Social participation following right hemisphere stroke

Influence of a cognitive-communication disorder

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DECLARATION

This work has not been previously submitted for a degree or diploma in any university program. To the best of my knowledge the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Ronelle Hewetson

CONTRIBUTION TO PAPERS INCLUDED IN THIS THESIS

The below list of articles and conference abstracts represent a summary of the dissemination of thesis results to date. Ronelle Hewetson was responsible for study design, obtaining ethical clearance, data collection and analysis and writing of all manuscripts and conference presentations. Research supervisors, Petrea Cornwell and David Shum, assisted with study design, data analysis and editing of the manuscripts. Ann McGuinness assisted with data management towards a conference abstract.

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The co-authors of these manuscripts give permission for the information in the above manuscripts to be included in the body of this thesis: Ronelle Hewetson, Dr Petrea Cornwell, Dr David Shum, Ms Ann McGuinness.

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ABSTRACT

Background

The ability to communicate is essential for engaging in social roles and maintaining relationships. Communication effectiveness or style may change suddenly following a stroke, and create negative consequences related to role engagement and relationship maintenance, which in turn may affect quality of life (QoL). A social isolation risk emerges, which has been explored for people with the communication impairment of aphasia. In response, the speech pathology community has been generating research about the impact of aphasia and establishing clinical service provision guidelines to ensure access to communication focussed rehabilitation.

At present, however, the variable influence of a cognitive-communication disorder (CCD) arising following right hemisphere (RH) stroke on social role and relationship maintenance has not received equitable speech pathology research nor clinical interest. The dearth of evidence is surprising as CCD occurs with similar frequency to aphasia, and the impairments that arise may alter both communication effectiveness and style. This thesis supports the statement by Margaret Blake that “work is needed to right this ship that is listing to the left” (Blake, 2016, p. 64) by exploring long-term outcomes following a RH stroke.

Research aims

The primary objective of the research was to explore social participation in the presence of a RH stroke, with a focus on risk factors for social participation restriction and the significance of participation change related to relationship maintenance and quality of life. Three aims were addressed, namely to 1) determine perceived change in social participation as reported by people with RH stroke (self-report) and significant others (proxy-report), to 2) explore risk factors for, and the ability of routinely administered acute-stage screens to predict, social participation restriction in people with a RH stroke, and lastly to establish the significance of the change by 3) exploring the relationship between social participation, social network change and quality of life in those with a CCD characterised by impaired social cognition.

Methodology

This research used a mixed methods approach, in which sequential explanatory and concurrent triangulation typologies allowed for exploration of aims across studies. A number of data collection and analysis methods were used. Firstly, a telephone survey, utilising the Sydney Psychosocial Reintegration Scale (SPRS-2), was conducted with 36 people with RH stroke and 33 significant others. Analysis allowed for description of social participation change, and comparison of reported change based on the presence or absence of CCD. Participant-proxy agreement was furthermore determined.

The second aim was addressed in a two-step process, firstly through a retrospective chart audit of 115 consecutively admitted patients with stroke that allowed a description of frequency of CCD and access to rehabilitation in comparison to people with aphasia. This was followed by establishing the sensitivity and specificity of routinely administered screens of cognition and communication related to predicting future social participation in people with RH stroke.

The third aim explored the impact or significance of social participation change, which was addressed through a multiple-case study method. Propositions related to changes in social networks, relationships and quality of life were confirmed or refuted for seven cases, drawing on multiple data sources including semi-structured interviews with participant-proxy dyads, and completion of a number of scales.

Key findings

The majority of participants with RH stroke (94.4%, $n = 34$) reported change in at least one SPRS-2 domain. The presence of CCD, however, had an impact on social participation as reported on the SPRS-2, which was significantly different to what was reported by participants without a communication impairment ($p = 0.02$). Inter-rater agreement indicated a fair participant-proxy dyad agreement in the group with CCD ($\kappa = 0.36$), and a moderate agreement in the group without CCD ($\kappa = 0.43$).

CCD (66% of RH stroke group, $n = 58$) was diagnosed with similar frequency to aphasia (68% of LH stroke group, $n = 57$), and hospital discharge with ongoing communication impairments was comparable. People with CCD were less likely to be referred for ongoing community-based rehabilitation than people with aphasia.

A comparison of acute hospital administered screening measures revealed that a communication screen was more sensitive in predicting who would experience changes in future social participation (77% accurately identified) than an executive function task (54%) and a global cognition screen (50%). The communication screen; that considered lexical-semantics, discourse, prosody and pragmatics, also yielded the fewest false negatives.

Lastly, the significance of social participation change was explored by considering changes to relationships, social roles and networks and perceptions of QoL. People with impaired social cognition post RH stroke experienced social network change, with a reduction in network size reported by 71.4% ($n = 5$). The loss of friends accounted for the greatest reduction in network size. Interpersonal relationship change was reported often ($n = 6$, 85.7%), with potential contributors to relationship change including altered personality, communication style and spousal roles. All participant-proxy dyads reported that QoL changed because of stroke, which was most apparent where valued social roles were lost. Energy, personality, thinking and family roles were the domains reported to be most affected on a QoL scale.

Conclusions and recommendations

This synthesis of qualitative and quantitative findings highlights the risk of social participation change that exists following a RH stroke in the presence of CCD. The research also provides the first description of the multifactorial process and experience of returning to and maintaining relationships, social roles and networks in the presence of CCD characterised by social cognition impairment. Addressing unmet social participation needs by improving social connectedness should form part of rehabilitation goals for people with RH stroke and those within their social networks. An exploration of social isolation risk factors present during the acute-stage post RH stroke is required to better inform rehabilitation timing and focus.

LIST OF ABBREVIATIONS

CCD	Cognitive-communication disorder
COWAT	Controlled oral word association test
ICF	International Classification of Functioning, Disability and Health
QoL	Quality of life
RH	Right hemisphere
SPRS-2	Sydney Psychosocial Reintegration Scale
SS-QOL	Stroke Specific Quality of Life Scale
TASIT-R	Awareness of Social Inference Test-Revised

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Chapter 1

Overview, Significance and Structure

“My friends didn’t keep in touch and I don’t see any of them now, but it doesn’t bother me ... I do still sometimes send my old friends a card for Christmas, but maybe my scribble of a handwriting puts them right off replying?”

(66-year-old, retired, single participant, with moderate CCD. Mobile on discharge home following 20 days of in-patient rehabilitation. Participant reported altered relationships with friends and family).

Setting the Scene

Communication encompasses our ability to read, write, speak, understand what we hear, and make sense of non-verbal messages. This highly complex ability to communicate, described as the “currency of relationships” (Parr, 1997, p. 44), facilitates social participation and interpersonal interactions. When our ability to communicate changes, as may occur following a stroke, social participation may become difficult and a risk of social isolation emerges. It is often only during community reintegration, the process of transitioning from hospital to home, that people with acquired impairments become aware of the impact of the impairment on their ability to return to social activities and roles (Taule & Raheim, 2014). This process of returning to community-based roles is considered a distinct rehabilitation phase (Bhagal, Teasell, Foley & Speechly, 2003). However, much of what has been published to guide rehabilitation is based on activity level impairments measured during hospital admission without a clear understanding of the predictive ability of these impairments on future social participation.

Though much interest in participation emerged in response to the International Classification of Functioning, Disability and Health Framework (ICF)(World Health Organization, 2001), the particular impact of a communication impairment remains poorly understood. The link between communication impairment and social participation following a stroke is an important one to explore as 50,000 people in Australia have a new or recurrent stroke every year (Stroke Foundation, 2013). Furthermore, from a health provider stance, it has been shown that social connectedness affects both mental and physical wellbeing (Berkman, Glass, Brissette & Seeman, 2000). Communication changes related to the acquired language disorder of aphasia, and subsequent changes to social participation, have received most attention in the literature when compared to other communication impairments acquired during adulthood. To date little is known about how a cognitive-communication disorder following a right hemisphere (RH) stroke relate to social participation.

Impairments found in those with a RH cognitive-communication disorder (CCD) are receiving increased research interest. However, a limited understanding of the interplay between cognition and communication complicates the reporting on a variation of patterns of deficits, as well as the design of rehabilitation (Blake, 2016). To date not enough is known that would allow for prediction of patterns and severity of impairments, expected gains in functional recovery nor how to support successful community reintegration (Ferré & Joanne, 2016). This paucity of evidence creates challenges for health care professionals in identifying

people who are at risk for social isolation, and therefore requiring ongoing support and rehabilitation. Service delivery, in particular, recent interest in early supported discharge following a stroke, challenges us to consider who would require rehabilitation within the community, what aspects most frequently require support and how to provide this support (Mayo et al., 2000).

It is postulated that the RH stroke population may be particularly vulnerable to social isolation due to the nature of their cognitive and communication difficulties. As stated by Mackenzie and colleagues (Mackenzie, Brady, Begg, & Lees, 2001, p. 93) “It is possible that communication style (following a RH stroke) is a relevant limiting factor”; and by Myers (Myers, 1978, p. 50) “the right hemisphere patient appears peculiarly unconcerned about the impact of his message, insensitive to his situation or to the environment ... inevitably his interaction with others will change”. One characteristic of CCD post RH stroke is impaired social cognition or the ability to interpret other people’s thoughts and feelings, which has been shown to influence interpersonal communications following a traumatic brain injury (TBI). Of concern is that the RH stroke population may face a particular risk of under identification of the support needed to return to their pre-stroke social roles due to reduced awareness and insight. Under identification may occur where those unfamiliar with the features of a RH CCD dismiss changes in communication as subtle. In addition, current assessment measures of CCD that do not include ecologically valid tasks, may underestimate the impact of observed impairments on social interactions and relationships (Coelho, Ylvisaker, & Turkstra, 2005).

Evaluating the social impact of stroke is topical and in line with principles outlined in the World Health Organisation ICF (WHO, 2001). Exploration of social participation in those with RH CCD may serve as a motivation for increased access to communication focussed rehabilitation. Such access has been described as surprisingly low in one study which found that out of 94% of people identified with a CCD post RH stroke within a rehabilitation setting, only 45% were referred to speech pathology services (Blake, Duffy, Myers, & Tompkins, 2002). This thesis endeavoured to answer questions about social participation following a RH stroke and in so doing assist those involved in stroke rehabilitation to increase the efficacy of therapy focus and efficiency of timing of intervention.

Research objective, study aims and hypotheses

The objective of the research is to investigate social participation following a RH stroke, with a particular focus on the facilitators and barriers to communication-based participation in those with a CCD. The research is framed within models that allow for a holistic consideration of factors related to the individual, but also the interplay between the individual and his or her social network. The following three specific aims will address a number of hypotheses drawn from the comprehensive literature review provided in Chapter 2, which together create insight into the research question.

Aim 1: To determine perceived change in social participation as reported by people with a RH stroke (self-report) and a significant other (proxy-report).

Hypothesis 1.1.: People living with a RH stroke will report changes in social participation.

Hypothesis 1.2.: Social participation change will be greater in people with a CCD compared to people without a communication impairment following RH stroke.

Hypothesis 1.3.: Participant-proxy agreement about social participation change will be lower when a CCD is present due to anosognosia.

Aim 2: To explore a risk profile for social participation restriction of people returning to community living following a RH stroke.

Hypothesis 2.1: At the point of discharge from an acute or rehabilitation setting, persons with CCD will have a risk profile (that includes environmental and impairment level information) for social participation restriction similar to people with aphasia.

Hypothesis 2.2: Routinely administered screens of cognition and communication will not be equally able to predict future social participation change in people with RH stroke.

Aim 3: To determine the significance of social participation change in terms of relationship maintenance, social network change and quality of life in those living with a CCD post RH stroke that is characterised by impaired social cognition.

Proposition 3.1.: People with social cognition impairment post RH stroke will experience social network change evident in a reduction of the size of the network and the frequency of contact with network members.

Proposition 3.2.: Relationships will change following a RH stroke, and with greater frequency in the presence of a more severe social cognition impairment.

Proposition 3.3.: Valued roles will be lost in the presence of social cognition impairment post RH stroke and where valued roles are lost a greater reduction in quality of life will be reported.

Thesis significance

The preceding scene setting introduction, to be further elaborated in Chapter 2, illustrates that despite available literature on the link between social participation changes and altered quality of life post stroke, relatively few studies have explored the impact that cognitive or communication changes post stroke have on social participation. People living with CCD secondary to a RH stroke present with communication strengths and challenges that are uniquely different from aphasia, which may in turn create different facilitators and barriers to participation. What remains largely unknown is the impact that specific communication and cognitive impairments, personal and environmental factors may have on the life outcomes of people with RH stroke. As a leading cause of disability, stroke may result in physical difficulties that can restrict community access and re-integration. Altered communication and cognitive skills are less visible than physical impairments, but equally prevalent and impact an individual's ability to return to roles and relationships within their community. The majority of our daily activities and our interaction with others require communication. The social impact of reduced social participation in the presence of a CCD, for both the person with a stroke and their significant others, are yet to be determined.

