will be argued that the DLA form forces patterns of collaboration which lead to disagreements about care needs in the direction of carers seeing more disability. Firstly the DLA form asks dyads to explicitly confront disability. This leads to a pattern of interaction which dyads avoid in everyday life and is unfamiliar to them. Carers adapt to the change in dynamic but PwABI continue to avoid disability.

Secondly, the complexity of the form leads carers to take over the task in order to get the form completed. Carers' total control of the task marginalises the PwABI and positions them as a "less than full member" of the interaction (Shakespeare & Clare, 2005, p. 329) whilst simultaneously positioning the carer as 'expert' on the PwABI. PwABI reject this negative positioning which leads to disagreements.

Thirdly, differences in perspectives on the audience, focus and scope of the DLA form task for carers and PwABI lead to divergent and incompatible goals. These differences in frames of reference for the task lead to disagreements between carers and PwABI, with PwABI minimising disability and carers maximising this.

The DLA Form Forces Dyads to Confront Disability: A Pattern of Interaction Avoided in Everyday Life

The first reason why there may be disagreements about levels of disability in the direction that the carer perceives greater difficulty is that filling in the DLA form forces

dyads to discuss explicitly the disability of the PwABI. The content of the form draws attention to the disability and what the PwABI cannot do, via the type of questioning used. The questions used in the form focus on deficit and the majority of questions begin, “Do you usually have difficulty...?” As the form is too difficult for many with cognitive impairment to fill in alone (Banks & Lawrence, 2005), it is necessary to confront disability in front of at least one other. This can be an uncomfortable process as answering ‘yes’ to any question leads the PwABI to be positioned as disabled and dependent and risks the PwABI’s positive sense of Self.

Confronting disability is a situation which carers and PwABI try to avoid in everyday interaction. As we saw in chapter four, carers often conceal the care work that they do in order to bolster the self-esteem and sense of independence and confidence that PwABI feel. The change in interactional dynamics brought about by needing to talk explicitly about the disability could lead to disagreements if one half of the dyad doesn’t make the shift from avoiding confronting the disability to facing it head on.

When filling in the DLA form, it is carers who find it easier to make the shift towards confronting the disability, whereas PwABI find openly articulating their problems more difficult. Suddenly being positioned explicitly as disabled is a negative experience for PwABI and is something they reject.

To illustrate the impact of answering questions which force dyads to talk explicitly about disability we turn to Mark (PwABI) and Maureen (carer). In the following extract, the pair are discussing question six: “Do you usually need help from another person to actively take part in hobbies, interests, social or religious activities?”

Carer [Maureen]: So taking it right back to basics, like working the TV, working the zeppelin, working the CD players.

PwABI [Mark]: If it's a new erm, like the new tele. I think I've gotta ask what to press. But once that's. I mean that's there and

Carer: I know, I know.

PwABI: If it's a complex piece of equipment.

Carer: Uhum

PwABI: But I mean I can go from the zeppelin there to that one and then through to the kitchen. That's 3 different things that I'm comfortable with.

Carer: Are you gonna record a programme for me the night?

PwABI: Listen, even before *[carer laughs]* if you're, the change of equipment is quite. I think not just me, most people find it a bit complex and that. Old people like me. *[Carer writes and PwABI moves along the sofa to read what the carer has written].*

Carer: Ok?

PwABI: Uhum

Carer: New equipment, like your internet.

PwABI: Yeah.

Carer: And your zeppelin, and the TV.

PwABI: It's hard to jump from one tele to another and

Carer: *[starts writing again. PwABI comes to look].*

PwABI: What you saying there?

Carer: Just help to rememb; remind you when you've got appointments and arrangements. You know if you were to go somewhere.

PwABI: That's why I keep a diary.

Carer: I know, I know.

PwABI: How many people are like that? They need to put

Carer: Just you

PwABI: Just me! *[Both laugh and carer turns the page]. [Carer has written that the PwABI “needs help with new electronic equipment”, “most days few minutes each time” and “help remembering appts/arrangements”.]*

[Dyad 23: Mark (60) PwABI and Maureen (56) carer. Married, five years post TBI after a fall]

In this excerpt, we see a disagreement in which the carer judges care needs as greater than the PwABI. The overt discussion of Mark's disability is difficult for Mark and he rejects the positioning as dependent and unable to use the electrical equipment in the home. Mark feels he is able to deal with electronics and puts any problems with this down to general problems that any person could face, such as dealing with electronic equipment or “old age”. This avoids confronting the disability Mark has as a result of ABI. However, whilst Mark is trying to explain his problems in this way, Maureen is confronting Mark's disability and discussing this explicitly in order to fulfil the obligations of the form. With Maureen following a pattern of interaction which confronts the disability and Mark avoiding this, there is inevitably disagreement. Maureen positions herself as the expert on

Mark's capabilities to engage in his hobbies and uses her role as writer to begin to fill in the form before consensus has been reached about the answer.

Carers Reveal the Work Which They Normally Try to Conceal

When confronting care needs, at times we see admissions of the work that carers do in the background, work which is often concealed in daily life. To illustrate this point is an excerpt from Sarah (PwABI) and Laura (carer). Sarah is partially sighted since her ABI and the pair are discussing Sarah's mobility issues in unfamiliar surroundings:

PwABI [Sarah]: And the most, well the last one that was actually a problem was when I was in Cyprus. And I was going to go to the loo, so I said "I'm just popping to the loo" and I didn't realise there were 2 stairs down before there were the stairs up so I was walking to go up the stairs like that *[simulates walking up stairs]* and as I was walking I went like that *[mimes falling]* so thank goodness there wasn't anyone sitting on that table there having their dinner, otherwise they'd have had a visitor *[laughs]*. That was the most recent, I think that was the last time I had a problem with that in a strange area.

Carer [Laura]: No, because I know now to watch for it.

PwABI: Aha, yes you warn me now.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

In this excerpt we see that Sarah has difficulties with her eyesight and this can cause her mobility issues when in an unfamiliar environment. She cites an example of when she was in a restaurant and the problems this caused. She suggests that this hasn't happened for a long time and this may be interpreted as Sarah making improvements at

navigating her way through strange places. However, Laura steps in here and reveals that this is not because Sarah has improved, but that instead it is because of Laura's vigilance in the background that Sarah has not recently encountered a problem. Laura reveals the background effort she puts in to avoid situations where Sarah could injure herself. This exchange reminds Sarah that she depends on Laura to keep her safe when moving around in unfamiliar surroundings, undermining her sense of independence.

In summary, collaborating to complete the claim form forces dyads to confront the PwABI's disability, a process avoided in everyday life. Carers adapt to this change in interactional dynamics and are able to address the disability explicitly, even revealing some of the support which they often conceal. However, PwABI continue to avoid confronting the disability caused by ABI. Instead they explain away their difficulties, normalising these and present a view of being more capable and independent than the viewpoint the carer presents. This results in disagreements where the carer perceives greater disability than the PwABI.

Carers Position Themselves as Experts on PwABI and Position PwABI as “Less than Full Members” of the Interaction

A second explanation for the disagreements seen is due to the complexity of the DLA form and the style of 'collaboration' this complexity causes. We saw in chapter six of the thesis that carers and PwABI were both involved in the collaborative process of completing a joint task. Although carers are in control of meta-cognition, for example initiating exchanges, determining whether a response is adequate and judging when a question is complete, it is often PwABI who have the final say within the task on such topics as who to invite for the meal and what to eat. By making decisions, PwABI feel involved in the task and this collaboration can be a positive experience for PwABI.

The claim form task is very different. It is a much harder task and its difficulty is demonstrated by the fact that carers were often seen to misinterpret or misread a question and thus made mistakes when filling in the form. Also, several carers mentioned that when filling in the form, they received additional help from others more experienced in the process, such as local voluntary groups. Also, carers often turned to the researcher during the task for assistance, seeking clarification about how the form was to be filled in. As well as differences in the complexity of the inviting for a meal task and the DLA form task, there is a difference in the importance of the answers. The answers given in the DLA task are the basis for assessment of eligibility for receipt of the benefit, so what is given as the answer is more important than in the more artificial meal task.

Due to the complexity of the form it can be assumed that the task is outwith the ZPD of the PwABI. As a result carers do not attempt to scaffold their partner's cognition or communication as this will not assist the PwABI to complete the task successfully. In addition, making decisions about the answers has been judged too important to leave to PwABI. On this basis, it would be best for carers to work alone. However, I have explicitly asked dyads to work together. This results in carers taking over the task completely. As we saw in the meal task, in the DLA form task carers are in charge of meta-cognition.

However, in the DLA form task carers also make the final decisions surrounding the PwABI's care needs. This results in a joint task where the PwABI is unable to contribute and cannot take responsibility for decisions. PwABI cannot feel the positive impact of collaboration which was present in the meal task. When a disagreement about care needs arises, the PwABI's perspective is often dismissed or ignored with the carer making the eventual decision about what answer to put, sometimes regardless of whether a consensus has been reached. As a result, the PwABI is positioned as a "less than full" member of the interaction (Shakespeare & Clare, 2005, p. 329) with carers ignoring the PwABI's point of

view about their own care needs. PwABI fight against this positioning of them as a less than full member of the interaction and attempt to assert their point of view.

To demonstrate carer control of the task, the dismissal of the perspective of the PwABI and the PwABI's continued effort to assert themselves in the interaction, we turn once again to Sarah (PwABI) and Laura (carer). This time the pair are answering question three: "Do you fall or stumble because of your illness or disability?" The pair have answered 'yes' to this question and are now discussing the occasions on which Sarah has fallen or stumbled. As this is a long extract, analysis is provided in stages:

Carer [Laura]: *[Reads out]* 'When did you last fall or stumble?'

PwABI [Sarah]: Erm about 2 years ago.

Carer: *[Interrupts, sounding exasperated]* No it's not, you stumble every, near enough every day. If you go on a wobbly surface or anything.

PwABI: Oh yeah but not a fall fall. A fall fall is

Carer: No, when did you last fall OR STUMBLE? *[Emphasises 'or stumble']*

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

As soon as the question of when Sarah's last fall or stumble happened is raised, we see a disagreement between the carer and the PwABI in the direction of the carer seeing more disability. The difference in opinion is large. The PwABI believes it has been two years since her last fall or stumble whereas the carer perceives that this is something which happens regularly. This is perhaps due to their differing interpretations of the question. The

carer focuses on the word “stumble” and the PwABI focuses on the word “fall”. The excerpt continues as follows:

PwABI: Or stumble, erm [*to self*] when did I last stumble? Erm

Carer: Yesterday when you were going into the shops with me cos it was, you told me I had taken you onto the wobbly surface and you went “oh aye”.

PwABI: Oh yes that's right I remember, that's right.

[Carer starts to write “yesterday”]

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

Once Sarah has been oriented to the part of the question which Laura deems most relevant, regarding the number of times Sarah stumbles rather than falls, the two can agree on an answer.

Carer: [...] Right, how often do you fall or stumble?

PwABI: Only when I'm on a surface area that I don't know.

Carer: Aha if you take

PwABI: If I go outside my routine.

Carer: Or if you take a wobble.

PwABI: Or if I take, I'm tired.

Carer: So it can be 4 or 5 times in a week.

PwABI: I actually wouldn't agree with that, I would probably go for one in a week.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

The pair have a further disagreement about the number of times Sarah stumbles. The PwABI feels that this is something that occurs in exceptional circumstances, when she is outside her comfort zone. The carer feels that the problem is a frequent one, that stumbling occurs several times in a week. However, the PwABI is unwilling to accept this estimate and suggests a lower one.

Carer: No.

PwABI: If I'm out of my comfort zone,

Carer: You can stand through there *[points]* and you suddenly say "oh I've just had a wobble" *[PwABI laughs]*.

PwABI: Yeah but I don't do it 4 or 5 times a week. I wouldn't agree with that. I would actually say probably, definitely once a week.

Carer: *[puts down pen and picks up water] [in a soft voice]* Och no Sarah, its more than that lovey.

PwABI: Is it?

Carer: Aha

PwABI: I don't really

Carer: Remember it's me who's with you sweetheart.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

The pair are at an impasse with neither backing down. The carer sees greater care needs than the PwABI does. The carer takes a moment out of the exchange by putting down her pen and picking up her water and then tries a different tactic to resolve the argument and get Sarah to see her point of view. The carer tries a softer approach, lowering her voice and using appeasing terms such as “lovey” and “sweetheart”. The carer positions herself as the expert on Suzanne’s mobility problems when she says “Remember it’s me who’s with you sweetheart”.

PwABI: Oh right aha ok, but I wouldnt go for as many as that. I think. If you think that then, if you remember that. I know I probably will have one but

[Carer writes]

Carer: Right.

PwABI: What, what, sorry, what answer did you put down there?

Carer: 15 times a month *[actually wrote 15/20 times]*, *[PwABI pulls a face]* and in the last year

PwABI: Oh right.