It is anticipated that the findings of this research will add evidence to the literature that considers the social outcomes of people with communication disability following RH stroke. Exploration of factors that reflect a risk for social participation restriction may serve as a motivation for the increased access to communication focussed rehabilitation for people with RH stroke. The findings will lead to an improved understanding of the need to identify people who may require rehabilitation and community-based support to facilitate return to social roles and relationships. Social isolation and unmet social communication needs hold potential consequences for health outcomes and health care costs and may influence perceptions of quality of life (Uchino, 2006). The findings will lead to an improved understanding of the interplay between CCD, unmet social participation needs and perceptions of quality of life, which will assist those involved in service provision for people with stroke and those within their social networks.

Thesis structure

This thesis contains seven chapters that reflect a process of exploring facilitators and barriers to social participation for people who have a CCD following a RH stroke. This is a thesis by publication, however additional traditional chapters are included to provide an overview of the topic area (Chapter Two), methods (Chapter Three), and final synthesis of findings and recommendations (Chapter Seven). Chapters Four and Five contain papers that have been published, while Chapter six contains content that is currently being prepared for publication. The published content has been minimally altered to be in line with the formatting used in the remainder of the thesis. Linking introductory and concluding statements are offered to improve continuity of content and to ensure that the thesis conveys a coherent account of findings. To avoid duplication, references are not provided at the end of each chapter, but rather compiled as a comprehensive list in the reference section.

- *Chapter Two* provides an overview of literature with direct relevance to this research. Current knowledge about social participation restrictions post RH stroke is outlined. Information pertaining to the potential impact of a communication impairment, including where social cognition impairment is present, on roles and relationships then leads on to a review of social network change and perceived quality of life in those with communication impairments post stroke.
- *Chapter Three* outlines the methodology and rationale for the study design. Reasons for data collection tool selection are related back to the theoretical frameworks that influenced the research and overall research objective.
- *Chapter Four* presents a publication that addresses aim one, relating to the nature and extent of social participation change reported by people with RH stroke and proxies. The chapter is concluded with questions that emerged related to the possibility of predicting social participation change and the significance of such change, which are addressed in Chapters Five and Six.
- *Chapter Five* commences with an overview of two studies that together address aim 2 of this research. The first study represents a publication that explored potential risk factors for social isolation, present in people with RH stroke, compared to people with aphasia. The second study, yet to be submitted for publication, considered feasibility of use of acute-stage screening tools to identify risk for future social participation change in those with RH stroke. The chapter is concluded with the contributions that the two related studies made to

the overall objective of this thesis, followed by questions that then required further exploration in Chapter Six.

- *Chapter Six* presents an exploration of three propositional statements based on data gathered from seven cases of people with social cognition impairment following RH stroke and significant others (proxy-participants). The propositional statements allow for an exploration of the significance or impact of social participation change on maintenance of relationships, social roles and social networks as well as on perceptions of quality of life.
- *Chapter Seven* provides a synthesis of key findings followed by the implications of the findings for clinical practice and future research.

Direct quotations from participant and proxy interviews are offered throughout the thesis to bring the experience of engaging in social roles and relationships to the forefront. All participants and proxies are de-identified and pseudonyms are used instead of actual names.

Chapter 2

Overview of the Literature

“I just cannot bear the noise in the background and people talking over each other. I can’t understand a thing they say. I come from a big family and we have lots of noisy parties, but you turn yourself away from invitations ... I don’t like laying into the little ones, it is not their fault that they are noisy. Now I will go visit my mother when she is alone and see people one on one. I used to love the club, but the noise keeps me away and my mates don’t get it they just think I’m difficult not that they would ask me what is going on either.”

(59-year-old male participant, unable to maintain his relationship with a partner nor return to employment post stroke, mild CCD, MMSE: 30/30, 28 days of in-patient rehabilitation)

This chapter provides an overview of current literature pertaining to social participation, in particular related to people with a communication impairment secondary to stroke. Firstly, social participation, as conceptualised within this body of research, is defined followed by an overview of the impact of social participation restrictions. The current paucity of literature related to social participation in those with RH stroke is presented to support the need for the current research.

Social Participation

Social participation defined

The term participation was described within the International Classification of Functioning, Disability and Health (ICF) as involvement in a life situation (WHO, 2001). The term participation has been used extensively in the literature to explore a range of concepts from functional capacity (activity), to performance (participation), and to physical access restriction within roles and contexts that may or may not involve interaction with others. The concept of social participation is not clearly defined in the literature and used interchangeably with social integration, community engagement, participation and community (re)integration. These different terms are not always conceptualised in research and a range of measures are used that may relate to different underlying concepts under exploration (Piškur et al., 2014). Concepts related to productivity, independence in performance of activities and relationships have been used to quantify levels of community reintegration. Community reintegration has been described as a process of returning to live within one's community following hospitalisation, which can be considered a distinct rehabilitation phase (Salzer, 2006).

This thesis and research use the term social participation as defined by Levasseur and colleagues (Levasseur, Richard, Gauvin, & Raymond, 2010) as the aims of the research are not related to a particular phase of rehabilitation, nor on functional capacity related to solitary activities but rather on inter-personal interactions. Levasseur and colleagues (Levasseur et al., 2010), identified 43 different definitions for social participation following a systematic review of literature, with most definitions including a person engaged in activities that involve others. Following the review, social participation was defined as a person's involvement in activities that provide interaction with others in society or the community (Levasseur et al., 2010).

The significance of social participation restriction post stroke

Altered social participation can lead to feelings of social isolation and can negatively affect both the person who has sustained a stroke as well as people within their social network (Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000). Change over time in social networks is one way to explore the process of involuntary participation restriction, and social isolation post stroke. Social networks of those living with stroke might be vulnerable to change in quantity (size) and content, or the ability to communicate and share activities. In one study, 64% of people with stroke reported a change in the frequency of contact with friends (Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002). Maintenance of group membership and social roles within these social networks may be challenging for those experiencing changed cognitive and communication ability. Positive gains in physical function, psychological resilience and overall perception of quality of life has been documented for those who have access to a large social network that offer interactions perceived to be supportive in nature (Hilari & Northcott, 2006; Hilari et al., 2010; Meijer, Kriek, Ihnenfeldt, & Vermeulen 2004).

Beyond the ability to maintain a social network, other factors also influence perceptions of social participation change, that being the extent of the restrictions on participation, loss of valued roles, and also difficulties maintaining relationships. The extent of restrictions on participation in social, recreational or vocational contexts has been found to be a strong predictor of health-related quality of life (QoL). It is particularly changes in ability to participate in roles that are highly valued by the individual, that is predictive of reduced self-reported quality of life (Haley, Roth, Kissela, Perkins, & Howard, 2011; Kersten, 2002).

The importance of relationships in maintaining satisfaction with QoL following stroke emerged as a key theme in a meta-synthesis of qualitative studies (Salter, Hellings, Foley, & Teasell, 2008). It was not merely having access to others that was important, but also the nature of the interactions. Relationships that were characterised by a shared understanding of what the person with stroke was experiencing, supported maintenance of the relationships and positively influenced perceptions of QoL.

Close friends or family members notice, and may themselves experience, increasing social isolation and are more inclined to attribute the change to stroke-related impairments than the person living with a RH stroke who may lack insight into the effect of impairments (Pinquart & Sorensen, 2000). Reduced life satisfaction has thus also been reported by spouses of people with acquired brain injury, which was related to loss of companionship, changes in leisure and social activities and a reduction in social support (Coombs, 2007). No studies were found that

explored changes that occur to social networks, nor on what it means to be a family member of someone presenting with CCD secondary to a RH stroke.

Social participation and acquired brain injury

Reported outcomes following an acquired brain injury historically focussed on physical functioning and the ability to engage in activities that are essential for self-care. A change in measuring outcomes from purely considering physical recovery to success in social participation and improved perceptions of QoL is now increasingly found in the literature. A broadening understanding of what encompasses the process of returning to community activities and roles post acquired brain injury (traumatic brain injury and stroke) have resulted in research reporting on factors as diverse as vocational participation, ability to perform activities of daily living and maintenance of social network (Novack, Bush, Meythaler, & Canupp, 2001; Willemse-van Son, Ribbers, Hop, & Stam, 2009; Winkler, Unsworth, & Sloan, 2006).

Changes to occupational or social activities and roles, together with restrictions to community access related to physical impairment, result in a reduction in social participation for many people. Fifty-three percent of people living with stroke report not having a meaningful social, recreational or occupational activity to fill the day, compared with 16% of aged-matched controls (Baumann, Couffignal, Le Bihan, & Chau, 2012).

A relatively large body of literature is available on social participation post stroke and traumatic brain injury in general, however few researchers have explored this concept from the perspective of someone living with an acquired communication impairment, partly as the presence of a communication disorder often results in exclusion from research samples. In the field of speech pathology, a small number of studies have considered social participation following a stroke for those with a change in communication ability, such as the description of social participation change for those with dysarthria (Brady, Clark, Dickson, Paton, & Barbour, 2011). An acquired language impairment has been shown to negatively influence social participation in a review of 18 articles (1960–2005) about participation in working age persons with aphasia (Dalemans, De Witte, Beurskens, Van Den Heuvel, & Wade, 2010).

The social participation outcome for people with aphasia (PWA) has been researched most extensively compared to other acquired communication impairments (Cruice, Worrall, & Hickson, 2006; Desrosiers et al., 2006; Le Dorze, Salois-Bellerose, Alepins, Croteau, & Hallé,

2014). Aphasia can result in restrictions in comprehension and production of language across written, auditory, verbal and gestural domains. Interpersonal relationships and social participation changed for those with aphasia, both in terms of frequency of contact with others and satisfaction with social relationships (Dalemans et al., 2010). With regards to frequency of engaging in communication-based activities, people with aphasia have fewer telephone conversations, and attend fewer social activities than aged matched controls without aphasia (Davidson, Worrall, & Hickson, 2003).

In addition to reduced quantity of communication activities, smaller social networks and fewer friends have also been identified in those with aphasia (Cruice et al., 2006; Hilari & Northcott, 2006). It is not only the size and frequency of contact with the social network that is affected, people with aphasia also report lower satisfaction with social networks and lower QoL than those without communication impairment following a stroke, which was present even when controlling for physical mobility (Hilari, 2011). Research indicate, that an interplay between quantity and quality of networks can determine physical and mental health outcomes (Antonucci, Ajrouch, & Birditt, 2014).

Cruice and colleagues (2006) encourage speech pathologists to develop an understanding of their clients' social participation needs and to include goals in rehabilitation that would support people with acquired communication impairments to maintain relationships. When health care professionals are not aware of, or minimise the less visible consequences of stroke and the impact of these on participation, it has been found to negatively impact on the sense of well-being in people living with stroke (Arntzen, 2015). The impact of social participation restriction on QoL makes successful community reintegration and relationship maintenance crucial goals of rehabilitation (Hilari & Northcott, 2006).

Social participation and right hemisphere stroke

Much less is known about social participation in those with a CCD secondary to a RH stroke. The available evidence was explored systematically. Published articles and reviews were searched in SCOPUS, CINAHL, and MEDLINE using the keywords "*stroke OR cerebrovascular accident OR cva*", "*social participation OR social engagement OR community integration*", combined with the Boolean operator *AND*, lastly, the limiter "right hemisphere" were used. The search was further limited to peer-reviewed papers

published electronically, in English, from March 2006 – March 2018. To avoid oversight of early seminal studies, secondary hand-searching reference lists of the final articles was employed, which generated no additional articles that met inclusion for this review. The search yielded 94 unique articles after duplicates were removed, as outlined in Figure 2.1.

Figure 2.1. Search strategy

Titles and abstracts were firstly considered, followed by full text reading in a screening process based on study selection criteria. Inclusion criteria were: i) adult participants with a diagnosis of RH stroke, ii) reporting on social participation outcomes, including participating in social roles, relationships and social networks. Studies were excluded if they i) reported social participation outcomes in aggregate irrespective of stroke location, ii) reported participation outcomes related to physical access to the community or engagement in solitary activities such as driving.

After 70 of the 94 abstracts were excluded as not meeting one or more of the selection criteria or focussing solely on the impact of physical mobility and upper limb functioning on community access, 24 articles remained. Phase two involved reading the remaining articles in full. A further 18 were excluded as they did not include participants with RH stroke or if they were included in the sample then their participation outcomes were reported as group data with those of participants with left hemispheric or cerebellar strokes. Only two articles described findings for RH stroke participants exclusively. A summary of the six articles that met the search criteria is provided in Table 2.1 and discussed below.

Overview of findings. The six articles that met the inclusion criteria of this search, provide preliminary insights into social participation for those with a RH stroke. All six studies addressed a clearly focused issue, with three employing quantitative methodology and three were qualitative studies. Purposeful sampling was used appropriately in the qualitative studies. Participants age (ranging from 36 to 86 years of age across articles), gender and time post stroke onset (ranging from one to 12 years across the articles) were reported.

Measures of social participation. The three studies (Cooper, Phillips, Johnston, Radlak, Hamilton, & McLeod, 2014; Hamzat, Olaleye & Akinwumi, 2014; Mackenzie et al., 2001) that made use of objective measures of social participation are described in Table 2.1. Measures were included to explore aspects such as numbers of social contacts, frequency of social activities and satisfaction with social function. Each of the studies utilised a different measure as summarised here. The Modified Functional Limitation Profile (mFLP: Pollard & Johnston, 2001), a 136 item scale items that relate to mobility, household, recreation, social interaction and work. The WHO-QoL BREF was the second measure allowing for gathering of information about QoL based on participants' perceptions of satisfaction with their physical health, psychological well-being, social relationships and functioning in the environment. Hamzat and colleagues (2014) used the Community Integration Questionnaire (CIQ)(Pollard & Johnston, 2001); and the London Handicap Scale (LHS)(Harwood et al., 1994) which asked participants to respond to questions about physical independence, social integration, economic self-sufficiency, mobility and orientation. Mackenzie and colleagues (Mackenzie et al., 2001) used the Communicative Effectiveness Index (CETI: Lomas et al., 1989) which allowed for quantifiable reporting on frequency of communication activity in real life settings as experienced at the time of completion of the CETI.

Table 2.1:

Summary of literature on social participation post right hemisphere stroke

Study	Participants	Measure of social participation	Findings
Arntzen, 2015	Nine participants with stroke and 13 family members. Exclusion criteria: severe cognitive or communication impairment. 39 – 72 years of age, 6 male, 6 months to 12 years post stroke. Six of nine participants with a RH stroke.	Self- and proxy-report using repeated in-depth interviews	Long-term stroke recovery trajectory is characterised by tensions between the lived body, participation and sense of self. Well-being and progress occurred when participants moved towards renewed relationships which required repositioning of roles. Participant-proxy dyads with RH stroke reported barriers to participation related to reduced initiation, physical impairments, difficulties with communication in noisy and group conversations, and ongoing need for strategies and aids to improve orientation and organisation.
Cooper, 2014	28 participants: 17 male, mean age 67.7 ± 9.1 years, mean time post stroke 413 ± 30.9 days, without pre-existing neurological or psychological conditions, without severe cognitive impairment. Ten of 28 participants with RH stroke. 40 age-matched controls.	Self-report using mFLP ¹ WHO-QoL BREF ²	Those with stroke (irrespective of lesion location) were significantly impaired in emotion perception compared to controls. Impairment in emotion perception found in those with stroke was significantly correlated with the mFLP Social Participation subscale and the Psychological domain of the WHO-QoL BREF.
Egbert, 2006	12 participants with RH stroke recruited through community groups: 10 male, mean age 60.7 ± 10.1 years, at least 6 months post stroke. A further 13 participants were caregivers of the RH participants.	Self- and proxy-report using semi structured interviews	Challenges were identified relating to physical impairments, cognitive-perceptual changes, emotional difficulties, activities of daily living, relationships, vocation, and financial circumstances. The degree of social participation appeared to be less dependent on level of disability than on the presence of external formal and informal resources such as social support from friends and family.

Hamzat, 2014	52 female participants: mean age 56.6 ± 9.9 years, mean time post stroke 26 months. 28 participants with a right hemisphere stroke, 24 with a left hemisphere lesion.	Self-report using the CIQ ³ and LHS ⁴	Functional ability was significantly correlated to social participation restriction irrespective of stroke lesion location. Difficulties were reported in community reintegration (return to roles) irrespective of stroke lesion location.
Mackenzie, 2001	35 participants with a right hemisphere stroke: 16 male, mean age 66 ± 11.1 years.	Self- and proxy-report using the CETI ⁵	25% of family members reported impairments in conversation participation for those with a diagnosed RH CCD.
Taule, 2014	Eight participants with mild stroke, 45 – 80 years of age. Three of eight participants with a RH stroke	Self-report using semi-structured interviews	Activities and participation were experienced as meaningful when prior roles and relationships could be maintained and when bodily functions did not create a barrier to participation. Participants with RH stroke reported challenges in maintaining roles and relationships. Changes in emotional reactions and therefore behaviour was one potential influence on relationship strain.

¹ mFLP = The Modified Functional Limitation Profile (Pollard & Johnston, 2001). ² WHO-QoL BREF = The World Health Organization Quality-of-Life measure (Organization, 1998). ³CIQ = Community Integration Questionnaires (Willer, 1993). ⁴LHS = The London Handicap Scale (Harwood, Rogers, Dickinson, & Ebrahim, 1994). ⁵CETI = Communicative Effectiveness Index (Lomas et al., 1989).

reporting on frequency of communication activity in real life settings as experienced at the time of completion of the CETI. Participants were asked about their degree of participation or satisfaction with participation as they were experiencing it at the time of the assessment. The reported level of participation is then compared to normative samples. The use of only objective measures that report current levels of participation may not adequately reveal changes in social participation that occurs following a particular event such as stroke. Measuring amount of participation, for example in terms of frequency of engagement in roles, also brings into question how norms are determined and if more contact equates to better social participation outcomes. A critique of objective measures that do not consider change in participation is offered in Chapter three. Social participation restrictions were reported by the remaining three studies, through subjective measures taking into consideration self and other reports (Arntzen, Borg, & Hamran, 2015; Egbert, et al., 2006; Taule & Raheim, 2014). Arntzen and colleagues (2015) conducted a longitudinal investigation into recovery following stroke, utilising in-depth interviews conducted with participants with stroke and their proxies.

Social participation outcomes. Changes in social participation were reported by all six reviewed papers. Mackenzie and colleagues (Mackenzie et al., 2001) explored what impact a RH stroke has on everyday communication function by requesting family members to provide information on communication activities in daily life. Sixty-six percent of the 35 participants presented with a CCD as determined by a clinical communication battery consisting of tasks requiring discourse comprehension and production, metaphor and synonym as well as inferred meaning interpretations. These 23 participants then comprised the experimental group for whom family members completed the CETI. An additional five items were included to the CETI based on clinical experiences of the research team with this population. The items related to following directions, making clear who or what he/she is talking about, appreciating a joke or humorous story, getting and sticking to the point in conversations and interpreting someone's feelings and emotions. Of significance to the question of social participation was that 25% of the family members reported persisting deficits in conversational participation in their family members with RH CCD. Mackenzie and colleagues (Mackenzie et al., 2001) provided greater detail about their participant characteristics than other studies, including age, gender, occupation, stroke type and vascular supply affected. In addition, only people who

were diagnosed with a CCD were included, thus strengthening interpretation of the likely prevalence of social participation restrictions in this population.

Taule and Raheim (2014) explored the meanings that eight participants with mild stroke attributed to activities and participation. Three participants were identified as having a RH stroke. One man with RH stroke in his fifties reported participation challenges despite good physical recovery, that he was slower in completing vocational tasks, that more concentration was required, and that he was not able to return to driving. Changes occurring in relationships post onset of stroke was another theme that emerged. One participant with RH stroke, reported a particular challenge in maintaining the relationship with his grandson. Another, noted that he was aware of marital role change, and was concerned that he was a burden for his wife. A potential challenge to relationship maintenance emerged in the words of a man with RH stroke who describe himself as a nicer person prior to the stroke, and that he was more prone to anger and impatience since the stroke. Impaired social capacity was a term used to capture isolation that participants were reporting, which was related to reduced physical and emotional access to others, in addition to altered behaviour and emotions in the person with RH stroke.

Hamzat, Olaleye and Akinwumi (2014) aimed to explore the relationship between functional ability and participation restriction of female stroke survivors, including those with a RH stroke. Of the 52 participants, 28 were described as presenting with an affected left side, which is assumed by this reviewer to indicate a RH stroke. The participants in this study with a RH stroke presented with significantly greater functional ability (FIM score), but comparable levels of lower restriction in participation (LHS score) and better community integration (CIQ score) than those with a LH stroke. The researchers provided a hypothesis as to why functional ability differences emerge, which they relate to limb dominance, that is, those with a RH lesion would retain the use of their right hand which was dominant for 51 of the 52 participants. It was also reported that a significant correlation between functional ability and community reintegration as well as participation restriction respectively was found in both RH and LH participants. Participant age and stroke type did not account for differences in this study. Unfortunately, the presence or absence of CCD was not identified. The authors state that more physically able participants showed greater community reintegration and fewer participation restrictions; however, the data for this was not presented. This relationship was not supported by other studies included in this review as described below.

Causes or risk factors associated with reduced social participation. A key finding from three studies examining potential causative factors, was that reduced social participation in those with a RH stroke did not seem to be related to level of activity limitation (Cooper et al., 2014; Egbert, 2006; Hamzat et al., 2014). Only one participant in a study by Arntzen and colleagues (2015) noted that participation in roles outside of the home was restricted as he required his wife to be present when accessing the community due to physical support needs. Beyond physical support needs, others noted barrier to participation caused by cognitive and/or communication impairments. For one man with RH stroke environmental cues and prospective memory aids were needed. Another woman with RH stroke reported that she participates in her vocational and social settings through highly structured procedures and a number of strategies. Despite the use of such techniques she still reported avoidance of contexts that required interacting with groups of people and in noisy environments.

Cooper and colleagues (2014) strived to determine the extent to which difficulties in emotion perception following stroke were associated with social participation outcome and activity limitation. The presence of difficulties with emotion perception was determined across visual, auditory and multimodal perceptual means. The Facial Expression of Emotion task (Young, Perrett, Calder, Sprengelmeyer, & Ekman, 2002) required visual recognition of emotions from facial expressions; auditory emotion perception was assessed using the Florida Affect Battery (Blonder, Bowers, & Heilman, 1998); whereas The Awareness of Social Inference Test (McDonald, Flanagan, Rollins, & Kinch, 2003) served as a multimodal emotion perception task. Results indicated that participants with stroke, irrespective of lesion location, were significantly impaired in emotion perception compared to controls. Impaired emotion perception was significantly correlated with lower social participation on the mFLP and reduced psychological quality of life on the WHOQoL-BREF. This significant correlation remained even after controlling for activity limitations, thus indicating that lower social participation in this sample group was unlikely due to activity limitations. Unfortunately, some results were reported for all stroke participants in aggregate, thus not allowing for detailed comparison of outcomes relative to lesion locations. In addition, apart from groups being defined as left hemisphere, right hemisphere and bilateral, insufficient information is provided about the participants to allow for exploration of differences based on lesion location (i.e. cortical or subcortical), nor about presence or absence of communication impairment. A further concern is the exclusive use of subjective outcomes based on self-report about social

participation and an assumption that what was reported at the time of the assessment was different from pre-stroke participation. Poor awareness of physical or cognitive-communication impairments or the likely functional impact of such impairments on the ability to engage in activities has been described as a characteristic feature of those with a RH stroke (Dai et al., 2014). The results do however present initial support to the hypothesis that those with a stroke including those with damage to the RH, and where emotional perception is altered, are at risk for social participation restrictions.

Factors that might promote social participation. Egbert, Koch, Coeling and Ayers (2006) implemented a qualitative research design in which the role of social support in the family and community integration of RH stroke survivors was described. The authors acknowledged the limited existing research that addresses the impact of a RH on the ability to integrate back into previous life roles. A stated aim was to identify communicative processes by which social support could assist people with RH stroke. To explore this topic broadly, and since limited existing evidence was available to narrow assessment areas and questions, an appropriate use of open-ended interviews was implemented. Very limited information was provided about the participants, who were described as people who identified themselves as someone who had a stroke involving the RH of the brain without any further information on stroke lesion location or type. As the authors specifically wanted to explore the impact of changes in communication ability following a RH stroke it is a limitation that the presence of a CCD was not determined during participant selection beyond self-reports. Caregiver views on social participation allowed for a broader understanding of the topic, however as the views of caregivers and stroke participants were combined it was not clear to what extent differences in perceptions of social participation were present. The majority of family members of those with a RH stroke rated the level of communication impairment as low. However, Mackenzie (Mackenzie et al., 2001) cautions that low levels of impairment may be sufficient to create significant changes in relationships, vocational and social roles. This was illustrated by similar return to work rates across those with right and left hemisphere lesions despite better overall communication outcomes for those with a RH stroke (Wozniak et al., 1999).