Carer: Well multiply 15 by 12, 5, 60, 12 on 12, 180 times.

PwABI: See I don't, see I think we're gonna disagree with this answer cos it all depends on what I'm doing, where I'm going and all this. Like now that I've finished college my routine's totally changed so every day I do different things, so

you know, so now my everyday things have changed now. So I'm not going to be in a situation when I might wobble or I may be in a situation where I will wobble cos I'm not where I normally am. So that answer might not be exactly like that. It could go up or down either way with that.

Carer: Aha but you can't. You've got to put down an answer so if you do it say 15 times in a month.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

Despite the carer's softer approach, the PwABI is still not backing down. The carer then tries another tactic, she uses the control she exerts by holding the pen to try and silence the PwABI by writing an answer. However, this does not end the disagreement as the PwABI immediately demands to know what the carer has written. The carer tells her that she has written 15 times a month. In reality the answer given is 15/20 times, a higher estimate which is in line with the carer believing that there are more care needs than the PwABI. This concealment of the answer put by the carer echoes the pattern of concealment we saw in chapter four of the thesis. Perhaps the difficulty in resolving the disagreement has led the carer to resort to more traditional patterns of interaction. The PwABI rightly suggests that the number of times she stumbles is not the same across the months but the carer points out that for the purposes of the task at hand, completing the form, it is necessary to decide upon a firm answer.

PwABI: Aha

Carer: Which is 3 or 4 times in a week then you've got to multiply the 15 by 12 for month, for a year.

PwABI: Right, ok but

Carer: Because you definitely do wobble and stumble.

PwABI: Oh I do but

Carer: You know 3 or 4 times a week.

PwABI: Right [*laughs tentatively*].

Carer: You do, you know that when you're going round Strathaven if you're

PwABI: Oh definitely in Strathaven.

Carer: There's an uneven bit in the pavement and you go "oops" and you grab on.

PwABI: Oh yeah I do that in Strathaven [*laughs*].

Carer: So it definitely happens 3 or 4 times a week so which is about 15 times a month.

PwABI: Ok.

Carer: So if you multiply 15 by 12 over a year it comes to 180 times.

PwABI: Aye ok but I just was thinking now that my routines not the same so I'm gonna be doing different things now, that could be lower or higher now you know cos I'm not at college anymore. [*To researcher*] I'm now a qualified masseur so if you know anybody.

Carer: [*Cuts in*]. Right [*moves on to next question*].

[Sarah (36) and Laura (68) are mother and daughter. Sarah experienced an ABI four years ago after she was hit by a car].

The carer tries to explain her reasoning for the apparently high numbers she has written on the form by firstly explaining the figures, then giving the PwABI a concrete example of when she stumbles. The PwABI appears to agree but then in the last turn continues to disagree with the carer. The carer brings the discussion to an end by moving on to the next question.

In this excerpt we can see that Laura and Sarah are locked in a battle of wills regarding the number of times Sarah stumbles. The pair disagree about what constitutes a stumble and how often this occurs. The question requires interpretation and what for one constitutes a 'wobble' for another constitutes a more serious case of 'stumbling'. The carer attempts to control the exchange, asserting her point of view as the 'correct' one. Laura positions herself as the expert on Sarah's mobility when she says "remember it's me who's with you sweetheart". Sarah tries to resist Laura's positioning of herself as 'expert' and the dismissal of Sarah's point of view throughout and insists that she stumbles less than Laura suggests. However, it is Laura who makes the final decision about the number of times Sarah stumbles.

This is one of the 40 examples of where there is a disagreement with the carer judging care needs to be greater than the PwABI. In 75% of these cases, as above, the answer put down on the form is in line with the carer's higher estimate of the PwABI's needs. This positioning of carers as 'experts' on the PwABI rather than PwABI being experts on themselves can be considered an insult to identity. As well as being positioned as dependent and disabled, PwABI are also positioned as not knowing themselves as well as another knows them. PwABI reject this positioning and fight for their right to be the

expert on themselves and this inevitably leads to disagreements where the carer sees greater disability than the PwABI.

Further examples of resistance from the PwABI come from Sarah in extract one and Mark in extract two:

Carer [Laura]: *[Reads aloud]* ‘How many days a week do you need someone to keep an eye on you?’ 52 weeks of the year *[Sarah smiles and points at Laura]*.

PwABI [Sarah]: That's not days of the week. *[Laura writes '7']*

Carer: 52 weeks of the year I said.

PwABI: I know but. No I don't agree with that actually. What you've just written down. I don't need people to look after me. What happens when you go away to Cyprus and you go away to your holiday which you're planning to book another holiday? You are away for a fortnight, who's going to look after me then?

Carer: No, I don't go away for a fortnight but anyway. Come on let's get on with this.

PwABI: That's not even, that's not a 7 day of the week question.

Carer: Sarah, I. I'm

PwABI: When I need help, I need help but I don't need help all the time.

Carer: No but maybe once every day you need help.

PwABI: Very rarely that.

PwABI: Sometimes, every day. Practically, you take something out of the freezer and say “Mum how long is that to be cooked for?” “Mum is that pork or is that lamb?”

PwABI: Aha that but I don't need help physically for things.

Carer: No but that's what it means.

PwABI: Oh I see right, assistance is what you mean.

Carer: *[Writes “seven” days. Carer moves on and reads aloud]* Would you have difficulty preparing and cooking a main meal for yourself?

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

In this extract there is a disagreement between PwABI (Sarah) and carer (Laura) and it is in the direction of the carer seeing more disability than the PwABI. Sarah resists being positioned as dependent and she also wants to make the point that she has understood the question properly, her mother has not. The question asks about days of the week, not weeks of the year. Thus, Sarah is correct in her criticism of her mother's answer as she is not answering the question asked. However, Sarah is over-ruled, despite making a valid point.

The second excerpt comes from Mark (PwABI) and Maureen (carer), who are discussing Mark's mobility indoors:

Carer [Maureen]: This is inside but if I was saying coffee tables and all sorts of stuff obstructing your. *[Reads aloud]* Do you fall and stumble? *[No pause left for answer]* Not particularly.

PwABI [Mark]: No.

Carer: *[To researcher]* It's a difficult one because he doesn't stumble much but he is, he can be unsteady. Stumbling doesn't really happen and you don't fall but.

PwABI: How do you know I'm unsteady? If it's a crowded room.

Carer: No but even just one day if you're tired,

PwABI: Oh if I'm tired.

Carer: You're not great erm. But you don't tend to fall I have to say you just tend to get a bit *[turns page]*.

PwABI: I wouldn't have thought I stumble at all.

[Dyad 23: Mark (60) PwABI and Maureen (56) carer. Married, five years post TBI after a fall]

In this excerpt, the PwABI (Mark) is resisting the carer's (Maureen) positioning of him as someone who is "unsteady" on his feet. The PwABI directly challenges the carer's positioning of herself as 'expert' on Mark's mobility when he says "How do you know I'm unsteady?" However, despite their resistance against being positioned as dependent and disabled, both Sarah and Mark lose their disagreements, as they did in earlier excerpts, and the form is filled in from the carer's perspective.

PwABI's conversational turns are ignored as well as their viewpoint

It is not just the PwABI's perspective which is ignored but also their attempts at communication, with carers often responding to their own previous turn rather than the next conversational turn of the PwABI.

To demonstrate the ways in which PwABI are ignored, excerpt one comes from Keith (PwABI) and Wendy (carer):

Carer [Wendy]: *[Reads aloud]* ‘Do you fall or stumble because of your illness or disability?’ Well I would say that's yes, a definite.

PwABI [Keith]: It was.

Carer: Cos how many times have you fallen flat on your face? *[Both laugh]* [...] and you sometimes help yourself but not all the time.

PwABI: No[t] really

Carer: No, usually you can get up yourself can't you? [...] and I'd say in the last year *[number of times PwABI has fallen]* roughly about *[looks at PwABI]*

PwABI: Nay fell

Carer: Just a couple of times, eh?

PwABI: I don't know

Carer: But you fell in the bath mind, you fell back in the bath.

[Dyad four: Keith (51) PwABI and Wendy (61) carer. Son-in-law and mother-in-law, 27 years post TBI after an RTA]

In this extract we see that Wendy makes the initial decision that Keith falls. Keith responds by saying that this “was” the case, perhaps indicating that he feels that this is a problem he faced in the past but not at present. Wendy responds by emphasising that Keith regularly falls. She then moves on to the next part of the question which asks about ability to get up once a fall has happened and she states that Keith is fine to get up alone. Here

Keith responds by saying that he cannot really help himself up. Wendy does respond to Keith's statement but continues to assert that he does not need assistance to get up. Keith then states that he has not fallen in the last year and this turn is ignored by Wendy as she asserts that he has fallen "a couple of times". The reader gains the sense that this conversation has only one interlocutor who is conversing with herself and that the answers given would remain the same regardless of whether her partner is present or not.

Excerpt two belongs to Derek (PwABI) and Elizabeth (carer). Derek has severe aphasia and for the majority of the task, Elizabeth fills in the form in silence without consulting Derek. Here she is filling in the section about social activities outside the home:

Carer [Elizabeth]: *[Turns page, reads question in head and ticks boxes without speaking]*

PwABI [Derek]: *What's that? [Points at page].*

Carer: *[Ignores Derek]. Right so we get, taking away, each time [...] [mumbles to self] every week for at least. I'll just put that.*

[Dyad eight: Derek (56) PwABI and Elizabeth (52) carer. Married, three years post stroke]

In the excerpt, Derek wishes to know what Elizabeth is writing and asks clearly with an accompanying gesture for Elizabeth to explain what she is writing. Elizabeth ignores Derek's conversational turn and continues to fill in the form, speaking softly to herself.

The final excerpt comes from Bill (PwABI) and Nena (carer). The pair are discussing question nine: “Would you have difficulty preparing or cooking a main meal for yourself?”

Carer [Nena]: Look here we go, you’ve got difficulty or need help planning a meal.

PwABI [Bill]: Well, no that doesn't bother me.

Carer: *[Sounds exasperated]* Bill! You keep putting the grill on and shutting the oven door and things like that. You don't really do any of the cooking so I do have to cook. You lack the motivation to cook. You would sit the whole day and eat nothing if I didn't. *[Carer ticks yes – difficulty preparing and cooking a main meal].*

PwABI: I would phone a Chinese or something *[Carer ignores PwABI].*

Carer: Right so no I'll put that down as, you do need someone to keep an eye on you to check that you're not leaving the oven on, that kind of thing.

PwABI: No I don't.

Carer: *[Ignores PwABI]* I'm gonna put 7 *[days a week help needed]* for that.

[Dyad 11: Bill (34) PwABI and Nena (32) carer. Married, three years post TBI after an RTA]

In this excerpt, the carer engages with the PwABI's initial statement of disagreement that he doesn't have a problem with cooking. However, she ignores his subsequent attempts to reject her estimation of his care needs in the area.

The carers in these extracts are completing the task as though they are doing it alone. The complexity of the task means that they feel scaffolding their partner's cognition will not be a useful endeavour as the task is outwith the PwABI's capabilities. Carers are focusing on getting the task done and this would be easier for them if the PwABI were not present. If the form were being completed for real, it seems likely that carers would fill the form in without the PwABI's input. The fact that I have explicitly asked them to work together has created a problem for carers and to get the task done they ignore the PwABI, both in terms of their perspective and their attempts at communication. The following excerpt demonstrates the difficult position that the researcher has put the carer in by asking dyads to work together. The researcher has just presented the dyad with the form and asked them to work together:

Carer [Elizabeth]: *[Pause]* Erm, we actually got help filling that form in cos we couldn't, it was just. Right, erm.

PwABI [Derek]: *[Makes a sound]*

[Both read in silence for a moment].

Carer: You, you need help with that *[Carer looks at PwABI]*.

PwABI: Don't, don't.

Carer: Right. *[Begins to read aloud]* 'Do you usually have difficulty', oh there's no point me reading it to you cos you'll no *[Carer points at page]*.

PwABI: *[Carer looks at PwABI]*. No.

Carer: *[To researcher]*. He can't. I usually just fill in forms for him and because he just. He reads fine and that but he can't, he *[looks stressed and turns to PwABI]*.

Carer: *[Sighs]* Right so it says do you have difficulty getting out of bed.

PwABI: Eh?

Carer: You don't have difficulty getting out of bed.

[Dyad eight: Derek (56) PwABI and Elizabeth (52) carer. Married, three years post stroke]

In this extract the carer finds it difficult to include the PwABI in the task. It becomes clear that this is a task which she would not choose to carry out with the PwABI and feels uncomfortable about the idea of 'collaborating' on this task.

By marginalising the point of view of the PwABI and ignoring their attempts at communicating about their abilities/disabilities when approaching this task, the carer is further positioning themselves as the 'expert' on the PwABI. Coupled with the rejection of the PwABI's point of view, ignoring their attempts at communication has the further potential to be damaging to the identity of the PwABI.