Themes of the supportive influence of family members and the importance of relationship maintenance were also reported by Arntzen and colleagues (2015). The emerging phenomenon, for all participants in their study (six of nine participants presented with a RH stroke), was that the trajectory of stroke recovery requires a struggle to overcome tensions between the lived

body, participation in everyday life and sense of self. The participants experienced progress and well-being when they were moving towards renewed relationships, which required repositioning of roles when participating in everyday life contexts. One challenge reported by a daughter about her father with RH stroke was his lack of initiative and tendency to adopt a passive attitude to engagement in life activities and roles. The outcome for them and others in this study was that relatives tended to take over tasks and roles. For one wife of a man with RH stroke this resulted in relationship role change, with her feeling more like a mother than wife. A theme that emerged for all participants was that a positive sense of self was more likely when opportunities were created or sought for activities within and outside the home. The facilitating role of a family member in this process was noted.

Methodological limitations present in some of these studies, in particular the lack of information on the presence or absence of a diagnosed CCD, limits the conclusions and significance of their findings in terms of the aims of this thesis. The inclusion of participants who were between one, and 12 years post stroke creates challenges in determining if social participation change was related directly to the onset of stroke, or due to other life events and stages. Changes in life roles with advancing age, or even changes in residential settings, may in and of itself alter social network access and extent of social participation. The reviewed literature provide insight into possible facilitators of social participation or conversely, barriers to participation that warrants elaboration. Cooper et al. (2014) was the only study reviewed that linked social participation to a particular aspect of the communication impairment, namely emotion perception. The influence of specific aspects of CCD on the ability of people with a RH stroke to resume and maintain social roles and relationships, requires further exploration.

Predictors of social participation

Numerous researchers have endeavoured to identify factors that are predictive of rehabilitation outcomes and success of community re-integration following acquired brain injury (stroke and traumatic brain injury). These endeavours are important since predictive models of functional outcomes may influence access to rehabilitation, which in turn has implications for service providers (efficiency of care) as well as patients (optimal care). Despite obvious benefits from the use of predictive or prognostic models of outcomes post stroke, a number of factors make the application of a single predictive model to people with stroke, irrespective of lesion location and impairments, challenging. Outcomes following a stroke are diverse, and likely prognostic

factors are multi-factorial, influenced by person-dependent variables such as age; environmental factors such as access to support; and by the location of the stroke and the nature and severity of concomitant impairments (Kwakkel & Kollen, 2013). There are also concerns that measures of capacity to perform an activity, administered during hospital admissions, may not be reflective of performance during real life tasks following discharge, thus questioning the utility of predictive models based purely on activity level measures. Change occurs over time following a stroke which motivates a longitudinal exploration of social participation. Despite these challenges prognostic models can and have been shown to provide valid estimates of risk when applied to people with similar characteristics (Jette, Keysor, Coster, Ni, & Haley, 2005). A number of factors have emerged in the stroke and TBI literature that could serve a predictive purpose in identifying people at risk for social participation restrictions.

Similarities and differences emerge when comparing community integration following a TBI with community integration following a stroke (Salter, Foley, Jutai, & Teasell, 2007). In the TBI population, male gender, older age (Fleming, Hassell & Chan, 1999; Harrison-Felix, Mann, Dijkers, Englander, & Kreutzer, 1998), being a member of a minority group (Hart, Whyte, Polansky, Kersey-Matusiak, & Fidler-Sheppard, 2005), and unemployment at the time of the injury (Harrison-Felix et al., 1998; Wagner, Hammond, Sasser, Wiercisiewski, & Norton, 2000) have been found to be prognostic socio-demographic factors of lower community integration or participation levels. Longer hospitalisation (Fleming, 1999), more severe injury (Winkler et al., 2006) impaired cognition (Fleming, 1999; Novack et al., 2001) discharge from acute care to a nursing home, and lower post-acute functional outcome scores on measures such as the Functional Independent Measure (FIM)(Rosenthal et al., 1996; Sander, Kreutzer, Rosenthal, Delmonico, & Young, 1996) have been identified as clinical factors, that may predict challenges to participating in community roles and activities.

Personal variables. Following a stroke, personal variables including older age (Lo, Cheng, & Wong, 2008), living arrangements pre-stroke, in particular pre-stroke residential care (Chau, Thompson, Twinn, Chang, & Woo 2009; Harwood, Pound & Ebrahim, 1997), unemployed at time of stroke (Baumann et al., 2012), recent divorce or separation (Baumann et al., 2012), not having access to a social network (Hilari et al., 2010) and being part of a lower socio-economic group pre-stroke were found to be significantly related to participation levels.

In contrast to the literature on TBI, female gender was associated with higher levels of participation restriction following a stroke (Di Carlo et al., 2003). Age emerged as a highly significant predictor of functional outcome in 14,256 people sampled in the Australian Stroke Unit Registry. A lower age was more likely to increase positive physical outcomes independent of stroke severity and characteristics, however such positive outcomes were not always found beyond physical outcomes as younger people with stroke may experience greater changes to relationship and vocational circumstances (Desrosiers et al., 2006). In addition to age, relationship status (i.e., presence of a partner) has been identified as a key variable that serves as a facilitator of increased social participation in those with the acquired communication disorder of aphasia (Code, 2003).

Clinical variables. Impairment level variables that have been linked to challenges in returning to community-based roles following a stroke include: the severity of physical impairment (D'Alisa, Baudo, Mauro, & Miscio, 2005), impaired cognition (Baumann et al., 2012) and lower post-acute functional outcome scores as per the FIM (D'Alisa et al., 2005; Sarno, 1997). The influence of stroke lesion location is not as easy to determine from the literature. Relatively few studies have compared different outcomes in relation to lesion location, and results tend to be reported in aggregate, where post stroke consequences are described irrespective of lesion location. A study by Ween and colleagues found that stroke lesion site, and controlling for stroke type, influenced FIM change, with those with RH lesions achieving lower gains in FIM scores than those with LH lesions (Ween, Alexander, D'Esposito & Roberts 1996). People with a RH stroke were reported to have poorer participation outcomes than those with LH stroke, however, potential reasons for this difference was not clearly elaborated and it was not indicated if participants in the RH group presented with a cognitive-communication impairment.

Previous research has reported a relationship between the ability to complete functional activities during rehabilitation (as measured on the FIM) and participation in community activities (Dalemans et al., 2010). It is easy to assume that this is likely due to the presence of more severe physical impairments, however a number of studies have found that social participation outcomes are influenced by other factors when the effect of physical ability has been controlled. It is not only the ability to mobilise and to perform activities of daily living but cognitive difficulties which may also predict ability to return to social roles. Information processing speed, anosognosia, working memory, cognitive flexibility and complex attention

have been shown to be significantly related to levels of engagement in activities and community integration (Hommel, Trabucco-Miguel, Joray, Naegele, Gonnet, & Jaillard, 2008; Vossell, Weiss, Eschenbeck, & Fink, 2011). Difficulties with social problem solving and inefficient discourse production, in particular time for completion of discourse tasks, have also been identified as prognostic of participation restrictions and as being strongly related to outcomes measured on the Community Integration Questionnaire – Social Integration (Hilari et al., 2010; Rath, Hennessy, & Leonard, 2003).

Communication impairments arising post stroke may also influence social participation (Le Dorze et al., 2014). In the field of Speech Pathology, studies have predominantly considered social participation for those with the acquired language impairment of aphasia, where the severity has been shown to be directly related to the extent of social participation restriction (Code, 2003; Barry & Douglas, 2000; Dalemans et al., 2010; Hilari et al., 2010; Howe, Worrall, & Hickson, 2008). Social participation outcomes for people with dysarthria have been reported in a study by Brady and colleagues (2011). A common theme across these studies is that stroke-related communication disorders negatively influence social participation with reported changes in frequency of contact with others and satisfaction with social relationships (Cruice et al., 2006; Brady et al., 2011; Dalemans, De Witte, Beurskens, Van Den Heuvel, & Wade, 2010). When looking beyond stroke to research on social participation following a TBI, communication impairments have also been demonstrated to be associated with a risk of reduced social participation (Struchen, Pappadis, Sander, Burrows, & Myszk, 2011).

Environmental variables. Both information environmental variables, such as social network access and community knowledge; as well as formal variables such as access to rehabilitation services have been shown to influence participation after a stroke (Rathe et al., 2003; Sarno, 1997). Dalemans and colleagues (Dalemans et al., 2010) found that environmental factors, such as greater knowledge of communication impairments within the community influence participation in persons living with a communication impairment (Howe et al., 2008). Knowledge about communication impairments also increase likely support options within vocational settings. The ability to return to vocational roles and engage in activities related to social participation has been shown to be dependent on factors such as workplace flexibility but also access to social support be that participation in those living with

aphasia (Le Dorze et al., 2014). Formal environmental support, such as having access to rehabilitation, has been shown to have a positive influence on future participation outcomes in a group of people with aphasia (Rath et al., 2003). Conversely, limited access to rehabilitation services post stroke have been identified as a barrier to social participation (Le Dorze et al., 2014). Social networks and interpersonal relationships that are considered supportive are other examples of informal environmental variables that influence participation, a relationship that has been described for people with aphasia (Le Dorze et al., 2014) as well as people with RH stroke (Arntzen et al., 2015; Egbert, 2006).

CCD Following RH Stroke

When considering aphasia, a language impairment arising predominantly from lesions in the left hemisphere, much has been reported historically, in popular media and through aphasia specific associations about the resulting communication difficulties. Systematic, scientific study is evident in historically documented cases dating back to the work of Paul Broca in 1861. This extended period of exploration of aphasia in terms of features and localisation, summarized in “the history of aphasia” by Prins and Bastiaanse (2006), has resulted in a significant body of evidence. Communication impairments that arise following RH stroke is a comparatively newer area of investigation and much remains to be explored in terms of patterns of impairment, relationship to lesion location, and about functional outcomes and intervention efficacy. It was only in the early 1960’s through the work of Eisenson, Critchley and Weinstein (Marien & Abutalebi, 2008) that the role of the RH in communication was identified, and interest grew in describing the unique areas of deficit.

Incidence

The incidence of CCD post RH stroke ranges from 50% to estimates of up to 80% in a sample of patients in a rehabilitation setting (Benton & Bryan, 1996; Joannette & Goulet, 1994). Following a chart audit of an in-patient rehabilitation unit in 2002, Blake et al (Blake et al., 2002) found that 96% of patients with RH stroke presented with at least one cognitive or communication deficit. Changes in communication specific areas of prosody, lexical-semantics, pragmatics and discourse has been reported to be as high as 78% (Ferré, 2009). Low scores on cognitive assessment tasks of attention, construction, reasoning and problem

solving have been reported in between 50 – 68% (Cherney, Halper, Kwasnica, Harvey, & Zhang, 2001). The incidence of cognitive deficits is important to consider as cognitive skills, in particular executive functions, support effective communication most notably during complex communication tasks. It is often in these more complex communication tasks where those with a RH stroke demonstrate changes in their communication ability and style. The considerable variance in prevalence estimates has been attributed to inconsistency in terminology, assessment practices, and sample selection (Brookshire & McNeil, 2014). Clinical caseload numbers estimate that around four people with RH stroke are seen by hospital based speech pathologists per month (range 2 – 8)(Blake, 2006) and that only 45% of those with RH stroke who are in rehabilitation settings, are being referred to speech pathology services (Blake et al., 2002). These referral numbers are surprisingly low considering the high incidence of CCD described above.

Characteristics

People with CCD present with different communication challenges compared to those living with aphasia. It has been said that people with aphasia communicate better than they speak, whereas those with RH CCD speak better than how they communicate. Myers continues to make the distinction between language and communication, “... speech and language do not represent the full measure of what we mean by communication. To communicate means more than to impart. It also means to participate ... these patients (with RH CCD) fail to participate (to communicate fully) despite their deceptively normal linguistic competence” (Myers, 1978, p. 49).

A combination of communication and neurocognitive deficits are documented post RH stroke (Côté, Payer, Giroux, & Joanne, 2007; Blake, 2011; Myers, 2001). Changes to interpersonal communication are often not related to deficits in access to and use of vocabulary and syntax, but rather considered to be consequences of underlying cognitive impairments such as changed perspective taking or theory of mind (ToM) and executive function skills which may result in poor interpretation of the extra-linguistic context (Abusamra, Côté, Joanne, & Ferreres, 2009). The most frequently reported communication difficulty observed by family members of people with a RH stroke, relates to their involvement during conversations that are fast paced and occurring amongst multiple communication partners (Mackenzie, 2001).

People who sustain a RH stroke are diverse in their cognitive-communication abilities, which has only relatively recently been explored according to distinct communication profiles (Côté et al., 2007; Blake et al., 2002). Communication deficits that emerge following a RH stroke can be described across lexical-semantics, discourse, prosody and pragmatics (Dara, Bang, Gottesman, & Hillis, 2014; Ferré, Ska, Lajoie, Bleau, & Joanne, 2011; Blake, 2006).