Filling in a claim form is not the only time that a carer is seen to be positioned as the 'expert' on the PwABI and that the carer's perspective on the PwABI is privileged over the PwABI's perspective on self. We saw in chapter five of the thesis that current self-report measures of self-awareness take ratings of capabilities from carers and PwABIs and judge the carer's ratings to be a more accurate rating of ability. The PwABI's divergence from the carer's rating is measured in order to consider levels of self-awareness. Consideration of the carer as a greater expert on the PwABI than the PwABI is can be considered stigmatising and disabling in and of itself. PwABI are seen to reject this positioning during the task and assert their own viewpoint on their capabilities by giving lower estimates of their disability than carers.

In summary, the complexity of the form and the importance of the answers given for DLA assessment leads carers to take over the task completely, marginalising the viewpoint of the PwABI and their attempts to participate in the task. Carers position themselves as the 'expert' on the PwABI and their needs, which is rejected by PwABI. This leads to disagreements with the carer stating greater disability than the PwABI.

Carers and PwABI are Approaching the Task From Incompatible Angles: Divergent Goals Lead to Disagreements

So far two possible reasons for the high number of disagreements in the direction of carers seeing greater disability when filling in the DLA claim form have been discussed. A further explanation is that carers and PwABI are approaching the DLA joint task from very different and often incompatible angles. PwABI attempt to minimise their disability in talk whereas carers try to maximise disability because of differences in the audiences that the carers and PwABI are filling in the form for, alongside different conceptualisations of the aims and focus of the task.

In terms of audience, for PwABI the audience they are aware of is relatively small. Their audience is the researcher and the carer as co-participant in the joint task. Conversely, the carers in this study are aware of a wider audience than the PwABI. The audience is not just the researcher and their partner in the task but also council and government agencies who control financial resources which have the potential to ease the financial burden that many families face.

To carers this is a real world task and they are often seen to be considering the wider audience and potential implications of the way they answer for that audience, even when assured that the form is for research purposes only. The following excerpt comes from Sheila (PwABI) and Bev (carer) and demonstrates the carer's awareness of a wider

audience beyond the research setting. I have just handed the form to the dyad when the carer says:

Carer [Bev]: Yeah, yeah. *[To researcher]* So this says “Claim for Living Allowance”. Does that go anywhere?

Researcher: Oh completely. Sorry, just for me, it goes no further whatsoever.

Carer: That's fine, yeah, yeah, right, ok.

Researcher: It's more the process of filling it in.

[Dyad 21: Sheila (50) PwABI and Bev (71) carer. Daughter and mother, time since TBI after an RTA unrecorded]

There are also differences in the aims of PwABI and carers. For the PwABI the main aim during the task is to save face and to present an able and independent version of self to their carer and researcher. So for PwABI, minimising disability is the primary aim. This may be to preserve self-esteem or as Clare and Shakespeare (2004) discuss it may be a form of “psychological resistance” (p. 227) in which PwABI offer up a picture of life progressing as it was before the injury in order to escape the uncertainty that cognitive impairment brings, as well as to avoid facing concerns about being a burden to loved ones. For carers, this is a real task that they have probably faced before. Their primary aim is to fill in the form in such a way that they will receive maximum benefits and as a result, the easing of financial burden. This requires maximising the disability of the PwABI.

Differences in frames of reference do not stop with audience and aim; there are also differences in focus. PwABI have a narrow focus, with emphasis on the present and the task at hand. PwABI are answering the question: what can I and what can't I do?

Conversely, carers have a wider focus beyond just the task at hand. Their focus is rooted in the future and securing sources of funding. In addition to securing funds, carers are focused on reducing practical and emotional burden in the future. Carers are asking a different question to PwABI: how can I best express my partner's difficulties in order to secure the maximum benefits we are entitled to and the maximum reduction of burden at a future point in time?

The next extract comes from Fran (PwABI) and Rachel (carer) and reveals the audience, aims and focus of the carer:

Carer [Rachel]: Absolutely, but that's very much it. Do you need any other, do you wanna expand on that?

PwABI [Fran]: What do you think?

Carer: Is this where the money is? Is this the fundamental one?

[Dyad five: Fran (52) PwABI and Rachel (54) carer. Co-habiting friends, two years post HSE]

In this extract, Rachel is trying to guess which questions and answers on the form are most relevant to securing maximum funding. Rachel is aware of the wider audience of the government body that assesses DLA and is trying to complete the form in a way that will appeal to assessors.

Differences between carer and PwABI frames of reference, related to audiences, aims and focus lead to disagreements when filling in the form. The following excerpt from Sarah (PwABI) and Laura (carer) demonstrates the incompatibility of PwABI and carer perceptions of the audience and the purpose of the task activity:

PwABI [Sarah]: That's another activity is my groups. Mum and I also teach horse riding on a Sunday. They pick me up to take me there.

Carer [Laura]: Aye but that's not, that's

PwABI: It is an activity, teaching, cos it's what I used to do before.

Carer: Aye, I know, but you cannae put that down on your DLA form [*Carer looks at researcher and laughs*].

PwABI: This isn't a DLA form, it's

Carer: It is your DLA form

PwABI: This is a, getting recorded for the University.

Carer: Yes, I know but it's [*starts reading out what she's written, mumbling*], 2 hours at a time

PwABI: I don't get paid for it, I do it because I'm helping somebody. The DLA people don't need to worry about these sorts of things. Going to my blind group is another thing, once a month, and also Headway on a Tuesday night. [*Carer writes "attending blind groups"*]. What else do I do? Not a whole lot actually. And then if I'm going to ask for other things, like if I'm going to visit somebody.

Carer: This is enough, the space is running out.

[Dyad three: Sarah (36) PwABI and Laura (67) carer. Daughter and mother, four years post TBI after being involved as a pedestrian in an RTA]

The PwABI's aim is to demonstrate all that she is able to do. The fact that she can assist in teaching riding is a boost to her self-esteem and she wants to communicate this,

both to the researcher and on the form. However, the carer is aware that the PwABI's teaching would not be viewed as an activity which should receive benefit by the DLA and would perhaps suggest that she is relatively able. The PwABI states her audience, the University, as she is taking part in research. At the same time the carer states her audience, the DLA funders. The PwABI is present focused, concentrating on the current task, whereas the carer is future focused, on benefits which could be received later. The PwABI in this extract is actually right in her estimation that this is not her DLA form per se but is instead a task being recorded for PhD research at the University. Yet the carer silences the PwABI by using the power associated with being the writer.

The process is also difficult for carers as they are trapped between competing expectations of carer as provider and carer as enabler

There is not just tension between incompatible frames of reference between carers and PwABI. Carers are trapped between incompatible frames within themselves when it comes to a task such as this. As we saw in chapter four, the role of carer is complex, multi-faceted and enshrouded in expectation. A carer is expected to be nurturing and enabling and preserve the self-esteem of the PwABI but conceal the burden of care. Simultaneously a carer is expected to look after the person with disability and secure essential resources to assist in the care process. DLA is one such resource. Thus, different aspects of the caring role are in tension with one another.

It is the resource-securing carer which wins out in this situation. This may be because this is the only chance to secure these funds whereas there are other opportunities to nurture the PwABI's self-esteem. Financial burden is a major issue for families adapting to ABI and funds must be secured. One study has reported that as few as 41% of people who sustained an ABI are found to be in work two years post injury (Van Velzen et al., 2009). As well as PwABI's reduced capacity for work, carers may also be required to

reduce their working hours or stop work altogether in order to assume a caring role (Carers UK, 2007). As a result, families adapting to ABI often cite financial worries as a major source of stress and burden (Ponsford, et al., 1995).

However, just because a decision has been made to focus on the dyad's relationship with the welfare system and to maximise disability in order to stand the best chance of securing funds, this does not mean that the carer is unaware of the potential impact on their relationship with the PwABI and the work that will need to be done after the task to bolster the PwABI. As a result, carers feel uncomfortable throughout the task. For example, during the recording of the joint task, Rachel, Fran's carer made four comments which revealed her discomfort at the task. They were:

On being showed the form "Oh God", when half way through the form, "I think we should have had this *[session]* organised at night because this is so, so depressing" *[sighs]* and "How much of this have we got to do Helen?" Finally on completion of the task Rachel shouts "YES!" *[Fran (52) and Rachel (54) are co-habiting friends. Fran experienced ABI two years ago after contracting encephalitis].*

Rachel is not the only carer to reveal her discomfort at the task. Here I have just presented the form to one dyad and the carer's response is this:

Carer [Leanne]: I hate DLA forms.

Researcher: You're not alone.

[Dyad 14: Peter (46) PwABI and Leanne (44) carer. Married, time since TBI after fall unrecorded]

This task is further complicated by an added dimension beyond the different expectations of the caring role and that is the research setting. Participants have been asked to work together to fill in the form and have been told that the researcher is looking at the ways in which informal carers and PwABI communicate and work together. Participants are aware that they are interacting under the researcher's gaze and they are uncertain about the researcher's precise motivations. There is a hidden power relation between the researcher and dyads which will impact upon the process of filling in the form. Carers wish to be good participants and will try to decipher what the researcher is looking for in order to fulfil the expectations of them as research participants. Is the researcher looking for the enabling carer in this task, who communicates well and gives voice to the PwABI? Or the practical, resource-securing carer who fills in the form as they would if they were faced with the task in the real world? Although carers wish to be 'good' participants, it is not clear to them what that entails.

This tension in filling in the form under unclear and competing expectations is revealed in talk by carers during the process of filling in the form. The following excerpt is from an exchange between Sheila (PwABI) and Bev (carer):

[PwABI turns page and both read question 7: "How many days a week do you have difficulty or need help with the care needs you have told us about?"]

PwABI [Sheila]: 7 days *[laughs]*

Carer [Bev]: Ah well, that's not really

PwABI: Well how many days do you think?

Carer: Well,

PwABI: That's quite a hard question really.

Carer: I mean you don't need, you don't need help, you can manage yourself very well. Aha you don't have difficulty or need help, you just. It's a wee bit hard. I mean this [*points*], this is definitely no, but that is [*sighs*] a wee bit of lack of confidence.

PwABI: In here, sometimes.

Carer: Just put sometimes, it's not a need is it, it's just, what's that word, confidence or encouragement or something like that. [*To researcher*] Sorry, I shouldn't be telling her that you know [*laughs*].

[Dyad 21: Sheila (50) PwABI and Bev (71) carer. Daughter and mother, time since TBI after an RTA unrecorded]

This is an unusual exchange during the tasks. Instead of the PwABI minimising their difficulties and the carer maximising them, it is the PwABI who maximises her difficulties. At the point when the carer addresses the researcher we see her caught in tension between competing expectations. Here Bev is doing several things at once. She is controlling the task in telling Sheila what to say, whilst simultaneously trying to boost Sheila's self-esteem by telling her that she just needs more confidence. At the same time Bev is aware of the researcher and is trying to be a good participant. Bev feels she has made a mistake according to the researcher's expectations by directing Sheila and telling her what to put in the form.

In summary, completing this task is a difficult process with conflicting expectations for carers. As we saw in chapter four, carers strive to be the perfect carer, but this is impossible to achieve. The claim form task is a real world example of where carers

cannot do everything. They cannot simultaneously nurture the self-esteem and identity of the PwABI whilst completing a difficult task to secure financial relief. It is also uncomfortable for carers when they are forced to maximise PwABI disability, as they regularly sacrifice personal recognition by concealing the realities of their caring role. Although carers are seen to marginalise the perspective of PwABI and position them as dependent, carers ultimately have the security of PwABI in mind and are faced with a situation in which there will always be a loss, either financially or in terms of PwABI self-esteem, depending on the approach taken.

Discussion

Summary

A previous questionnaire study found that claimants felt the DLA form was difficult to complete (Banks & Lawrence, 2005). This is the first time that the *process* of completing the DLA form has been examined. The preceding analysis has demonstrated that the process of collaborating to complete the DLA form was fraught with disagreements with carers consistently judging the disability of PwABI to be greater than PwABI did.

Analysis of video recordings of dyads collaborating to complete the task showed that the form forces an approach to interaction which confronts the disability, an approach which PwABI struggle to adapt to and which causes discomfort in carers. Perspectives of carers and PwABI differ greatly in terms of audience, aims and focus and these divergent perspectives are incompatible with one another, leading to differing conceptualisations of how the form should be completed. In order to get this complex form completed, carers take over the process, positioning themselves as controller of the task and expert, marginalising the point of view and interactional contributions of the care-receiver (Sabat & Harré, 1992). As collaboration breaks down, carers focus on completing the form with

the aim of maximising funding received whereas PwABI fight against the negative identity positioning that the DLA form and the collaboration create. These factors ultimately converge to cause disagreements where the carer maximises the disability and PwABI minimise this.

Collaborating to complete the DLA form undermines the work that dyads do in creating a shared reality. Carers conceal the burden of care, creating a divergence where PwABI underestimate the work carers need to put in to assist PwABI, thus heightening PwABI sense of independence. These adaptive divergences are to some extent revealed when completing the form and this threatens the balance within relationships.

This task included only one section of the DLA form with nine questions: “Help with your care needs during the day”. There are five further sections in the full 55 page form. Completing the full version will take considerably longer and will probably lead to many further disagreements, more negative identity positioning for the PwABI and increased discomfort for carers. Previous discussion of stigma has focused on the outcomes of claiming disability benefits. It has been suggested that receipt of benefits may increase people’s sense of legitimacy and reduce stigma. However, the system is considered unpredictable in terms of who would be successful in receiving benefits and rejection can have a negative impact in terms of confidence in legitimacy of disability and their claim (Pudney et al., 2006). Although the focus of discussion has been around the impact of whether people are successful in their claim, this chapter has shown that very process of applying risks stigmatising claimants, regardless of the outcome of the claim.

This thesis is being written at a time of great change in the organisation of benefits systems. DLA will be replaced in April 2013 by a new system, Personal Independence Payment (PIP). The new system will involve some changes to the eligibility assessment

process. It is anticipated that the new system will involve the majority of applicants receiving a face-to-face consultation with trained assessors to determine eligibility and rate of PIP benefit. However, draft regulations suggest that there will still be a claim form component to the assessment and that when attending the face to face consultation, applicants will be invited to bring another person with them, such as a family member, friend or advocate. Therefore, despite the proposed changes, issues of identity and differing perspectives on disability will still be present in the PIP assessment process.

One interesting outcome of the current study is that PwABI attempted to minimise their disabilities during assessment. Public mistrust surrounds the benefits system with many references in the mass media to 'benefit cheats'. Although attention is often paid to those who falsely claim benefits, Department for Work and Pensions figures estimate that false claimants represent just 0.5% of claimants (Brindle, 2011). This research suggests a more common but under-represented problem may be those who suffer severe disabilities but find this difficult to confront during assessment.

Another key point is the differing conceptualisations of disability within and between dyads. Questions in the new assessment must be clear and precise and assessors should be aware that disability/ability is viewed and felt differently by different people. Currently the questions issued require interpretation. For example, even between one carer and one PwABI, the conceptualisation of a stumble differs greatly. What for one person is a serious stumble is for another a mere wobble. Idiosyncratic meaning making systems are utilised by individuals in defining disability and incorporating those definitions into identity (Bowen et al., 2010). Approaches to assessment need to be sensitive to the differences in meaning making systems across applicants.

Although assessors of PIP will be ‘trained’ it is unlikely that identity issues, face-saving tendencies in those with cognitive impairment and differing conceptualisations of disability between family members will be featured within such training. Further research into the process of applying for benefits is required with greater participant numbers and a variety of disabling conditions to better understand the implications of benefit application for those who are applying.

A caution regarding the heterogeneity of the sample

As for previous chapters, approaching the DLA form has been considered at the ‘carer’ level without separating out the different types of relationship and it must be acknowledged that issues may have been missed due to this amalgamation. However, when analysing the rate and direction of contestations across relationship groups the results appear relatively homogeneous. Of the 22 dyads who completed the task, ten of these were romantic partners, nine were parent-child relationships (one of these between mother and son-in-law), two were sibling relationships and one was a friend dyad. When analysing the data for all 22 dyads regardless of whether dyads answered yes or no to all questions, romantic partners had 22 questions on which there was a disagreement and 19 of these contestations were in the direction of the carer seeing more disability with three in the direction of the PwABI seeing more disability. Parent-child dyads had 25 questions on which there was a disagreement and 23 of these contestations were in the direction of the carer seeing more disability with two disagreements in the direction of the PwABI seeing more disability. The two sibling dyads had four contestations between them, all in the direction of the carer seeing more disability. Finally the one friend dyad had one contestation in the direction of the PwABI seeing more disability. Thus, at least in terms of disagreement about care needs, this was present in each of the relationship types and the numbers appear comparable. Only the friend dyad had no disagreements in the direction of

the carer seeing more disability but the majority of disagreements across the other relationship types were in the direction of the carer seeing greater disability. Perhaps the nature of the DLA task and the competing expectations faced by carers and PwABI when completing this task lead to a similar approach by dyads regardless of their relationship type.

Conclusion

This chapter has addressed processes of collaboration on a complex real world task that many informal care dyads will face in attempting to secure much needed financial assistance. When care partnerships work together to fill in the DLA form, patterns of interaction are forced which lead to disagreements, marginalisation of the person with disability and discomfort for carers. The process of securing funds which aim to relieve disability is itself disabling and can undermine much of the work that carers do to bolster PwABI self-esteem in everyday life. The implications for identity and relationships of confronting disability to access benefits needs to be considered during development of new disability benefit assessment methods.

Chapter Eight – Discussion and Contributions

This research has been conducted at a time of great political and economic change. A change from Labour to Conservative coalition government and a global recession have shifted political and societal agendas. However, despite the changing political and financial landscape in the UK over the last three years, social care has remained a hot topic. Pressure on social care systems in the UK is increasing and the government has recently been described by opposition leaders as “out of touch with the growing crisis in care” (Triggle, 2011, para. 7). Accordingly, there have been major calls for social care reforms. The number of people requiring care is rising yet the bleak economic outlook makes meeting the rising cost of social care for the elderly and disabled increasingly difficult. Funding to care services has been cut across local governments and the cost of council services has risen (“Social Care System”, 2011). As the cost of formal care rises, it places increasing pressure on informal carers to provide essential support. A greater understanding of the issues facing the disabled and their informal carers can help to direct what limited funding and resources there are to where they are most needed by those directly involved in providing and receiving care. This PhD research has advanced a relational standpoint, focusing on *processes* of adaptation, complementing the individual, outcome focused approaches which are more traditionally found in the brain injury and informal care literatures.

This chapter will summarise the answers to each of the eight research questions and consider the implications for literature, discuss theoretical and applied contributions, address limitations and suggest directions for future research. The chapter will also draw together the findings from the analyses in an attempt to make broader points about identity, cognitive and practical adaptation within relationships following ABI.

Question 1a: Are There any Disagreements and/or Misunderstandings Between Carers and People with Acquired Brain Injury (PwABI) Regarding Carer Identity?

Chapter four compared numerical ratings given by carers regarding their own identity, their perceptions of PwABI ratings on carer identity and the ratings PwABI actually gave regarding carer identity. Disagreements were frequent, with carers seeing themselves more negatively than PwABI saw them. Carers feel they are overprotective, stifling their partners and getting irritable with them. They lack confidence in their abilities, feel they are taking on a lot of responsibility and they feel embarrassed and unintelligent. However, there was little corresponding misunderstanding about carer identity, thus carers understood how PwABI would rate them.

Question 1b: How can the Pattern of Divergences be Explained?

The data set comprising videos of discussion between participants and researcher during the rating task was analysed to explore the source of disagreements about carer identity. It was found that carers work to conceal the burden of care from PwABI in order to boost PwABI self-esteem and identity. Concealment can lead PwABI to underestimate the impact of the caring role and judge their carers to be coping better than they are. However, disagreements are compounded by the negative effects of concealing the burden of care on carer identity. If carers are concealing the burden of care then they cannot receive recognition for the work they do. A dialogical analysis showed that carers do not receive recognition from significant others, nor do they receive recognition in the abstract, as they struggle to fulfil culturally held notions of the 'ideal carer'. This leaves carers feeling extremely negative about themselves and can further account for the disagreements found in the analysis of numerical ratings.

Implications of Research Findings: Theoretical and Empirical Contributions

The literature on carer experience suggests that providing informal care can have a negative impact on carers' physical and mental health (Braun et al., 2009; Kreutzer et al., 1994), subjective well-being (McPherson et al., 2000) and quality of life (Greenwood et al., 2009). This research has contributed to discussion of *why* this is the case. Taking a relational approach has highlighted the ways in which care-receiver and care-giver identities are interwoven. When taking on the role of care-giver, care-givers are no longer responsible for just their own identity, but the identity of their partner too. The effort required to maintain the partner's identity, and the methods which must be used to achieve this goal, can in turn impact on the carer's identity. Perry (2002) discussed the concept of "interpretive caring" (p. 310), describing the process of caring as more than merely providing support for the care-receiver. Care-givers were seen to support the relationship, maintaining both partners through a complex emotional, cognitive and behavioural process which compensates for changes in ability levels and behaviour. Thus the care-receiver and the relationship are seen by carers as an "extension of oneself" (Badr et al., 2007, p. 211) and as a result it is the carer's priority to protect their partner and the relationship. It has previously been suggested that care-givers achieve protection of their partner by concealing care, concealing the extent of their knowledge about illness and care trajectories, and concealing the distress that the burden of care creates (Thomas et al., 2002; Gillespie et al., 2010; Hutchinson et al., 1997). These findings are supported by the present research. As well as protecting the care-receiver, concealment allows informal care dyads to engage in a joint performance to others outside the care dyad, further maintaining and fostering self-esteem and a positive sense of identity in PwABI (Goffman, 1959).

What previous research has not done is examine the *effects* of concealment on the identity of carers. This research has elucidated that the link between concealment and

negative outcomes is one of recognition. Using a dialogical approach, this research has demonstrated that carers are denied recognition from a variety of sources when they choose to conceal the burden of care. Lack of recognition impacts negatively on carer self-esteem and identity and frustrates carers. Carers' choice to conceal, despite the detrimental impact for them in terms gaining recognition for the caring role, highlights the selflessness of carers. They do not just maintain both partners as Perry (2002) suggests. Carers go further than this by prioritising their partner's identity and self-esteem, sacrificing their own in the process.

Applied Contribution

Lack of recognition in carers is a new finding and must be replicated in future studies before any generalisations can be made. However, the finding of a lack of recognition for carers as a result of concealment of the burden of care could have implications for the type of support provided for carers. Concealment is a strategy chosen by carers, yet they need recognition for their own positive sense of self-esteem and identity. There are a limited number of sources from which recognition can come without the risk of revealing concealed care and jeopardising the reality carers have worked to create. Two possible sources of positive recognition are health services and carer support groups.

Health services

Recognition could be a pertinent issue to be considered during the follow up suggested by clinical guidelines (SIGN, 2009). Health services are well placed to assist carers to receive recognition for the work they do, as professionals are aware of the extent and nature of the care which will need to be provided by carers in the long term. During follow up, there should be some one-on-one time between professionals and carers to provide opportunities for carers to be given positive recognition. It is essential that

opportunities for recognition are considered beyond the short term, as recognition was a key issue for carers in this study, even though they were a mean of 7.84 years post injury.

In addition to providing recognition directly, health services can further facilitate the recognition process by helping carers to find other avenues for recognition. The Department of Health highlighted in December that a major problem is that carers often don't realise that there are services available in the community to help and support them (Winnett, 2011). It is the responsibility of health services to provide carers with detailed, up-to-date information about local services for carers. Information can be passed to carers on discharge from rehabilitation, from GPs or during follow up. It is suggested that information should particularly focus on carer only support groups.

Support groups

Support groups may provide the positive recognition that carers seek. Support groups provide a safe space where carers can share their experiences without the presence of care-receivers. Support groups have been shown to be beneficial for well-being (Foster, 2011). Being with other people who are "in the same boat" allows for "connecting through shared experience" (Foster, 2011, p. 59), including the sharing of practical advice and coping strategies (Butow et al., 2007; Benbow et al., 2009; Locock & Brown, 2010). Although much research has been conducted into support groups, they have never been examined in terms of the recognition they provide their attendees, and there has not been a lot of work on support groups for carers in the area of ABI.

What must be addressed in this discussion is the fact that support groups were not a significant other identified in carers' talk surrounding the rating task. Given that eight dyads were recruited from Headway groups which provide long term support to PwABI and family members, this is a surprising finding. However, it is not clear that the eight

carers recruited from Headway were receiving the type of support that the carer only support groups described above provide, and it is this type of support which is best placed to provide recognition. Of the eight carers recruited from Headway, two were affiliated with Headway only as part of a mailing list and heard about my study from an advert in the newsletter, two carers did not attend Headway group meetings with their partners with ABI, two did attend meetings but PwABI and carers all met as one group and remained as such throughout the meeting, and the final two carers had partners who attended a day centre alone several times a week. This provided respite but perhaps not the chance for carers only to meet, as a group, to freely share their experiences and give and receive recognition without risking revealing the extent of their concealment and burden to their partners. It is a limitation of this research that carers were not asked precisely what support they were currently receiving from local groups and services.

Suggestions for Future Research

Exploration of recognition for carers was not an initial aim of the research, thus it is not reflected in the initial research questions or the questions asked in the rating task. However, recognition is the key emergent theme from the analysis of data sets one and two regarding carer identity. Future research should explicitly address recognition in carers. This research found few avenues of recognition for carers but on the basis of the literature it is likely that carer only support groups could provide carers with much needed recognition. A suggestion for future research would be to observe support groups and to interview attendees and facilitators to address the question: what recognition do support groups provide to carers?