Firstly, impaired lexical-semantic skills may be evident during verbal fluency tasks, comprehension of complex sentence structures such as reversible sentences, and when interpreting figurative or abstract language such as novel metaphors (Bohrn, Altmann, & Jacobs, 2012; Varley, 1995). The lexical-semantic impairment is evident on tasks that require more complex lexical processing and is therefore likely reflecting a disruption of cognitive processes used in the manipulation of language (Varley, 1995).

Inefficient discourse comprehension and production is the second impaired communication domain and relates to deficiency in quantity and content. Content may be poorly organized without relevance to the topic. In terms of quantity, two patterns of discourse production are described, a hypo-responsive pattern in which a paucity of information is produced and a hyper-responsive pattern characterised by verbosity or an excess of information (Blake, 2006; Blake et al., 2002).

Thirdly, aprosodia refers to impairment in the comprehension and/or use of prosodic features of intensity, rate and pitch. Either or both of the two components of aprosodia, that being lexical or affective aprosodia may be impaired following a RH stroke making it difficult to distinguish between commands and questions or to interpret a speaker's emotional intent (Leon, 2005).

Pragmatics is the fourth communication domain that may be altered following a RH stroke. Pragmatics can be understood as the ongoing process of producing and understanding contextually based communication that occurs between communication partners and may require adaptation on the part of either or both to ensure that communication is effective. Based on interactional approaches as described by Perkins (2011), pragmatic ability is therefore dependent on cognitive, linguistic and sensorimotor processes that occur when people interact (Perkins, 2011).

Theoretical models

A number of theoretical models have been proposed to account for the difficulties found in those with RH stroke. Firstly, the *cognitive resource hypothesis* states that performance variability between domain-specific tasks and cognitively-demanding tasks, such as inferential reasoning required during a discourse comprehension task, is due to underlying deficits in attention and working memory (Monetta & Joannette, 2003). Secondly, the *coarse coding deficit hypothesis* proposes that the RH serves an important function in activating and maintaining distant word meanings (Beeman, 1993; Tompkins, Scharp, Meigh, & Fassbinder, 2008). Based on this theory, a coarse semantic coding deficit occurs and can be observed in reduced speed or accuracy of activation of particular features and meanings of words which in turn impacts on comprehension of implied information. Thirdly, the *suppression deficit hypothesis* similarly offers an explanation for comprehension difficulties during discourse, as it states that a range of interpretive possibilities are activated which should then be followed by a suppression mechanism of possibilities that do not fit given the broader context (Tompkins, Baumgaertner, Lehman, & Fassbinder, 2000). Comprehension difficulties according to this theory, are evident in tasks requiring inferential reasoning or interpretation of ambiguous language. Coarse coding could reduce the activation of particular meanings of words and suppression deficits could slow the mechanism that would exclude contextually irrelevant possibilities, which in turn requires the cognitive resource of attention. Lastly, the *social cognition deficit hypothesis* postulates that impaired comprehension, during discourse tasks, is based on an underlying impaired network involved in ToM, or the ability to understand and interpret thoughts, feelings and intentions of others (Brownell & Martino, 1998; Mildner, 2008). The theories add value to our understanding of underlying mechanisms that may account for impairments observed in those with RH CCD, however, little empirical study has been done to compare the utility of theories in predicting participation outcomes.

Current literature describing CCD present post RH stroke provide insights into impairment level changes pertaining to either communication or cognition. Beyond the level of impairment less is known about performance of everyday communication-based activities and the long-term impact on participation in social activities and roles. These everyday communication-based activities occur within everyday interpersonal situations which might be particularly vulnerable in the presence of social cognition impairment. The social cognition deficit hypothesis is of particular interest to this thesis as a relationship between impaired social cognition and social participation will be explored.

Social Cognition and RH Stroke

Lesions involving the right side of the brain have been shown to result in impairments that are very different to those that occur following a stroke in the left hemisphere. In particular it is the presence of cognitive deficits related to executive function, visual processing and attention, and non-linguistic aspects of communication such as interpretation of emotion in facial expressions and aprosodia that occurs in some with a RH stroke. Beyond the paper by Cooper and colleagues that reported on impaired emotion interpretation, the potential influence of the inability to interpret other people's thoughts, feelings and intentions on social participation post RH stroke is not known. Evidence in the field of social cognition following traumatic brain injury supports the notion that poor emotion perception and social inferential reasoning is of functional significance and a source of interpersonal difficulty (McDonald, Honan, Kelly, Byom, & Rushby, 2014).

Social cognition is our ability to pay attention to and interpret the interpersonal cues that are essential to our ability to make sense of and predict other people's behaviour and also our ability to communicate effectively (McDonald et al., 2014). Social functioning and communication-based participation are dependent on social cognition, making this an important concept to explore further within the current program of research (Baron-Cohen, Tager-Flusberg, & Cohen, 2000; Malle, Moses, & Baldwin 2001). Social cognition has been described as consisting of two components, that of emotional processing including emotion perception and empathy, and ToM (Shamay-Tsoory, Tibi-Elhanany, & Aharon-Peretz, 2006). Impairments in affect recognition from facial expressions have been documented in those with RH stroke, and found to relate to reduced interpersonal communication and relationship satisfaction (Borod, Bloom, Brickman, Nakhutina, & Curko, 2002; Brozgold et al., 1998).

It is not only the recognition and expression of emotion in facial expressions that may change following a RH stroke but also the ability to interpret emotional and linguistic intentions based on prosodic features of speech (Dara et al., 2014). Receptive aprosodia has been identified as one underlying cause of deficits in social cognition (Macrae & Bodenhausen, 2000). This link between emotion perception and social functioning was shown by McDonald and colleagues who found that emotion perception deficits were linked to social functioning difficulties in 21 adults with TBI (McDonald et al., 2014). Difficulty on the Awareness of Social Inference Test (TASIT), an ecologically valid TOM assessment, was evident in their sample when comments were not explicitly or literally stated and when a mismatch was present

between words and non-verbal expressions of emotions across both first-order ToM tasks (judging speakers emotions and beliefs) and second-order ToM tasks (what a speaker intended their conversational partners to believe)(McDonald & Flanagan, 2004). ToM is a developmental skill that allows us to draw inferences about other people's mental states or what they are thinking, feeling and planning to do. ToM can be subdivided into a cognitive component which relates to our inferential reasoning about other peoples' beliefs, motivations and thoughts; and an affective or empathic component which is our ability to understand the feelings of other people (Coricelli, 2005). Deficits in this mentalizing process have been found in adults with schizophrenia as well as in adults with damage to brain regions, generally involving the temporo-parietal junction, amygdalae, orbital frontal cortex and medial frontal lobes (Frith & Frith, 2003). Further refinement of functions within these brain areas have shown that different areas result in differences between the ability to inhibit one's own perspective versus inferring someone else's perspective (Samson, Apperly, Kathirgamanathan, & Humphreys, 2005; Vogeley et al., 2001). Lesions in the right temporo-parietal junction have been linked to impaired ability to attribute mental states to others whereas lesions to right inferior frontal gyrus have been implicated in deficits in inhibiting one's own perspective during ToM tasks (Happé, Brownell, & Winner, 1999; Saxe & Wexler, 2005; Vogeley et al., 2001).

It is acknowledged that debate continues in the literature as to the nature of social cognition impairment in those with RH stroke and whether difficulties observed are purely related to cognitive deficits such as impaired working memory or facial emotional recognition. Determining the presence and nature of ToM abilities continues to be an area of disagreement in the literature as different assessment approaches are likely requiring different cognitive mechanisms (Ahmed & Miller, 2011). Examples include false belief tasks, interpretation of visual images and sequences, faux pax tasks requiring story interpretations, interpretation of emotional facial expressions in photographs and the interpretation of emotion through prosodic features of speech (Apperly, Samson, Chiavarino, Bickerton, & Humphreys, 2007). It is the high cognitive and language demand inherent in some of these tasks that have received the greatest criticism, as deficits may reflect underlying restricted working memory rather than deficits in assigning a ToM (Apperly et al., 2007; Tompkins et al., 2008).

A number of factors emerged following a review of the literature that warrant exploration within this thesis. The factors are hypothesised to create a risk or to serve a protective function for social participation in people with RH stroke, namely: impairment related variables of

cognition (presence of impairment on global measure of cognition, executive function task, social cognition) and communication (presence of CCD), as well as environmental variables of formal (access to rehabilitation) and informal support (social network characteristics).

The aims of this thesis were influenced by current gaps in the evidence as reviewed in this chapter, in particular the need to explore the variable influence of CCD on social participation. In Aim 1 the hypothesis that social participation change would be greater in people with a CCD compared to people without a communication impairment following RH stroke was explored. Furthermore, Aim 2 considers impaired cognition in relation to future social participation change in people with RH stroke. A number of hypotheses were tested in Aim 3 related to the significance of social participation change for a group of people with CCD characterised by social cognition impairment. This, more focussed exploration of purposefully selected participants would add evidence for those concerned with the long-term outcomes of people with CCD post RH stroke.

Chapter 3

Overview of Aims and Methods

“The doctor said I was doing very well and I only stayed at the hospital for two days. But when I got home I started to realise that I wasn’t the same. I came back to my own house without needing help, I live with my husband. If anything, the change has been in me, I seem to stay away from close friends more and more. Struggle with the way they look at me. My speech was a bit slurred but not much and I thought I could understand what I heard and read pretty well. But put me in a group of people and I struggle to follow the conversation, which was a big surprise for me as everyone said that I was fine.”

(62-year-old married participant, unable to return to employment post stroke, no CCD diagnosed, MMSE: 28/30, no rehabilitation)

Chapter two reviewed the literature on social participation in the presence of communication impairment, and highlighted characteristics of CCD post RH stroke that may impact social participation. As communication underpins our interactions with others within our community, be that at home or at work, it is important to explore this dimension as a variable that can influence successful social participation following a RH stroke.

Chapter three presents theoretical frameworks and other considerations that influenced decisions about how to approach an exploration of social participation. The information is presented to form a rationale for the thesis and for the methods and measures used to address each of the three aims in this thesis. The use of a conceptual model that encompasses the multidimensional nature of what social participation means from a communication participation perspective, and which acknowledges the transactional nature of interpersonal communication relationships would be an important addition to rehabilitation program planning in which the final goal is to support community re-integration.

Theoretical Frameworks and Conceptual Models

Measuring and describing social participation

A number of aspects of social participation may be measured and outcomes of such measures have been researched in relation to adults with TBI and stroke in general. In addition to social activities and ability to return to social roles, measures are also available to explore the significance or value that a person places on changed social participation and reported quality of life following acquired brain injury.

The aspects of social participation measured in this program of research were influenced by conceptual models of the ICF (WHO, 2001), Levasseur taxonomy of social activities (Levasseur et al., 2010), the Social Network Convey Model (Antonucci & Akiyama, 1987) and the philosophical underpinnings of phenomenology in recognition of multidimensional facilitators and barriers to participation. It has been stated that measures that only focus on the performance of particular activities that are related to social roles will not adequately capture the full meaning of social participation and significance of changed participation (Ueda, 2003). For this reason, in this research, a combination of objective and subjective measures were identified to fully explore facilitators and barriers to social participation, and how these relate

to communication between the person who has sustained a RH stroke and his/her family member.

Participation and the interplay of health, personal and environmental factors

Firstly, to provide a holistic description of potential health, personal and environmental facilitators and barriers to social participation for people with a RH stroke, the use of the International Classification of Functioning, Disability and Health framework (ICF)(WHO, 2001) was considered an appropriate theoretical frame. The ICF framework has been used to provide a holistic description of the impact of a number of specific health-related conditions including spinal cord injury, cerebral palsy and aphasia post stroke (dos Santos, Pavão, de Campos, & Rocha, 2012; Simmons-Mackie & Kagan, 2007; Van de Velde, Bracke, Van Hove, Josephsson, & Vanderstraeten, 2010), however, has not been utilised with respect to people with a CCD post RH stroke.

The ICF, grounded within a biopsychosocial model, conceptualises a health condition, and how particular characteristics of the individual and their environment interact, to either support or hinder the ability to participate (WHO, 2002). The person's capacity to execute a task may not reflect their performance within a societal context, thus it is understood that a given environment or the nature of a particular social role (e.g. vocational role) may result in a different profile of performance. Historically, outcomes post stroke seldom moved beyond a level of impairment or the capacity to perform an activity within a standardised setting (Douglas, Swanson, Gee, & Bellamy, 2005). In reviewing the literature that relate specifically to people who have a communication impairment secondary to a RH stroke a similar pattern of paucity of participation focussed outcomes is apparent. A taxonomy of nine key activities is included in the ICF: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life (WHO, 2001). This program of research explored three key ICF activities, that being communication, interpersonal interactions and relationships, and social and civic life.