Empirical exploration of the role of health services with regards to carers is another avenue for future research. Are health services doing enough for carers? It would be

interesting to explore systematically the amount and type of support and advice given to carers across settings and services, as it is likely that this will vary. Research could specifically assess what is currently being done for carers by neuro-rehabilitation services, on and after PwABI discharge and assess the feasibility and modes of providing positive recognition to carers during any follow up they receive.

Question 2a: Are There any Disagreements and/or Misunderstandings Between Carers and PwABI Regarding PwABI Identity?

Chapter five used numerical ratings given by PwABI regarding their own identity and their perceptions of carer ratings on PwABI identity, alongside the ratings carers actually gave regarding PwABI identity. There was only one disagreement and corresponding misunderstanding about PwABI identity. This was on the item self-centred. PwABI disagreed with and misunderstood their partner's viewpoint on this item, believing that they are less self-centred, and believing that their carers would rate them as less self-centred than they did. There was no disagreement or misunderstanding on the other 13 identity rating task items. The overall lack of divergences of perspective suggests that PwABI and their care-givers are in alignment in their perspectives about PwABI identity in this sample, using this rating task.

Question 2b: How Can the Pattern of Divergences be Explained?

The lack of divergences found regarding PwABI identity was unexpected on the basis of the literature which suggested that divergences would be present. The lack of divergences was explained by the rating method used in this research. The rating method allows analyses to be conducted at the level of the relationship, separates disagreements and misunderstandings, provides quantitative and qualitative mapping of perspectives, treats both viewpoints in a relationship as equal and acknowledges the co-construction of shared realities in relationships. The rating method used in this research thus provides a

more balanced view of perspectives within relationships, accounting for the lack of divergences found in this study.

However, it must be acknowledged that there are alternative explanations for the apparent alignment of perspectives found in the rating task and these relate principally to the methodology. This research was conducted with a relatively small sample, using a new method which is unstandardised and the data was gathered by one researcher using a limited number of items. Therefore, it may be as a result of the methodology that there was a lack of divergences observed in this study. Limitations in the rating task methodology will be considered in more detail below.

Implications of Research Findings: Theoretical and Empirical Contributions

In answering questions 2a and 2b, the thesis considered self-awareness, and compared self-report discrepancy rating methodologies, one traditional measurement to assess self-awareness, with the rating task used in this research. With this thesis I do not wish to enter into a discourse of whether PwABI are aware or unaware. However, the consideration of the way in which self-awareness is conceptualised and measured via discrepancy rating scales raises an important issue for this type of measurement system, namely that relational phenomena are being considered at the individual level.

To measure the level of self-awareness displayed by PwABI, PwABI's perspectives are elicited and measured against their carers' ratings, thus measuring a relationship between perspectives. However, analysis of the relational data occurs at the individual level as discrepancies between the ratings of PwABI and carers are used to define individual PwABI's level of self-awareness. Use of such scales makes the implicit assumption that PwABI's ratings are the reason for any large, positive divergences in perspectives within the relationship as carers' ratings may be considered a 'more accurate'

account (if in enough alignment with professionals in a rehabilitation setting), and are used as a benchmark to measure deviations by PwABI (Bowen et al., 2010). Although multiple methods of assessment are likely to be used, if a positive discrepancy is found then this could contribute to labelling PwABI as unaware. Of course, discrepancy scales are only one way of measuring self-awareness. Interview methods such as the Self Awareness of Deficits Interview (Bogod et al., 2003) and professional assessments may well avoid the biases discussed in chapter five and may be used alongside discrepancy measures in diagnosing a person as having self-awareness deficits.

The rating method which is used in this research shows promise as a tool to measure perspectives in relationships, by providing a truly relational approach to examining perspectives in relationships. This can complement existing methods, as it measures two viewpoints simultaneously but also takes the relationship as the basic unit of analysis (Jasper, Moore, Whittaker & Gillespie, 2011).

It was discussed in chapter one that the process of adaptation in relationships may be fraught with difficulties as care-receivers and care-givers experience divergent practical, social and emotional demands and that this can lead to divergences in perspectives. What was not considered in chapter one but should now be considered on the basis of the results of the present analysis, is that rather than pulling relationships apart, the methods by which relationships adapt can actually lead to convergences of perspectives in relationships. Dyads can work together to develop shared realities, related or not to objective truth, which assist relationships to navigate the changed world they inhabit since ABI. PwABI are at risk of negative outcomes after ABI, such as stigma (Goffman, 1963) and an inability to reintegrate fully, such as by returning to employment (Wood & McMillan, 2001). We saw in chapter four that a lot of effort goes into constructing shared

realities, albeit engineered by carers, which can allow PwABI to feel good about themselves, despite the dependency that the injury creates. The convergences of perspective found in chapter five show the potential for alignment of perspectives regarding PwABI identity in relationships. It is therefore felt that consideration of convergences of perspectives that relationships work so hard to create, not just divergences, can add to the literature on perspectives and relational adjustment after injury.

Applied Contributions

The main applied contribution of the findings to question 2a and 2b is the rating method used in this research. This holds promise as a tool in future research and in practice. In research the method can map convergences and divergences of perspectives in a variety of relationships and the presentation of the rating method facilitates the collection of both quantitative and qualitative data, allowing the researcher not just to map convergences and divergences of perspective in the interpersonal realm, but to go beyond these and locate their sources (Jasper et al., 2011). In practice, the rating method can be used as a tool to elicit the perspectives of care-receivers or to compare their perspectives with the real and imagined perspectives of others, without privileging any viewpoint. With its presentation with Talking Mats, the rating method can help PwABI to talk through their perspectives with clinicians so holds promise as a therapeutic tool also. The rating task addressed identity, a facet of survivors which is not as dependent on functional, cognitive and behavioural ability as other domains which have been documented as sources of disagreement within relationships, such as the ability to perform tasks of daily living which was addressed in chapter seven. Discussion in terms of identity, i.e. the foundations of who a person 'is' within couples therapy may provide a language which allows carers and PwABI to find shared and agreed upon conceptualisations of the survivor which are positive for both sides of the relationship.

Limitations of the Rating Task Methodology

Although the rating task shows promise, as mentioned above, it has limitations which need to be overcome and it must be acknowledged that the finding of an alignment of perspectives on PwABI identity may be a result of these methodological limitations. The following section considers two methodological limitations in particular and how these limitations may have affected the results.

The rating task items are unsophisticated

It can be argued that the 14 rating task items are not sophisticated enough and may result in an unwillingness on the part of carers to answer honestly. It is obvious which of the fourteen items are 'good', such as kind, supportive and independent and which are 'bad', such as lazy, self-centred and confused. Also, the visual presentation on the mat emphasises to carers the ratings they give and the pattern the ratings form together. As we saw in chapter four, carers have as a primary aim to protect their partners, thus it will not be easy for them to rate their partner negatively to the researcher, particularly when being filmed. There is also an element of mistrust about whether the PwABI will see the mat. Carers often asked before we began whether I would share with their partners what they had said, so this was clearly a concern to them. Even when reassured that this would not happen, carers may have been reluctant to place negative symbols at a high rating for this reason. In addition, the PwABI was always nearby as a result of the nature of the testing sessions and could have entered the room at any time, seeing the mat. More sophisticated and varied items, which do not reveal their orientation so readily would perhaps improve this limitation.

Perspectives on identity cannot be reduced to a single numerical rating

Another limitation is that identity items, such as 'independent' are too complex to be reduced to a single numerical rating. As discussed in chapter one, when roles change,

previously held roles and identities do not disappear, but become layered with new identities and may be in tension with them. The viewpoint of carers on their partner's identity will contain ideas about who their partner was pre-injury, who they are now and who they hope they will be in the future. Despite me requesting a rating of how PwABI are now, this is not easy to give as different viewpoints on the PwABI in time are not isolated and may overlap. In addition, concepts in the task such as 'independent' are abstract and decontextualised, as PwABI may be independent in some domains and not others. Therefore, a single numerical rating attempts to elicit a black or white response from carers, over-simplifying the phenomena when the reality cannot be reduced to one 'rating'. However, when carers talk through their ratings with the researcher they begin to explore the grey areas surrounding the concepts and that may be more illuminating than the initial ratings. When completing the rating task, carers are seen to hesitate and change their ratings. If the researcher carefully probes these uncertainties and changes in opinion in talk, then rich information on perspectives can be revealed.

Six of the 28 carers became emotional and cried during the rating task, particularly when discussing their ratings, which highlights that the task does represent something real for carers and taps into difficult feelings for them. Initial ratings do provide a useful starting point for discussion and as we saw in chapter four, ratings can highlight relational trends. Therefore, I do not suggest that the ratings should be abandoned. However, limitations associated with the ratings need to be addressed and it is important not to over-rely on ratings or use ratings only in data collection and analysis. Once elicited, ratings should then be discussed and the discussions should be central to the analysis.

Suggestions for Future Research

On the basis of the unexpected finding of alignment of PwABI and carer perspectives regarding PwABI and the potential limitations within the rating task methodology, the next step would be a replication of the present research to provide a more robust test of the findings. Improvements to the methodology can be made on the basis of discussion of limitations in this chapter and chapter five.

Analysis of questions 2a and 2b has raised the question of what other relational phenomenon are analysed at the individual level within the rehabilitation literature? This research has focused on self-awareness. However, there are many other deficits which may be experienced after ABI which have a social dimension. For example, personality change is considered pervasive, particularly in the case of severe traumatic injuries (Brooks, 1994) and this supposedly leads to divergences of perspectives. Some PwABI samples have also been described as having difficulty relating to other people (Ponsford et al., 1995). It would be interesting to examine other deficits and the way they are conceptualised and measured to see if relational aspects of these phenomena are treated at the individual level.

Adaptation of Identity in Informal Care Relationships Following ABI

Consideration of the Findings of Chapters Four and Five Together

Adaptation of identity in informal care relationships following ABI was studied relationally using a rating task method which mapped perspectives on own identity, partner identity and estimates of the perspectives of others on own identity. It is the first time that perspectives on both sides of the relationship after ABI have been systematically mapped. Findings revealed that there were five significant disagreements about carer identity with carers seeing themselves more negatively than their partners see them, but without much misunderstanding. In contrast there was just one disagreement about PwABI identity and this disagreement had corresponding misunderstanding. PwABI saw themselves as less

self-centred than their partners saw them and thought carers would rate them as less self-centred than they did. Therefore, there is alignment between perspectives of PwABI and their carers in this study regarding PwABI identity.

Contradictions between Findings in Chapters Four and Five

Concealment was a strategy described in chapter four, so there should be divergences about PwABI identity as a result

If carers are concealing the burden of care from PwABI in order to enhance PwABI self-esteem and their sense of independence and confidence, then theoretically we should expect to see divergences on these items in the analysis of question 2a. This was not the case. However, this convergence can actually be explained by concealment. In the analysis in chapter four it was discussed that carers do not just conceal from PwABI, but from other people also. It follows then that carers may be concealing from the researcher when completing the rating task. For example, in the extract from Vicky in chapter four, in talk she described the fact that she had to redo a lot of what her husband did around the house, but hid this from him to protect his self-esteem and make him feel more independent. This would suggest that she should rate him lower than he rates himself on the independence item. However, when looking at her ratings, she rated Chris as a four (my partner is), the highest rating of independence in the task. If carers are also concealing to the researcher during their ratings then this is a further limitation of the methodology as it suggests the ratings are artificial. However, when carers were probed about their ratings and a dialogue began, carers would often admit to concealment. Vicky only admitted to the work she does and how she conceals this after much discussion around the items and she became very emotional when she discussed her concealment. This further highlights that concealment may be even more pervasive than it initially appears in the data, as admitting concealment is difficult and not all carers will have revealed the extent of their concealment to the

researcher, as an outsider to the relationship. Thus, the ratings may best be considered a precursor to discussion, which may be more illuminating than the ratings themselves. Alternatively, items could be discussed first and a rating given at the end of the discussion. This may lead to more honest numerical ratings than when they are elicited before discussion.

If carers are concealing from the researcher in their ratings, then this provides an alternative explanation for the finding of convergences about PwABI identity, as carers may have been concealing their true ratings about their partner from the researcher during the task, thus hiding what is actually a divergence. Perhaps the finding of convergence about PwABI is further evidence of carer concealment and is a demonstration of relational self-presentation, engineered by carers?

What Does this Research Add to Understanding of Identity?

Relational theory has much to offer in understanding the picture for people after ABI. Dialogical theory presented in chapter one of the thesis proposes that it is through relationships that our perspectives are created, sustained, changed and developed (Mead, 1934; Gillespie, 2006; Hermans et al., 1992). If we conceptualise and measure people at the individual level only, so much of adaptation to deficits and changed roles is missed. After ABI, PwABI may become care-receivers and family members may become care-givers. This results in changed roles and domains of responsibility, changes in the way people relate to one another and changes in how people view themselves. We exist only in relation to others, therefore, adaptation will take place in relation to others also. This PhD research has elucidated relational processes of identity adaptation and provides a starting point for future research which emphasises conceptualisation and measurement at the relational level.

The findings of chapters four and five have implications for family therapy after ABI. It has previously been assumed that some divergences of perspective in relationships are problematic and require therapeutic intervention (for example, Walls et al., 1977; Robinson et al., 2007; Cruice et al., 2005). However, this research highlights that certain divergences of perspective may be deliberate creations, produced through self-presentation and even manipulation. These divergences may have an adaptive purpose, for example, to help PwABI to navigate the dilemma of needing care but not wanting to appear or feel as though they need care. It is important that clinicians are sensitised to potential issues surrounding concealment and the sometimes deliberate creation of divergent perspectives in relationships. The decision to address possible concealment and divergences of perspective during the therapeutic process should always take account of the function of these divergences within a relational system. As a result this research cautions against the unreflective sharing of perspectives which may be detrimental to the balance of a relationship adapting to ABI. However, with the consent of family members it may be possible and even necessary to explore divergences with families. For example, despite their choice to do so, carer concealment leads to negative consequences for identity and sense of recognition. As well as being detrimental for carers, the very process of concealment may be detrimental for the relationship, preventing real connection and intimacy and creating a malignant social psychology within dyads. Thus, there may be a case for reducing such interpersonal divergences despite their adaptive purpose. This process may be approached in a number of ways, for example via narrative therapy. During narrative therapy issues may be ‘externalised’ to reconstruct them as something ‘outside’ the relationship, rather than a source of division arising from within individuals or the relationship. Once externalised, two or more people can re-approach a problem collectively and find a shared way forward. Such an approach may facilitate reconnection

and recognition within the relationship in the context of disagreements and misunderstandings (Bowen et al., 2010).

When taken together, the findings from chapters four and five provide a novel result, finding fewer divergences about PwABI identity than carer identity. Perhaps carers struggle more to adapt to their role as care-givers than PwABI struggle to adapt to the role of care-receiver? This may be because care-receivers receive a lot of support in adapting to ABI, and this support comes mostly from care-givers, who sacrifice their own identity in working to protect the PwABI. The literature has focused on identity when assuming a care-receiver role over identity when assuming a care-giver role. Likewise, therapies aimed at identity have traditionally been aimed at care-receivers (for example, Ylvisaker & Feeney, 2000; Dewar & Gracey, 2007). This research requires replication and improvements to overcome the limitations of the methodology, but provides preliminary evidence that further research into and assistance for care-givers as they adapt to changed roles and identities and the impact of their choice to conceal would be timely.

Question 3a: What Strategies do Carers and PwABI Use in Collaboration on a Joint Task?

Data set three, videos of carers and PwABI engaging in a joint task, planning inviting a friend or relative round for a meal, was analysed to answer this question. Analysis of strategies shows that completing a joint task is a collaborative process. Carers utilise a toolbox of strategies to direct the background of the task but PwABI are in charge of the foreground, making task decisions. However, carers dominate the collaborative process and control where and how PwABI contribute.

Question 3b: Is the Type of Input Provided by Carers on the Joint Task Comparable to Scaffolding as Described in the Child Development Literature?

Data set three was further analysed to address question 3b. The scaffolding metaphor was met in two ways: the type of strategies used and the flexibility with which these strategies were used. Strategies were chosen which were suitable for use with PwABI and the amount of input varied with question difficulty. However, removal of supports is unlikely over time and this may lead to frustration in carers.

Implications of Research Findings: Theoretical and Empirical Contributions

O'Neill and Gillespie (2008) called for research assessing the strategies used by care-givers and care-receivers when collaborating on joint tasks. This research has answered these calls using a relational, process oriented approach. The strategies used by both care-givers and care-receivers in interaction when planning inviting a friend or relative round for a meal have been mapped. The method and analysis chosen for this research has avoided criticisms of previous research, namely that the novice's input tends to be considered only in terms of whether or not they provided an appropriate response to the expert's input (Rogoff, 1998), as it has considered equally the contribution of both expert and novice. This research adds to the growing picture of assistive and augmentative collaboration and adds to explanations of why close care relationships improve care-receiver participation (Hinckley, 2006; Lyons et al., 1995). The findings are in line with previous research which has shown that carers employ a range of subtle strategies to assist care-receivers (Gillespie et al., in prep.; Shakespeare & Clare, 2005) and that care-givers are seen as a source of help by care-receivers (Oyebode et al., 2009). The research is also in line with the findings of Shakespeare and Clare (2005), who suggested that care-givers take on a directing role, drawing care-receivers into the task and helping to build their self-esteem by facilitating their participation.

However, the present research adds to previous research on strategies as it shows that as well as facilitating the care-receivers involvement in the task, the direction provided by carers can at times stifle care-receivers as care-givers sometimes pressurise PwABI to make decisions and these decisions must be in line with both care-giver interpretations of the task and care-giver perspectives of suitable answers for the task.

This research moves discussion of assistive and augmentative communication forward in another way also. What previous research on strategies used in collaboration on joint tasks between care-givers and care-receivers has not endeavoured to discover is the applicability of the scaffolding metaphor for adults with cognitive impairment. This PhD research has provided a starting point for considering scaffolding in such a sample. Where the scaffolding metaphor ceases to be relevant is in removal of supports and it is this facet of scaffolding which is key to future discussion of the applicability of the metaphor to adults with cognitive impairment. It may be that a developmental theory is simply not applicable to the case of brain injury as recovery is not necessarily a ‘developmental’ process. It is up to future research to further assess the notion of removal of supports as it was beyond the scope of this research to assess the capacity for learning on tasks of daily living in PwABI and the differences in interactional dynamics where mastery is and is not achievable. Carers were seen in this task to experience frustration. Future research with longitudinal data could aim to establish why frustration is present. Is it as a result of burden due to the constant input required from them? Or is frustration unrelated to the issue of removal of supports?

Applied Contributions

With increasing pressure on informal carers in society, a major goal for the future should be to relieve the burden that carers face. The dyads in this study are an average of

7.84 years post injury so have over time developed strategies and modes of collaboration which assist PwABI to participate in tasks. Information on strategies to use to assist people with cognitive impairment could be incorporated into the advice component of follow up after injury (SIGN, 2009).

The major applied contribution arising from the analysis of questions 3a and 3b is the possibilities that strategy information holds for the assistive technologies field. Proot et al., (2000) suggested that continual input from carers left carers feeling burdened and care-givers positioned as dependent, child-like and intruded upon. The ideal assistive technology would be one which removes the need for carers to constantly provide support on the same ADLs. Progress has already been made in this area with technologies such as the GUIDE (O'Neill & Gillespie, 2008; O'Neill et al., 2010), a verbal prompt system which simulates the kind of input that carers would give. Such systems show potential in allowing care-receivers to feel more independent and can relieve the pressure on carers to constantly provide task oriented input. Information on the naturalistic interactions between carers and those they care for on tasks and the strategies carers use to facilitate care-receiver involvement can only enhance the design and development of such technologies

Suggestions for Future Research

What this research has avoided is entering into debates on the effectiveness of strategies. What may be effective at one time, in one context, with a particular individual may be ineffective at another time, in another context with the same or a different person. The goal of the activity is also relevant in terms of effectiveness and goals may be competing during the completion of a single task. What strategies may be useful when attempting to build a sense of confidence in a task under no time limitations will be different from what may be useful when trying to complete a task quickly or when

working on a task such as the claim form task discussed in chapter seven, the result of which has serious future repercussions. Yet issues of effectiveness need to be teased out if information on strategies is to be provided to new carers or incorporated into assistive technologies which aim to simulate carer input. It is a methodological challenge for future research to consider the ways in which strategy effectiveness can be assessed.

Question 4a: What Happens When Carers and PwABI Collaborate to Fill in the Disability Living Allowance (DLA) Claim Form?

Carers and PwABI were seen to disagree frequently when completing part of the DLA form. These disagreements were in the direction of the carer seeing more disability than the PwABI in 93.02% of cases.

Question 4b: Why do Carers See More Disability than PwABI When Filling in the DLA Form?

Carers were found to see greater disability than PwABI due to the communication required to complete the form. Dyads are forced to confront disability, a pattern of interaction they avoid in everyday life. Carers adapt to this change in interactional style whereas PwABI avoid confronting the disability. The complexity of the form forced carers to take over the task completely to get it done. As a result, carers marginalise PwABI point of view and position themselves as 'expert' on the PwABI. Although carers may be best placed to judge, this positioning of self as 'expert' denied PwABI input into the task and marginalised their viewpoint. Differences in frames of reference regarding audience, aim and scope lead carers to maximise the disability and PwABI to minimise this.

Implications of Research Findings: Theoretical and Empirical Contributions

It was discussed in chapter two that what previous research there is on strategies and scaffolding has focused on relatively simple and artificial tasks. Yet, after ABI there are often complex forms to be filled in, to gain compensation, to acquire benefits, to deal

with driving authorities, and so forth. Little attention has been paid in the literature to such complex tasks and how they are dealt with in informal care relationships. DLA was chosen as the object of enquiry as this is a long and complex form which has been described as difficult to fill in (Banks & Lawrence, 2005; Salway et al., 2007) but is frequently required to be completed by PwABI to access much needed financial relief. Despite being described as complex and difficult to complete, no study to date has examined how this form is completed after brain injury. The findings of this study contribute to the literature on processes of collaboration as this is a complex and real world task and provide empirical detail on what happens when task demands force patterns of communication which are avoided in everyday life.

This task was originally designed to be analysed alongside the planning inviting a friend or relative for a meal task, adding a more complex, real world task to enhance discussion of strategies used in collaboration and scaffolding. However, after the research testing began it soon became clear that this task promoted qualitatively different interactions between care-givers and PwABI than the meal task which could not be ignored in analysis. Analysis of identity showed that care dyads avoid confronting the disability of the PwABI in everyday life and instead favour patterns of interaction which are characterised by concealment and adaptive divergences of perspective. Disability claim forms force dyads to confront the disability, and this leads to interactions characterised by disagreements. The process undermines the work that carers do to conceal the burden of care and threatens the reality which is created and presented within and beyond the relationship.

In the analysis of questions 3a and 3b, carers were seen to use strategies to give over control of the foreground of the task to PwABI, although carers controlled to some

extent how and where PwABI contributed. In the DLA task, where the answers given were important and the task was complex, any interactional rights which had previously been given to PwABI on the meal task were removed and carers took over completely. This left PwABI positioned as less than expert on their own capabilities and unable to contribute to the task. Therefore, forms which are the gateway to access enabling funds actually disable care-receivers and cause problematic interactions within relationships.

Applied Contributions

The disability benefits system is due to change to Personal Independence Payments in 2013, although this change has many opponents and is currently being protested against by a coalition of charities who claim that reforms may leave thousands in poverty (“DLA: Pressure on Government”, 2012) . One of the aims of the new system is to be less focused on impairment and more emphasis is to be placed on what is required for people to be able to participate in daily life. However, assessment will always by its nature require care-receivers to confront their disability in front of others, be this assessors or care-givers or both. This is a difficult and potentially stigmatising process for care-receivers. Those involved in assessment should be made aware of issues of face-saving, self-presentation and minimizing of disability in front of others by care-receivers and should be aware of the implications of having a care-giver present or absent during assessment. Assessment methods must be devised which minimise the potential for negative impact on those being assessed.

Suggestions for Future Research

The analysis of dyads completing part of the DLA claim form have implications not just for disability benefits but we must ask how many forms that are required to be completed by people with disabilities are in themselves disabling and impossible for care-receivers to access independently? Future directions involve raising awareness of the

myriad issues which such forms may create, for example, that they are too complex, impossible to access by those with cognitive impairment, risk stigmatisation and marginalisation and threaten care-receiver self-esteem.

Limitations of the Joint Tasks

It is necessary to consider limitations of the methods used to assess collaboration in joint tasks. It has previously been argued in this thesis that the inviting a friend or relative around for a meal task is artificial and only covered the planning of a task, without assessing what dyads actually did when someone was coming over for dinner. A comparison between observations of planning and executing joint tasks would be an interesting avenue for future research. The DLA claim form task was introduced as a more ‘real world’ task. However, it was a limitation that I did not establish how many dyads had previously filled in this form, and how many were receiving DLA currently or in the past. I also did not have an objective measure of functioning to establish what PwABI could and could not do in terms of the tasks mentioned on the DLA form. Therefore, it is impossible to establish how the level of functioning corresponds to the answers given in the form. It was discussed in chapter seven that carers and PwABI were sometimes confused about the audience for the task. There was mistrust about where the details written on the form would go and this may also have affected the answers given. However, although a potential limitation, this mistrust may actually have led dyads to complete the form as they would if actually applying for DLA, thus reducing artificiality. Another limitation of the joint tasks was that I remained in the room whilst dyads completed the task. This may have created demand characteristics and may be different from the way the tasks would have been completed if I were absent from the room, a situation more akin to a real world scenario. Finally, neither of the tasks truly tapped into activities of daily living, as neither completing the DLA form, nor inviting someone round for dinner are daily events. Other

tasks which are more related to the practical daily activities that care relationships engage in, such as actually creating a meal or doing the laundry, could be observed in future research.