A summary of measures that are in line with the ICF concept of participation as provided by Tate was used to guide selection of available social participation tools (Tate, 2014). Tate grouped measures within an ICF tree and according to *other rated* versus *self-reported*, considering both frequency of activities and perceptions of quality. A third tier in the ICF tree is that of *client-centered* measures in which qualitative methodology is used to explore the

person's own experiences and perceptions (Tate, 2014). In this program of research, other rated tools (proxy-reported) were deemed essential as a supplement to self-reported tools. Proxy reports were included to address the challenge of potential self-report underestimation, which may result from the presence of reduced insight which occur in some people following a RH stroke. A further motivation for including a family member's perspective on social participation is the central role that family members occupy within communication exchanges that occur in naturalistic settings. As such, they have a unique insight into everyday participation challenges that a family member with RH CCD may have (Tompkins, Lehman, Wyatt, & Schulz, 1998).

The Disability Creation Process (DCP) Model also influenced the selection of data collection tools and methods. In particular the way in which life in the community is conceptualised and how it incorporates a person's ability to engage in social roles and to maintain close relationships. According to the DCP Model, social role and relationship success may be hampered or supported by environmental factors and personal characteristic, unique to a particular social situation (Fougeyrollas, Noreau, Bergeron, Cloutier, Dion & St Michel, 1998). This research was particularly interested in exploring factors related to communication environments that might hamper success in interpersonal relationship maintenance.

A taxonomy of communication-based participation

The ICF definition of participation does not necessarily require the presence of another person as much of what we engage in during our lives is not transactional nor reliant on the need to communicate with others. As this research is uniquely interested in social roles and activities in which interaction occurs with others, the addition of a taxonomy of social activities (Levasseur et al., 2010) was considered important. The use of this taxonomy allowed for greater detail when describing the interaction of a person with the social environment in terms of type of social interaction and likely goal of the interaction. This research focussed specifically on Levasseur's levels three to six of social participation, as outlined in Table 3.1., to specify the proximity and goal of involvement with others. The goals of activities within the levels range from being orientated to basic needs (levels 1 and 2), socially oriented (level 3), task oriented (level 4), oriented towards helping others (level 5) and level 6, being society oriented.

Table 3.1.:

Levasseur et al (2010) taxonomy of social activities

Levels	Proximity to others	Description of the levels of involvement
First level	Alone	Doing an activity in preparation for connecting with other people.
Second level	In parallel	Being surrounded by other people.
Third level	In interaction	Interacting with others without physical contact.
Fourth level	In interaction	Doing an activity with others.
Fifth level	In interaction	Helping others.
Sixth level	In interaction	Contributing to a community.

Transactional dimension of social participation

This research is particularly interested in communication within social roles and relationships, and given that most communication is transactional in nature, it was also important to explore perceptions and experiences of communication partners. The Convoy Model of social relations allowed for exploration of the transactional dimension of communication and social participation as it occurs across different circles of a social network. The research methodology of this program of research was therefore also influenced by the socio-ecological model (Stokols, 1996) upon which the Convoy Model (Antonucci & Akiyama, 1987) is based which allowed for exploration of dimensions of social participation as it is experienced by the person and his/her communication partner. As communication underpins our interactions with others within our community, be that at home or at work, it is important to explore this dimension as a variable that can influence successful return to community living following a RH stroke. Interdependence as a contributor to relationship maintenance and therefore successful participation is focussed on in this research, rather than independence in a person's ability to, as per the colloquial definition of community integration, 'have something to do, somewhere to live, and someone to love' (Cott, Wiles, & Devitt, 2007; Dijkers, 1998). The use of conceptual models that encompass the multidimensional nature of what social participation means from a communication participation perspective, and which acknowledges the transactional nature of interpersonal communication relationships was an important addition.

Aims and Methods

To enable a systematic exploration of perceptions of social participation change as well as factors that hinder or support the return to and maintenance of social roles and relationships a mixed method approach was required. A number of data collection methods and measures were used to, in the words of Greene, report on “*multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished*” (2008, p. 20).

The relationship between the qualitative and quantitative study components differed across the aims. Data that was collected and analysed in relation to aim one of this thesis, set the scene for exploring potential reasons for the findings in aim 2. This approach is in line with a sequential exploratory typology. Concurrent triangulation was used to address aim 3, as qualitative and quantitative data were collected and analysed at the same time, and given equal weighting, to address a number of propositions (Creswell & Plano, 2011).

Methods and participants across research aims

Figure 3.1. provides a summary of the research methods used across the three aims of this thesis. Measures used to collect data are introduced in this section and described in detail in the following section.

Aim one reported on in *Chapter 4* of this thesis, was to determine social participation change as reported by people with a RH stroke and a significant other. A telephone survey was conducted with 36 participants all with RH stroke and significant others. A random selection occurred of patients consecutively admitted to a single facility over a two-year period, with a diagnosis of first onset, unilateral RH stroke and no prior history of neurological and psychological impairment. The Sydney Psychosocial Reintegration Scale (SPRS-2: Tate, 2011) was utilised to gather data on perceived social participation change. Independent *t-tests* allowed for comparison across groups based on the presence or absence of CCD post RH stroke, for participant and proxy groups respectively. Inter-rater correlation coefficient was used to establish participant-proxy agreement of change in social participation. The method and measure allowed for reporting of data related to i) self-reported changes in social participation following a RH stroke based on presence or absence of CCD, and ii) agreement between self and significant other reports of social participation change following a RH stroke.

Research aims		Data collection methods and participants
Aim one	To determine perceived change in social participation as reported by people with a RH stroke (self-report) and a significant other (proxy-report).	Survey completion and semi-structured interview via telephone with 36 participants with first onset RH stroke, without prior neurological nor psychological impairments, and with 33 significant others.
Aim two	To explore a risk profile for social participation restriction of people returning to community living following a stroke RH stroke.	Study one: Retrospective chart audit of 115 consecutive admissions representing 57 patients with first onset LH stroke and 58 participants with first onset RH stroke. Study two: Comparison of acute-stroke assessment data with future social participation results for 36 participants with RH stroke (same participants as included in aim one).
Aim three	Determine the significance of social participation change in relation to relationship maintenance, social network change and QoL in people with CCD characterised by impaired social cognition.	A multiple case study in which three propositions are considered across seven cases (participant-proxy dyads). Case sampling saw recruitment of participants with a diagnosed CCD and social cognition impairment, residing in their pre-stroke residential setting, and with a proxy participant who either lived with them or who was in daily contact with the participant.

Figure 3.1: Summary of research methods and data collection tools across research aims

Aim two consisted of two studies both exploring risks for social participation restriction of people returning to community living following a RH stroke, with findings reported in *Chapter 5* of this thesis. The first study entailed a retrospective chart audit of consecutively admitted patients over a two-year period. The audit allowed exploration of the hypothesis that at the point of discharge from an acute or rehabilitation setting following a stroke, persons with a RH CCD would have social participation risk that is similar to people with aphasia. The method allowed for collection of data related to communication and/or cognitive impairments, access to rehabilitation, and functional outcomes based on the Functional Independence Measure (FIM: Folstein, Robins & Helzer, 1983). Within group change and between group differences were analysed using Student's *t*-test, Chi-square test for independence and one-way ANOVA.

A linear multiple regression was performed to assess the impact of theoretically selected risk factor (severity of communication impairment) on functional outcomes for patients with CCD. The relationship among the factors were investigated using Pearson's r and Spearman's Rho correlations prior to undertaking the regression analysis. The second study explored if routinely administered acute-stage screens of communication and cognition can predict social participation change in people with RH stroke with or without CCD. Social participation change was determined on the SPRS-R (Tate, 2011), which was collected through a phone survey. Data obtained from medical records included presence or absence of CCD based on an informal screening measure administered by speech pathologists, Australian Therapy Outcome Measure (AusTOM: Perry et al., 2004); Mini Mental State Examination (MMSE: Folstein, Robins & Helzer, 1983); Controlled Oral Word Association test - assessment of verbal fluency with phonemic constraint (COWAT F-A-S: Loonstra, Tarlow & Sellars, 2010). Associations between social participation change and impairments in cognition and communication as determined during hospital admission was explored using the Student's t -test and through establishment of sensitivity and specificity.

To explore the significance of social participation change, a multiple case study design was utilised to address *Aim three*, which is presented in *Chapter 6*. The significance of social participation change was related to relationship maintenance, social network change and reported changes in quality of life. Selection of participants was based on the presence of CCD and impaired social cognition. Social cognition impairment was determined using the Awareness of Social Inference Test-Revised (TASIT-R: McDonald, et al., 2003). A number of measures were used to explore the propositional statements including the Stroke Specific Quality of Life Scale (SS-QOL: Williams, Weinberger, Harris, Clark, & Biller, 1999), The Measure of Participation in Conversation (MPC: Togher, Pwer, Tate, McDonald, & Rietdijk, 2010), Role Checklist (Oakley, Kielhofner, Barris, & Reichler, 1986), as well as semi-structured interviews with participant-proxy dyads to allow for analysis of social network and relationship change (Refer to Appendix A).

Data collection measures

The selection of data collection measures was influenced by different conceptual models that informed the approach to exploring the aims of this thesis (refer to Figure 3.2). The measures

also relate directly to factors that emerged from the reviewed literature, in particular factors that were hypothesised to have an influence on social participation in people with RH stroke.

ICF Framework and DCP Model		Social Convey Model and Levaseur Taxonomy	
Impairment Body structure and function	Medical record data <ul style="list-style-type: none"> ▪ Stroke location and onset ▪ CCD presence and severity (AusTOM¹, TASIT-R²) ▪ Impaired cognition (MMSE³, COWAT: F-A-S⁴) 	Social network analysis	Self-and proxy-report Change in: <ul style="list-style-type: none"> ▪ network composition and size ▪ frequency of contact ▪ relationships
Participation	Self-and proxy reported social participation <ul style="list-style-type: none"> ▪ SPRS-2⁵ ▪ semi-structured interview ▪ SS-QOL⁶ 	Social role analysis	Self-and proxy-report Change or loss of valued roles: <ul style="list-style-type: none"> ▪ The Role Checklist ▪ semi-structured interview
Activity Communication based activities	Medical record <ul style="list-style-type: none"> ▪ FIM⁷ Self- and proxy-report <ul style="list-style-type: none"> ▪ SPRS-2 ▪ SS-QOL ▪ MPC⁸ 		
Contextual Environmental and personal factors	Medical record <ul style="list-style-type: none"> ▪ demographic information Self-and proxy-report <ul style="list-style-type: none"> ▪ semi-structured interview 		

¹AusTOM: Australian Therapy Outcome Measure (Perry et al., 2004); ²TASIT-R: Awareness of Social Inference Test-Revised (McDonald, et al., 2003); ³MMSE: Mini Mental State Examination (Folstein, et al., 1983); ⁴F-A-S: Controlled oral word association test - assessment of verbal fluency with phonemic constraint (Loonstra, et al., 2010); ⁵SPRS-2: Sydney Psychosocial Reintegration Scale (Tate, 2011); ⁶SS-QOL: Stroke Specific Quality of Life Scale (Williams, et al., 1999); ⁷FIM: Functional Independence Measure (Guide for the Uniform Data Set for Medical Rehabilitation, 1997); ⁸MPC: The Measure of Participation in Conversation (Togher, et al., 2010)

Figure 3.2: Measures in relation to conceptual models.

Measures to determine personal variables. Participant demographic details were gathered through medical chart audit, and as reported by participants and proxies during interviews. The variable explored in this research related to relationship status and relationship change. Other details such as age, vocational status, residential setting pre- and post-stroke were reported.

Measures to determine impairment related variables. To describe the impairment present in the participants, information was gathered from medical records as reported by treating healthcare professionals, including speech pathologists. Changes in structure, such as the type and location of the stroke, was based on radiological evaluations conducted during acute hospital admissions as documented in medical records. Changes in function, that being the presence and severity of impairments in mobility, communication and cognition were similarly determined from reported performance on a range of assessment tools routinely used at the site of data collection.

Communication impairment. The presence of a communication impairment was based on findings from a routinely administered screening assessment protocol that evaluated performance across discourse production, prosody (receptive and expressive), lexical-semantics, pragmatics and functional reading and writing. Social cognition impairment was determined based on results obtained on the Awareness of Social Inference Test, (TASIT-R, McDonald et al., 2003). The TASIT-R allows for evaluation of interpretation of emotions and theory of mind judgments. The test consists of three parts, the first evaluating emotion recognition based on 28 videoed vignettes of Australian actors, supported with normative data from 134 neurologically intact adults aged 14 to 60. Parts 2 and 3 evaluate social inferential reasoning which requires interpretation of paralinguistic cues, such as prosodic features of speech and contextual knowledge, which might indicate sincerity versus sarcasm as an example. Normative data is again presented based on 171 and 186 neurologically intact adults between 14 and 50 years of age for part 2 and part 3 respectively. Reliability data (range from 0.74 to 0.88) is available based on adults with TBI. Validity has been established, with the TASIT-R associated with other measures of facial expression interpretation and executive function tasks (McDonald, Bomhofen, Shum, Long, Saunders & Neulinger, 2006). The Australian Therapy Outcome Measures (AusTOMS)(Perry et al., 2004) identified severity of communication impairment, which was included as it was a routinely used measure in the data collection site. Refer to Appendix B for the AusTOM items used in this thesis.

Impairment in cognition. The MMSE (Folstein, et al., 1983) and COWAT: F-A-S measure identified impairments in global cognition and executive function skills respectively. The MMSE is a 30-point questionnaire where a score less than 24 indicates the presence of cognitive impairment. The MMSE was included as it was routinely used within the study's data collection site. However, low levels of sensitivity among those with mild cognitive impairment following a RH stroke has been reported in addition to being affected by age and

level of education (Tombaugh & McIntyre, 1992). Executive function was based on results from the COWAT: F-A-S. Verbal fluency with phonemic constraint (F-A-S), was selected as it has been shown to provide insight into executive function ability, and this association was found to be stronger than performance on verbal fluency with semantic constraint tasks (Shao, Janse, Visser & Meyer, 2014). The selection was further influenced by screening assessment tasks routinely administered at the site where data collection occurred. COWAT: F-A-S has been used as a test of executive control ability in adults with TBI (Hanks, Rapport, Millis, & Deshpande, 1999). It is acknowledged that COWAT: F-A-S performance may reflect a number of cognitive aspects such as inhibition, self-initiation, and switching ability (Hirshorn & Thompson-Schill, 2006). COWAT: F-A-S norms are available to reflect differences in performance related to age and education (Loonstra, Tarolow & Sellers, 2010). This was similarly considered when interpreting the scores of this study.

Measures of activity related variables. Ability to engage in activities of daily living with or without support was determined at the point of hospital discharge using the Functional Independence Measure (FIM)(Guide for the Uniform Data Set for Medical Rehabilitation, 1997), and following return to social roles and relationships using the SPRS-2 (Tate, 2011) and SS-QOL (Williams, et al., 1999).

Activity related data at the point of hospital discharge. A FIM score was reported for participants commencing and completing rehabilitation. The FIM is used to determine the level of independence across self-care, sphincter control, transfers, locomotion, and cognition (comprehension, expression, social interaction, problem solving, and memory). A seven-point scale represents amount of observed assistance required from 1 (total assistance) to 7 (total independence). The FIM has demonstrated reliability and validity as a rehabilitation outcome measure, however, it is acknowledged that communicative and cognitive functioning are not comprehensively evaluated (Frymark, 2004; Ottenbacher, Hsu, Granger, & Fiedler, 1996).

Activity related data following return to community living. All other activity level information was based on self and proxy-reports of ability to engage in activities, in particular communication-based activities, as part of the SPRS-2 (Tate, 2011), SS-QOL (Williams, et al., 1999) and semi-structured interviews. Supplementation of the SPRS-2 and SS-QOL with semi-structured interview data was deemed necessary as prior research indicated that despite high independence ratings on measures of ADLs, patients with mild stroke may still experience stroke-related disabilities (Edwards, Hahn, Baum, & Dromerick, 2006).

Perceived QoL was determined using the Stroke Specific Quality of Life Scale (SS-QOL; Williams, et al., 1999). The SS-QOL was developed and validated specifically for people with stroke. The scale includes 49 items encompassing 12 domains, viz energy, family roles, language, mobility, mood, personality, self-care, social roles, thinking, vision, upper extremity function, and work/productivity. The SS-QOL was completed in an interview format with participant-proxy dyads in which they were asked to rank each item on a 5-point Likert scale where higher scores indicate better function or less change since the stroke. A SS-QOL domain scores of ≥ 4 is reflective of relatively good QoL and a domain score < 4 as an impaired QoL (Fisher, et al., 2009). The use of a participant-proxy consensus process on the SS-QOL was again used as a preferable approach to excluding participants with reduced insight post stroke. Participant-proxy agreement on scales of QoL has been found to be moderate to substantial in the post-acute stroke period with overestimation of impairments by proxies more prevalent during the acute period (Oczkowski & O'Donnell, 2010). No participants were in the acute phase of stroke recovery. To further increase participant-proxy agreement, as recommended when proxy report is used on the SS-QOL, all proxies were living with the participants and in daily contact with them (Lynn Snow, Cook, Lin, Morgan & Magaziner, 2005; Muus, Petzold & Ringsberg, 2009).

Measures to determine participation. To determine social participation, a combination of objective and subjective measures was required. The SPRS-2 (Tate, 2011), a 12-item rating scale of participation, developed for use with people who have sustained a brain injury and who are living in the community was selected. Items are grouped across occupational activity for work and leisure, interpersonal relationships and independent living skills, domains in which people who have sustained brain injuries tend to experience difficulty. The SPRS-2 has been found to have high internal consistency, concurrent validity with other comparable scales and construct validity. The SPRS-2 was considered a suitable objective measure for this research, since it evaluates social participation rather than merely observing activities for which other measures, such as the Community Integration Questionnaire, have been criticised (CIQ: Kuipers, Kendall, Fleming, & Tate, 2004). Another feature of the scale is that it allows for exploration of social participation before the onset of stroke as well as evaluation of current levels of reported participation. This feature addresses a shortcoming of other measures that report on frequency of social participation activity, without considering a context of what the

person's activity across different social roles might have been prior to a stroke. Objective measures are criticised for an inferred notion that more activity or more social contacts represent greater social participation and more successful return to social roles and activities. The SPRS-2 addresses a number of categories in the ICF and therefore adheres to the theoretical framework within which this program of research is positioned, including ICF Category 3: Communication and ICF Category 7: Interpersonal interactions and relationships. The SS-QOL (Williams, et al., 1999) provided additional data relating to change at the level of participation as did themes that emerged following semi-structured interviews.

Measures to explore environmental variables. The two environmental variables explored in this research related to informal support obtained through a social network, and secondly formal support obtained through access to rehabilitation. Access to rehabilitation was determined through medical chart audit. A social network varies in structure (size, composition, contact frequency, proximity) as well as perceived quality, and has been found to be influenced by personal variables such as gender and environmental factors such as specific role demands. The social network Convoy Model (Antonucci et al., 2014) and Levasseur et al's taxonomy (Levasseur, et al., 2010) were selected as methods to explore social networks based on frequency and function of social contacts; relationship of social contacts to the person; importance of the social contact to the person (inner, middle, outer circle); and the perceived quality of the contact (positive, negative). The Convoy Model contends that individuals interact with others who move with them through their life course and experiences of health conditions (Antonucci et al., 2014).

In addition to exploring social networks, this research also determined the importance that participants place on their ability to continue to perform social activities across different social roles, for example roles within the family or within vocational contexts. It is particularly restrictions in ability to participate in valued roles that may influence perceptions of quality of life post stroke. The Role Checklist (Oakley et al., 1986) allowed for identification of difficulties with returning to different roles and the individual perceptions of importance of such roles. The Role Checklist is not specific to any diagnostic population, is designed for use with young to older adults, and comprises two parts. The first part explores past, present and planned roles. The second part asks the participant to assign a significance or value to each role. To obtain a truly complete reflection of the process and experience of returning to social roles and activities, quantitative measures were deemed insufficient and were therefore supplemented by qualitative information gathered through semi-structured interviews.

The exploratory nature of this thesis was required as limited current evidence is available to allow for interpretation of potential facilitators and barriers to social participation. There is no literature that explores the experience of returning to social roles and maintenance of relationships in the presence of a RH CCD. Qualitative methodologies allow for a shift from perceptions held by health care service providers to understanding the experiences and subjective needs of people with a particular health condition. A meta-synthesis of qualitative studies on experiences of stroke found that rehabilitation goals based purely on quantitative measures of impairment level tasks may not be in line with what persons with stroke consider of greatest importance (Salter, Hellings, Foley, Teasell, 2008). Where health care professionals and patients experience discrepancies in identified goals for rehabilitation a secondary handicap may result which in turn can increase feelings of social isolation (Liu, 2005; Vincent et al., 2007). Taken together, results from objective measures and subjective reports would lead to the identification of factors that influence social participation and that may serve as predictors of social isolation.

Chapter 4

Aim 1 - Describing Social Participation Change

“Organising definitely has changed, he now needs more time and can get flustered still when there is too much choice or when there are time pressures. When he returned to work he realised he was not as good at it as before and given the demands on a software engineer the redundancy was likely a reflection of him not coping. He is improving in his communication, but he still needs things to be very concrete and he will miss subtleties. His face is now more expression-full too... But sometimes he knows that it is not obvious, so he has learned how to compensate, which he does by always saying what he thinks and feels out loud ...”

(Wife of 49-year-old male participant, who was discharged home following 40 days of in-patient rehabilitation during which 4 speech pathology sessions were accessed for dysphagia. Mild CCD, MMSE: 27/30)

The literature reviewed in *Chapter Two* provides an overview of the current paucity of evidence related to long-term outcomes for people with CCD post RH stroke. Social participation is established as a stroke-rehabilitation outcome that, if not addressed, may impact a person's well-being. *Chapter Four* provides data that addresses this gap in our current knowledge, by determining perceived change in social participation as reported by people with a RH stroke and a significant other. Three hypotheses are tested in Chapter four, namely 1) people living with a RH stroke will report changes in their social participation, 2) social participation change will be greater in people with a CCD compared to people without a communication impairment following RH stroke, and 3) differences in perceptions about social participation change will emerge when comparing participant and proxy reports. The following is a published manuscript with minor changes to formatting according to APA style guidelines.

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Introduction

Communication is a complex ability that encompasses interpreting and expressing thoughts, feelings and intentions. Effective communication facilitates interpersonal interactions, with communication described as the “currency of relationships” (Parr, Byng, Gilpin, & Ireland, 1997, pg. 44). A change in communication, as may occur following stroke can influence interpersonal interactions and the ability to participate in social activities and social roles. Though much interest in social participation emerged in response to the International Classification of Functioning, Disability and Health Framework (ICF)(World Health Organization, 2001), the particular impact of a communication impairment on community integration and participation remains poorly understood.

Historically, assessment of stroke outcomes focussed on the in-patient phase of rehabilitation and on impairment level outcomes rather than community integration and participation (Salzer & Baron, 2006). Community integration is a distinct phase of rehabilitation starting from the point of discharge from hospital when the person resumes prior social activities and roles. Despite an increasing understanding of the importance of addressing participation and quality of life as rehabilitation goals, participation-focussed interventions for

people with communication impairments are still emerging and often guided by general philosophies rather than evidence-based techniques (Baylor, Burns, Eadie, Britton, & Yorkston, 2011; Laliberté, Alary Gauvreau, & Le Dorze, 2016). One possible reason why experiences of social participation of people with stroke-related communication impairments are less evident in the literature, is that the presence of communication disorder is at times a criterion for exclusion from study samples (Cruice, Worrall, & Hickson, 2006).

Changes in vocational and leisure activities, increased dependence on others (Brown, Gordon, & Spielman, 2003), reduced ability to maintain close relationships (King, Shade-Zelow, Carlson, Feldman, & Philip, 2002; Novack, Bush, Meythaler, & Canupp, 2001), and altered perceptions of emotional wellbeing (Ownsworth, Little, Turner, Hawkes, & Shum, 2008; Turner, Fleming, Cornwell, Haines, & Ownsworth, 2009) have been reported in people following a stroke and also traumatic brain injury (TBI). In the field of speech-language pathology a small number of studies have considered social participation following a stroke in people with changed communication ability. Social participation outcomes for people with aphasia (PWA) have been researched most extensively (Cruice et al., 2006; Le Dorze, et al., 2014), with one study on social participation outcomes in people with dysarthria by Brady, and colleagues (2011). A common theme across these studies is that stroke-related communication disorders negatively influence social participation with reported changes in frequency of contact with others and satisfaction with social relationships (Cruice et al., 2006; Brady et al., 2011; Dalemans, De Witte, Beurskens, Van Den Heuvel, & Wade, 2010). Communication contributes to our sense of self, and the loss of communication ability or opportunity impacts on identity and social connectedness as reported in PWA (Parr et al., 1997). PWA experience changes to their social participation at greater frequency than their peers without aphasia even when post-stroke physical impairment that may reduce community access is controlled for (Cruice et al., 2006; Hilari et al., 2010).