Contradictions between Findings Across the Thesis

A high level of disagreement between care-givers and care-receivers about PwABI's ability to participate in tasks of daily living was found in the analysis of question 4a, with carers seeing greater difficulty in participation than PwABI. This finding in analysis of question 4a in chapter seven contrasts in two key ways with earlier findings in the thesis from the identity rating task and it is necessary to acknowledge these contradictions and explore their potential sources.

Why was there a high level of disagreement on the DLA task when dyads appeared aligned about PwABI on the identity rating task?

One explanation for the contradiction surrounds the issue of carer mistrust about where the information from the research was going to go. As mentioned earlier, carers were nervous that PwABI were going to see their ratings of them in the rating task and they are equally worried in the DLA task that the information they give is going to fall into the hands of assessment bodies. Upon seeing the DLA task sheet, several carers asked whether anyone else would see the information they gave and when completing the rating task they asked if their partner would see their completed mats. Even though participants were reassured that the information was for the researcher alone, carers were still addressing an invisible third party, beyond the researcher, and in the joint task this was the DLA assessors, and in the rating task it was their partner. This affected the way carers approached the two tasks and would lead to different responses on each due to the different 'audiences'. If the third party was their partner, whose self-esteem they wish to protect, they may have concealed from the researcher and minimised disability. However, if the

third party was the DLA assessors, then they would maximise the disability as this is most likely to secure the benefit. Why then did the PwABI not maximise their disability for the DLA assessors? Perhaps both PwABI and carers experienced two demands, identity and DLA assessors, but for PwABI the identity demand was stronger, while for carers who are privy to the realities of the financial situation the assessors were a stronger audience.

Another alternative explanation is that the rating task and the DLA form are assessing different domains of PwABI functioning. The rating task was about identity, who the PwABI 'is', whereas the DLA task addresses what the PwABI can 'do', leading to different conceptualisations. However, the difference between findings may come down principally to methodology. The rating task has certain limitations inherent in its methodology which the DLA task overcomes. For example, the DLA task is more concrete and based on specific examples, thus avoiding the abstract decontextualisation of the rating task. On this basis, the DLA task could be considered more informative and thus the suggestion that there is more disagreement about PwABI than the rating task implies is persuasive.

Why do PwABI promote ability in the DLA task when they admit to disability in the rating task?

The second contradiction in findings comes from the differences in PwABI response in the rating task and the DLA task. The high disagreement in the DLA task with PwABI judging their disability to be lower than their carers do would be the result expected if PwABI lack self-awareness. However, in the analysis in chapter five, extracts were presented from PwABI demonstrating awareness of their deficits and the functional implications of these deficits on their own lives. Why is there a difference? One explanation is the difference in the methodologies. The rating task explores PwABI perspectives on self. It allows PwABI to consider individually, in their own time their

position on each item, thus PwABI draw their own line in the sand regarding their ability level. In the DLA task, the carer is present and contributing to the positioning, and often it is the carer who draws the line in the sand, setting a disabled starting point. To complete the task the two people then need to work together to achieve a consensus position and write the corresponding answer on the form. Thus, they are very different tasks in terms of the way in which PwABI's perspectives are elicited.

The conversational patterns that the DLA task creates may lead to a defensive response by PwABI. As Bowen et al. (2010) explicate in their discussion of conversational patterns between professionals and PwABI, when a PwABI is confronted with a deficit by another person, this can be seen as accusatory by PwABI as the professional is "making value judgements about the intimate attributes at the core of one's identity/self" (p. 123). The minimisation of disability by PwABI in the DLA task may be seen as a case of defensive posturing in the face of a significant other making judgements about the PwABI's abilities.

Self-awareness is a complex phenomenon, fluctuating in space and time and varying across domains (Clare, 2004; Clare et al., 2008). On the basis of previous research, Bowen et al. (2010) suggest that the amount of self-awareness displayed by PwABI varies depending on the way perspectives are elicited as ultimately PwABI are always reporting *to* another. They suggest that concise questioning can reduce the gap between PwABI's and others' ratings, and that in cases of anosognosia, discussion of deficits in the third person and externalisation and discussion of deficits in relation to discrete incidents can all elicit more self-aware response. This last example of discussion of discrete incidents is interesting as the opposite was the case with PwABI in this study. Although the populations differed, the result of more self-aware responses in PwABI when disability

and identity were addressed in the abstract in this study seems counter-intuitive and modes of response elicitation require more exploration in the future.

Cognitive/Practical Adaptation in Informal Care Relationships Following ABI

Previous research has discovered improved quality of life relative to other care-receivers for care-receivers who had a close informal care relationship (Hinckley, 2006; Lyons et al., 1995). This research has shown the complex and subtle ways in which cognition adapts within dyads to facilitate maximum participation in practical activities of daily living for PwABI. As seen in chapter four of the thesis, as well as carers seeing PwABI identity as an extension of the carer, that is they must maintain identity at the level of the relationship, the same can be said of cognition. Carers pick up the slack created by cognitive impairment and scaffold their partner's cognition to help them participate in collaborative tasks. Carers flexibly apply a range of strategies to direct the background of tasks, allowing PwABI to take control of the foreground of tasks. However, there are downsides to the work that carers do. The input they provide is complex, but due to cognitive impairment, there is doubt about whether the scaffolding put in place by carers can ever be fully removed. There was evidence of frustration in carers and removal of scaffolding may be the cause, although the lack of longitudinal data in this study does not allow us to test such a hypothesis. Also, the direction provided to enable PwABI and provide them with more equal interactional rights can actually be disabling. PwABI are often unable to contribute freely, but must do so within the parameters set by carers. When a task is complex, such as the DLA task, carer's direction becomes total and the input of PwABI is rejected or ignored.

Implications for Carers From the Thesis as a Whole

Family members intuitively know how to support their partners when they become ill or disabled. Carers put those they care for first, going to great lengths to help care-

receivers to feel positive about themselves. What carers don't know how to do is to loosen the reins on themselves and their partners. Carers are desperate to 'get it right' and compare themselves to imagined notions of the 'perfect' carer. They strive to provide for and protect their partners, emotionally, physically, practically and financially. This leaves them burdened, frustrated, anxious, with a negative view of themselves and lacking recognition. What is clear from this research is that carers need more support to be carers. This is not the first time this recommendation has been made, but it is proposed that future research and practical support needs to be targeted at the area of recognition for carers. Health services should consider providing opportunities for recognition during follow up and up to date information regarding local support services should be provided to carers. Future research should also target finding ways to help reduce the need for constant input from carers in daily living, perhaps through assistive technology development.

Implications for PwABI From the Thesis as a Whole

It is important to stress that carers appear to be doing their best to protect and care for PwABI and may go to heroic lengths to do this. However, despite their best intentions, this research has shown that carers can marginalise the viewpoint of care-receivers, which can be stigmatising (Sabat & Harré, 1992). As described in chapter one of the thesis, a person who is stigmatised is separated from others as a result of difference, in this case that they have a brain injury, and it is this difference which becomes the defining feature of that individual (Charmaz, 2000; Spicker, 1984).

Shakespeare and Clare (2005) discuss "problematizing the mundane" (p. 328), where mundane occurrences during interaction, such as forgetting a name, are reconceptualised as indicative of a deeper process, such as disease progression, when the person forgetting a name has a diagnosis of dementia. The same is true of PwABI in the

case of discrepancy rating scales which use a significant other's ratings. If perspectives between regular married couples are elicited and compared, there will likely be disagreements (Laing et al., 1966). However, if PwABI disagree with carers, the scoring system of discrepancy scales contains the implicit assumption that disagreements are the result of PwABI lacking self-awareness, rather than considering these disagreements as something relational. This serves to marginalise the point of view of PwABI.

Marginalisation of PwABI point of view can also come inadvertently from carers. Carers work extremely hard to protect PwABI and to assist them to achieve everyday tasks. However, this protection can be so rigid that it begins to silence the PwABI. Carers are trying so hard in joint tasks (they hand the foreground over to PwABI in the meal task; they try to complete the task appropriately for research; and they try to fill in the DLA form in a way which will maximise benefit entitlement) that they inadvertently marginalise PwABI perspectives, thus enablement becomes disabling. PwABI can participate in discussion about inviting someone for a meal or completing the DLA form, but they cannot add to this discussion, as if they deviate from the carer's script, then their viewpoint may be dismissed or ignored. Shakespeare and Clare (2005) discussed the way people with cognitive impairment are cast as "less than full members" (p. 329) of an interaction. This is a process which is exacerbated by PwABI being unable to express a viewpoint or contribution which is not in line with the carer's viewpoint.

This research has shown that PwABI have a voice and has demonstrated methods which allow this voice to be expressed. The rating task method and its administration as used in this research is a tool which can be useful in future research and practice. Despite its limitations, this method gave PwABI equal rights in the task, as ratings were treated as equal to the ratings of carers. In terms of allowing people with cognitive impairment to

give their views and explore these in talk where possible, the method holds promise. In the joint tasks, the sociocultural, process oriented approach considered PwABI interaction beyond whether they provided appropriate task responses and considered their engagement on an equal footing to carers (Rogoff, 1998).

Limitations of Standardised Measures Used

It is acknowledged that both the ACE-R and the FAB have limitations. The ACE-R is a brief screen which does not represent all the relevant domains of disability in a brain injured sample. The ACE-R is also not in a format which is accessible to everyone after brain injury. The tool could not be administered to all participants as it requires the ability to write and the ability to see the questions. For participants with physical and visual impairments it was impossible to engage fully with the measure in the format in which it was presented. As global scores were used in the study, this led to just 18 of the 28 participants having usable global scores on the measure, potentially skewing results on the levels of cognitive impairment in the sample as a whole.

The FAB was found by the researcher to lack sensitivity to frontal lobe deficits. Only one participant scored below the threshold of normal performance despite several participants or their significant others stating that they had dysexecutive syndrome. As with the ACE-R, the tool could not be administered to all participants as its format was inaccessible to those with visual impairment.

The ACE-R and FAB were administered at the end of the Talking Mats session as this was the only point during data collection at which the researcher was alone with the PwABI. As completion of the Talking Mats was relatively complex, this may have left participants fatigued when beginning the cognitive tests, further biasing the results (Carlsson et al.,

2007). The tools had questions which duplicated each other (the lexical fluency question), which participants may have found frustrating.

Limitations of a generalised methodology

The research used Talking Mats for every participant and qualitative data was derived from the discussions surrounding the ratings made using the Talking Mats. Although increasing consistency, this generalised approach did not take into account the varying levels and domains of disability and needs across survivors and can thus be criticised for not empowering individual participants to participate in the research in accordance with their own strengths and additional support requirements. For example, even in the case of communication impairment, there is an ideal need to tailor the methodology depending on whether the participant has dysarthria or aphasia (Carlsson et al., 2007).

Limitations of the Sample

It is acknowledged that this research reflects the view and experiences of a relatively small group of participants and thus the findings are not claimed to be generalisable to all dyads following ABI. The sample was heterogeneous in terms of type of injury and relationships, including some PwABI who had experienced traumatic injury and some whose injury was acquired after stroke or HSE. Dyads came from a variety of relationships and previous research has shown differences in the experience of changed roles depending on prior relationship, for example whether carers are parents or spouses (Ponsford et al., 1995). The sample consisted of people who came forward to take part, therefore, the characteristics of this sample may differ from those who chose not to come forward when they received research information packs.

The heterogeneity of the sample and the consideration of all relationship types as care-giver/care-receiver relationships leads to several weaknesses in the analysis. Firstly, the structure of relationships varies. It could be argued that romantic relationships are based more on reciprocity, equality and a meeting of minds than parent-child or sibling relationships. Thus, it is not surprising that it has been argued that romantic partners may particularly struggle to adapt to having a brain injured partner (Ponsford et al., 1995) and that the issues which affect couples relationships may be unique (Bowen et al., 2010). As well as the rupture occurring to romantic relationships being the biggest, the nature of romantic relationships is also most unstable. For romantic partners and friends there is a level of choice surrounding the decision to become and continue to be a care-giver. For family relationships, there is less choice surrounding the decision to take on the role of care-giver. The grouping of all carers under one label ignores these fundamental differences in the structure and function of various types of relationship and the unique issues which face different types of dyad.

The grouping of everyone in the study under the ‘carer’ label may also ignore important facets of those carers’ personal identity constructions. Participants may own their own, favoured conceptualisations of their identities in the context of the brain injury, for example the identity of wife, husband, Mum, Dad, confidante, companion, brother, sister. It is acknowledged that the imposition of the title of ‘carer’ by the researcher may be in itself disempowering to significant others and ignores the variety and salience of participants’ own personally meaningful identity constructions.

The generalisability of the results

It is acknowledged that there are limitations to the ability to generalise from the results of this research due to small participant numbers and the heterogeneity of the

sample. The purpose of the research is to sensitise researchers and clinicians to some of the myriad issues which may be facing informal care dyads as they adapt in the medium to long term to ABI. Even though there is diversity in findings there are some overall patterns which it is important to highlight and explore further in future research. These issues will not occur in all cases, and it is not possible on the basis of this research to pinpoint to whom and when such situations as concealment may occur. However, it is important to sensitise those working within the ABI arena and beyond to these issues.

Conclusion

This PhD research has provided new insights into relational processes of adaptation in informal care relationships following ABI. Relational adaptation of identity and cognition is a complex process, characterised by triumphs and difficulties. Carers provide subtle, tailored support to protect PwABI, care for them and increase their ability to engage in ADLs without risking their sense of independence and confidence. Patterns of adaptive divergences of perspective and co-presentation allow relationships to navigate daily life. However, the protection and the assistance that carers provide to facilitate PwABI participation can sometimes result in the marginalisation of the PwABI's viewpoint and contribution, and can leave carers feeling anxious, frustrated and negative about their own identity.

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Appendix A



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Adapting to Acquired Brain Injury

Task 2 - Inviting a friend or relative round for a meal

I would like you to work through the following task together.

Imagine that you are going to invite a friend or relative around for a meal in your home. I would like you to discuss the various stages of planning and activity you will have to go through. Could you discuss the following issues together, agree upon an answer, and then write the answer in the space provided.

Who will you invite? (first name only)

How will you invite them?

When will you have the meal?

Who will do the shopping?

What food will you make?

Who will prepare the ingredients?

Who will do the cooking?

Who will lay the table?

Once you are satisfied with the plans for the meal, then imagine that you have almost finished preparing the meal, and your friend or relative is expected to arrive in 10 minutes. As you are bringing the food out and putting it on the table, it gets knocked over. There is food all over the table and floor. With your guest arriving in 10 minutes, what would you do?

Appendix B

Table B.1

Examples of Strategy Coding Used in the Inviting a Friend or Relative for a Meal Task

| Strategy | Example |
|-----------------------------------|--|
| Writing | N/A |
| Initiating exchange | “Right, right, you’re gonnae invite a friend or relative for something to eat, ok?” |
| Question | “Right, who would you like to invite for a meal Keith?” |
| Checking agreement | “I think we would ring a takeaway, don’t you?” |
| Steering | “Salad, cold meat salad.” “Ok so you don’t want to try something different?” “Spaghetti Bolognese, curry, erm toastie cheese, erm what else is there? Scrambled eggs?” “Well there’s books full of recipes. You’d better find out if she’s a vegetarian first. ” |
| Speaking for | “Or would you rather?” “I’d rather [pause]” “ Email, yes ” |
| Rephrasing | “Is there anybody in particular you would like? If you were going to have anybody who would you like? ” |
| Suggest alternative | “I’ve never made roast venison before [...]” “ Do another roast, lamb? ” “Ok, I’ll do roast lamb.” |
| Offering options | “What kind of veg would you like? Sweetcorn, peas or carrots? ” |
| Prompting | “Out of that lot who would you like to invite?” “I don’t know” “ Well think about it. Who do you think?” |
| Chunking | “What will we make... For a starter , maybe [...]” |
| Gesturing | “How will you invite them?” “Phone” [mimes putting a phone against her ear] |
| Making decision | “and your sweet?” “erm, a sticky toffee pudding ” [writes this] |
| Judging response adequacy | [reads aloud] What food would you make? I would” “phone the Chinese” “right I’d probably” “phone the Indian” “ No, we’re making [emphasises word ‘making’] a meal Brian ” |
| Judging completion | “I’d just like to marinate my steaks which I do on a weekly basis anyway.” “Right, never mind, we’ve done the cooking. [reads aloud] Who will lay the table? ” |
| Correcting | “Yep and then improvise [PwABI spells ‘improvise’ wrong], P-R-O. ” |
| Setting limits | “also I would accompany that with a glass of wine” “No, it’s just saying food. It’s nothing about alcoholic consumption [looks away]” “alright, ok but I would have a bottle of red wine with it anyway” “Yes, aha but that’s not the point” |
| Using assistive technology | [hands D his picture book] “Who would you like to invite? Choose somebody from your book.” |
| Requesting help (from partner) | “[C dictates while N writes]. Rescue, rescue as much as possible and then improvise as much as possible.” “ Is that right? ” |
| Requesting help (from researcher) | “Stella and Norman?” [to researcher] “ Can we say two people? ” “Yes, of course you can, yes” “That’s not a problem then” |
| Joking | “The food is all over the table and floor. What you gonna do?” “ Blame you [laughter] ” |
| Repeating | “What kind of food do you want?” “Um, that’s you aye” “Um, what kind of food do you want? ” |

Note. Where part of the conversation is highlighted in red in the table, this indicates the point in the exchange at which coding for that strategy took place.

Appendix C

Disability Living Allowance **Claim for a Person Aged 16 or Over**

Your care needs during the day

During the day includes the evening

By care needs we mean help or supervision, due to an illness or disability, with:

- Everyday tasks like getting in and out of bed, dressing, washing
- Taking part in certain hobbies, interests, social or religious activities, or
- Communication.

Help means physical help, guidance or encouragement from someone else so you can do the task.

Use the tick boxes to tell us about the difficulty you have or the help you usually need.

It is important that you tell us about the difficulty you have or the help you need, whether you get the help or not.

For example

If you need help to get to and use the toilet four times a day, you would fill in the boxes as shown below.

- | I have difficulty or need help: | How often? | How long each time? |
|--|-------------------|----------------------------|
| • With my toilet needs | 4 | 5 minutes |

Your care needs during the day (continued)

1. Do you usually have difficulty or do you need help getting out of bed in the morning or getting into bed at night?

Yes Please tick the boxes that apply to you. No Go to question 2.

- | I have difficulty or need help: | How often? | How long each time? |
|---------------------------------|----------------------|---------------------------|
| • getting into bed | <input type="text"/> | <input type="text"/> mins |
| • getting out of bed | <input type="text"/> | <input type="text"/> mins |

- | I have difficulty concentrating or motivating myself and need: | How often? | How long each time? |
|--|----------------------|---------------------------|
| • encouraging to get out of bed in the morning | <input type="text"/> | <input type="text"/> mins |
| • encouraging to go to bed at night | <input type="text"/> | <input type="text"/> mins |

Is there anything else you want to tell us about the difficulties you have or the help you need getting in or out of bed at night?

For example, you may go back to bed during the day or stay in bed all day.

Yes Tell us in the box below. No Go to question 2.

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Your care needs during the day (continued)

2. Do you usually have difficulty or do you need help with moving around indoors? By indoors we mean anywhere inside, not just the place where you live.

Yes Please tick the boxes that apply to you No Go to Question 3

I have difficulty or need help:

How often?

- Walking around indoors
- Going up or downstairs
- Getting in or out of a chair
- Transferring to and from a wheelchair

I have difficulty concentrating or motivating myself and need:

How often?

- Encouraging or reminding to move around indoors

Is there anything else you want to tell us about the difficulty you have or the help you need with moving around indoors?

For example, you may hold on to furniture to get about or it may take you a long time.

Yes tell us in the box below. No Go to question 3.

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| |

Your care needs during the day (continued)

3. Do you fall or stumble because of your illnesses or disabilities?

For example, you may fall or stumble because you have weak muscles, stiff joints or your knees give way, or you may have problems with your sight, or you may faint, feel dizzy, blackout or have a fit.

Yes Please continue below

No Go to question 4.

What happens when you fall or stumble?

Tell us why you fall or stumble and if you hurt yourself.

| |
|--|
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| |

Do you need help to get up after a fall?

Tell us if you have difficulty getting up after a fall and the help you need from someone else.

Yes Tell us in the box below.

No Go to question 4.

| |
|--|
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| |

When did you last fall or stumble?

If you don't know the exact date, tell us roughly when this was.

How often do you fall or stumble?

Tell us roughly how many times you have

last month

fallen or stumbled in the last month or year

last year

Your care needs during the day (continued)

4. Do you usually have difficulty or do you need help with taking your medicines or with your medical treatment?

This means things like injections, an inhaler, eye drops, physiotherapy, oxygen therapy, speech therapy, monitoring treatment, coping with side effects, and help from mental-health services. It includes handling medicine and understanding which medicines to take, how much to take and when to take them.

Yes Please continue below.

No Go to question 5.

Please tell us what help you need and how often you need this help.

I have difficulty or need help: How often? How long each time?

- Taking my medicine minutes
- With my treatment or therapy minutes

I have difficulty concentrating or How often? How long each time?

Motivating myself and need:

- encouraging or reminding minutes
to take my medication
- encouraging or reminding minutes
about my treatment or therapy

Is there anything else you want to tell us about the difficulty you have or the help you need taking your medication or with medical treatment?

Yes tell us in the box below.

No Go to question 5.

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Your care needs during the day (continued)

5. Do you usually need help from another person to communicate with other people? For example, you may have a mental-health problem, learning disability, sight, hearing or speech difficulty and need help to communicate. Please answer as if using your normal aids, such as glasses or a hearing aid.

Yes Please tick the boxes that apply to you. **No** Go to question 6

I have difficulty or need help:

- Understanding people I do not know well
- Being understood by people who do not know me well
- Concentrating or remembering things
- Answering or using the phone
- Reading letters, filling in forms, replying to mail
- Asking for help when I need it

Is there anything else you want to tell us about the difficulty you have or the help you need from another person to communicate with other people?

For example, you use British Sign Language (BSL).

Yes Tell us about your communication needs in the box below. **No** Go to question 6

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Your care needs during the day (continued)

6. Do you usually need help from another person to actively take part in hobbies, interests, social or religious activities?

We need this information because we can take into account the help you need or would need to take part in these activities, as well as the other help you need during the day.

Yes Please continue below.

No Go to Question 7.

Tell us about the activities and the help you need from another person at home.

| What you do or would like to do. | What help do you need or would you need from another person to do this? | How often would you do this and how long would you need this help each time? |
|---|---|--|
| <p>Example</p> <p>Listening to music</p> | <p>I cannot see and my wife has to find the disc I want and put it in the player.</p> | <p>Four or five times a week, one to two minutes each time.</p> |
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Tell us about the activities and the help you need from another person **when you go out.**

| What you do or would like to do. | What help do you need or would you need from another person to do this? | How often would you do this and how long would you need this help each time? |
|------------------------------------|---|--|
| <p>Example swimming</p> | <p>When I go to the swimming pool I need help to get changed, to dry myself and to get in and out of the pool</p> | <p>Four or five times a week, 30 minutes each time.</p> |
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If you need some more space to tell us about hobbies, interests, social or religious activities please continue below.

Your care needs during the day (continued)

7. How many days a week do you have difficulty or need help with the days care needs you have told us about?

8. Do you usually need someone to keep an eye on you?

For example, you may have a mental-health problem, learning disability, sight, hearing or speech difficulty and need supervision.

Yes Please tick the boxes that apply to you No Go to question 9

How long can you be safely left for at a time

Please tell us why you need supervision:

- To prevent danger to myself or others
- I am not aware of common dangers
- I am at risk of neglecting myself
- I am at risk of harming myself
- I may wander
- To discourage antisocial or aggressive behaviour
- I may have fits, dizzy spells or blackouts
- I may get confused
- I may hear voices or experience thoughts that disrupt my thinking

Is there anything else you want to tell us about the supervision you need from another person?

Yes Tell us in the box below No Go to question 9.

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Your care needs during the day (continued)

How many days a week do you need someone da days to keep an eye on you?

9. Would you have difficulty preparing and cooking a main meal for yourself?

This means planning and preparing a freshly cooked main meal for yourself on a traditional cooker (in other words, not using a microwave oven or convenience foods), assuming you have all the ingredients you need.

This does not mean reheating ready-made meals or convenience foods.

Yes Please continue below

No The form is complete.

- I have difficulty or need help planning a meal, for example, measuring amounts, following a logical order of tasks, or telling when food is cooked properly.
- I lack the motivation to cook
- I have physical difficulties, for example, coping with hot pans, peeling and chopping vegetables, or using taps, switches, knobs, kitchen utensils or can-openers, or carrying, lifting, standing or moving about to perform tasks.
- I would be at risk of injury preparing a cooked main meal for myself.

How many days a week would you need this help Days

Is there anything else you want to tell us about the difficulty you would have planning, preparing and cooking a main meal?

Yes Tell us in the box below

No The form is complete.

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