As a relatively new area of enquiry, less is known about the cognitive-communication disorder (CCD) and social participation changes that emerge following a right hemisphere (RH) stroke (Blake, 2016). The impairments in this RH stroke population have been described as subtle which may in turn lead to under-identification of CCD, reduced access to rehabilitation services, as well as an underestimation of the potential impact of CCD on the person's ability to return to social roles and to maintain and form relationships (Klonoff, Sheperd, O'Brien, Chiapello, & Dennis, 1990; Blake, 2016).

People living with RH CCD present with different communication strengths and challenges compared to PWA or people with dysarthria, which may in turn create different facilitators and barriers to social participation (Vigneau, et al., 2011). It is now understood that a combination of communication deficits (across lexical-semantics, discourse, pragmatics and prosody), and cognitive deficits (neurocognition and social cognition) occur following a RH stroke (Côté, Payer, Giroux, & Joannette, 2007; Blake, 2011). Changes to communication are not only related to deficits in access and use of vocabulary and syntax, but also a consequence of non-linguistic aspects of communication such as interpretation of emotion in facial expressions and aprosodia, cognitive impairments such as impaired executive function and awareness, and altered social cognition related to theory of mind or perspective taking (Abusamra, Côté, Joannette, & Ferreres, 2009). Communication-based participation is dependent on intact communication, cognition and social cognition skills (Baron-Cohen, Tager-Flusberg, & Cohen, 2000). Evidence in the field of social cognition following TBI supports the notion that poor social inferential reasoning is a source of interpersonal difficulty (McDonald, Honan, Kelly, Byom, & Rushby, 2014). Undertaking and maintaining social roles following stroke, especially more complex roles, have been shown to be influenced by other cognitive deficits such as impaired memory and insight (Viscogliosi, Desrosiers, Belleville, Caro, Ska, & BRAD Group, 2011).

Beyond the level of impairment little is known about performance of everyday communication-based activities and the long-term impact on participation. It has been postulated that people with CCD post RH stroke face a particular risk for social participation restrictions due to the nature of their cognitive and communication difficulties; however, an account of social participation changes as reported by people with CCD is currently not available. “The right hemisphere patient appears peculiarly unconcerned about the impact of his message, insensitive to his situation or to the environment ... inevitably his interaction with others will change” (Myers, 1978, p. 50).

Prior research on social participation following stroke report predominantly on three aspects of community integration, namely vocational and leisure activity, interpersonal relationships and independent living skills (Salter, Foley, Jutai, Bayley, & Teasell, 2008; Sander, Clark, & Pappadis, 2010). A number of assessment tools are available to report on participation in people with stroke in general such as the Frenchay Activities Index (FAI: Schuling, de Haan, Limburg, & Groenier, 1993), looking in more detail at communication-linked participation (e.g. Community Integration Questionnaire, CIQ: Djikers, 2000), to quantify social activity

participation (e.g. Social Activities Checklist: Cruice, 2001), and specifically for PWA, the Assessment for Living with Aphasia (ALA: Kagan, Simmons-Mackie, Victor, Carling-Rowland, Hoch, Huijbregts, et al., 2011).

The evaluation of social participation is by no means a straightforward process. Many available assessment tools attempt to quantify the levels of social participation by evaluating productivity (e.g. number of places that a person goes to in a week), independence in performance of activities, and frequency of contact with people within a social network as well as the size of the social network. Measuring the frequency of social interactions or size of social networks following a stroke makes an assumption that a greater activity level or larger social network equates to greater success in participation, an assumption that does not account for variability in social participation that is present between people. Evaluating the frequency of performing pre-determined activities and roles also creates a challenge, as people may not share universal activities and roles, nor may they consider pre-determined activities and roles of equal importance.

A person-centered approach on the other hand addresses these challenges through the use of self-report measures of change in participation, and was the approach used by the current study. Self-report measure of change in participation due to stroke allows for evaluation of the extent of change in personally salient social activities and roles, or the degree of satisfaction with current social participation where each person becomes their own norm (Sander et al., 2010; McColl, Davies, Carlson, Johnston, & Minnes, 2001).

The Sydney Psychosocial Reintegration Scale (SPRS-2: Tate, 2011), a 12-item rating scale, allows for exploration of change (Form A) that has occurred in participation due to an acquired brain injury, as well as current status of participation (Form B) from participant and proxy reports (refer to Appendix C for outline of scale items). The current study used Form A to evaluate change in social activities as reported by the person with stroke and a proxy rather than quantifying current levels of activities. Proxy report allows for exploration of change in participation in people who may have reduced awareness or insight, an impairment that is found in some people following a RH stroke. Participant-proxy report differences in PWA have been noted; however, at a group level the differences were felt to introduce only a modest amount of bias and conclude that the use of proxy reports in populations who have communication impairments is preferable to excluding them from research investigations (Hilari, Owen & Farrelly, 2007). The SPRS-2 was developed for use with people who have TBI and used in research with other neurological populations including stroke. The SPRS-2 has sound

psychometric properties and has been shown to have a high level of internal consistency (Cronbach's alpha of 0.9), inter-rater reliability (correlation coefficient of 0.95) and to be correlated with other measures of community integration for people with acquired brain injury such as the CIQ (Kuipers, Kendall, Fleming, & Tate, 2004).

The rehabilitation needs and outcomes of people with CCD arising post RH stroke is an under-researched area with a paucity of current evidence to guide our rehabilitation planning (Blake, 2016). The influence of CCD on community-based participation, where unique demands of particular social roles influence the success of communication activities, remains an important research domain for rehabilitation professionals (Douglas, Swanson, Gee, & Bellamy, 2005). Facilitators and barriers to social participation and how to support successful community integration on discharge from acute and rehabilitation care are currently not known for those with a CCD post RH stroke. This paucity of evidence creates challenges for health care professionals in identifying people who are at risk for social isolation.

The findings from this study will increase awareness that people with CCD following RH stroke may require rehabilitation and community-based support to facilitate return to social activities and roles. Social isolation and unmet social communication needs hold consequences for health outcomes and health care costs and may influence perceptions of quality of life for those with RH stroke and those within their social networks (Uchino, 2006; Berkman, Glass, Brissette, & Seeman, 2000). This research is an initial exploration of social participation following a RH stroke and aims to (1) describe reported changes in social participation following a RH stroke, (2) compare social participation changes in the presence or absence of CCD, and (3) compare self and proxy reports of changes in social participation.

Method

This study documented perceived change to social participation following a RH stroke through a survey method. Ethical approval was obtained from the research ethics committees of the relevant university and health service, HREC/15/QPCH/13.

Participants

Potential participants were identified through a chart audit of patients who had a diagnosis of right hemispheric stroke confirmed on instrumental assessment. The audit was completed at a single hospital in Australia of patients admitted consecutively over a two-year period. Those with prior

neurological events, a history of dementia or mood disorders, or with a hospital length of stay (LOS) of less than two days were excluded. Of 155 people admitted with stroke who met the inclusion criteria of unilateral, first onset stroke without concomitant history of dementia or prior neurological events, sixty-three (63) were found to have a RH stroke.

The majority of the 63 patients with RH stroke were assessed by a speech-language pathologist during their hospital admission (92%, $n = 58$). A standard screening assessment protocol was used to identify the presence of CCD with assessment tasks across the domains of lexical-semantics, discourse, pragmatics and prosody. Forty (40) of the 58 potential participants were randomly sampled and invited by mailed letter and follow up phone call, to complete a telephone survey. Specific inclusion criteria for the participants with RH stroke (participants) were (1) six to 33-months post stroke; (2) 18 years of age or older; and (3) English as a primary language. In addition, a significant other (proxy) for each participant was invited to participate who met the inclusion criteria of being (1) a family member or friend identified by the participant; (2) who had at least weekly contact with the participant; (3) 18 years of age or older; and (4) English as a primary language.

Measure and Procedure

Form A of the SPRS-2 (Tate, 2011) was administered via telephone interview to reduce nonresponse bias. The primary investigator (a speech-language pathologist with experience working with people with acquired communication impairment) conducted the phone interviews with both participants and their proxies with no more than one week separating the interviews. Information about the content of the SPRS-2 was mailed to participants prior to the phone interview to allow time for familiarity with the SPRS-2 domains, viz. Occupational Activities at work and leisure (OA), Interpersonal Relationships (IR) and Independent Living Skills (LS) and the rating scale. Each item requires selection from a 5-point scale from 0 = extreme degree of change to 4 = no change. The total score of the SPRS-2 ranges from 0 to 48 with a higher score indicating greater levels of participation or psychosocial functioning.

Data management and analysis

Survey data for each participant were matched to a proxy, that being the person that they identified as a regular conversation partner. Data from both sources were entered into a Statistical Package

for the Social Sciences (SPSS V22.0) spreadsheet in a re-identifiable format using participant codes established for the study. To address aim 1, descriptive statistics represented demographic and clinical information as well as degree of reported change in social participation across SPRS-2 domains for all participants with RH stroke. To address aim 2: participants were stratified based on presence or absence of CCD, then independent group comparison tests (independent *t*-tests) were used to compare change in social participation following stroke across the two groups (group 1: CCD present; group 2: CCD absent). Significance was set at $p < .05$. Total SPRS-2 raw scores were converted to logit scores as per the SPRS-2 scoring procedure. To address aim 3: comparison of participant and proxy reports of change in social participation utilised independent group comparison tests. Difference scores were created for each participant-proxy dyad, and participant-proxy agreement calculated using percent agreement and kappa coefficients. Kappa statistics were interpreted as reflecting poor agreement if less than 0.2, fair agreement if between 0.21 and 0.4, moderate agreement between 0.41 – 0.6, good agreement between 0.61 – 0.8, and very good agreement if greater than 0.81 (Landis & Koch, 1977).

Results

Demographic information collected through participant report at the time of interview and through retrospective chart audit is summarised in Table 3.1. Ninety-percent ($n = 36$) of the 40 potential participants who were invited to participate, consented and completed the telephone survey. Two invited participants declined and another two were deemed ineligible due to reported diagnosis of dementia since onset of stroke. Time from hospital discharge to participation in the survey ranged from six to 33 months ($M = 18.5$, $SD = 6.6$ months).

Thirty-three participants consented to a family member or friend being invited to participate. Proxies were predominantly direct family members of the participants, being a spouse/partner (51.5%, $n = 17$), adult child (30.3%, $n = 10$), sibling (12.1%, $n = 4$), or parent (3.0%, $n = 1$). One participant identified a friend (3.0%, $n = 1$) as the person with whom she had the most frequent contact.

Table 4.1:

Characteristics of the RH participants at time of stroke onset (N = 36)

Demographic and clinical information		<i>M, SD</i>	<i>% (n)</i>
Age	In years	65.94, 13.09	-
Gender	Male	-	58.3 (21)
Occupational status	Employed	-	38.9 (14)
Relationship status	In a relationship	-	61.2 (17)
Residence prior to admission	Home on own	-	27.8 (10)
	Home with family	-	66.6 (24)
	Residential low care setting	-	5.6 (2)
Stroke location	Right cortical	-	69.4 (25)
	Right cortical and/or subcortical	-	30.6 (11)
Stroke type	Ischemic	-	94.4 (34)
	Haemorrhagic	-	5.6 (2)
Hospital length of stay	In days	20.69, 22.73	-
Access to in-patient rehabilitation	Yes	-	50.0 (18)
Cognitive-communication disorder severity ¹	None	-	41.7 (15)
	Mild	-	33.3 (12)
	Moderate-severe	-	25.0 (9)
Independently mobile ²	Prior to stroke	-	100.0 (36)
	On discharge from hospital	-	91.6 (33)

Note: ¹Severity of CCD based on the Australia Therapy Outcome Measure (AusTOM: Perry, Morris, Unsworth, Duckett, Skeat, Dodd, Taylor, & Reilly, 2004); ²Independently mobile = nil supervision or physical support, with or without single point stick or walker.

Changes in social participation: participant perspective

The majority of participants reported changes in at least one of the three SPRS-2 domains with only two participants reporting no change across all domains. As a group, the degree of change varied across OA, IR and LS (refer to Figure 4.1).

Occupational Activities. Thirty participants (83.3%) reported changes in OA. The OA item most frequently reported as changed because of stroke was *Leisure type and Frequency*. Changes in the ability to engage in the same leisure activities or with similar frequency were reported by 33 participants (91.6%), a change which was rated as moderate to extreme in degree by 41.6%, of

Figure 4.1: Degree of change in social participation across SPRS-2 domains as reported by people with right hemisphere stroke ($N = 36$)

participants ($n = 15$). *Work type and skills* was another OA area that changed for many. Half of the participants (50%, $n = 7$) who were employed prior to the stroke could not return to employment and a further three participants (21%) reported that they required modification to their work roles and duties to enable return to employment.

Interpersonal Relationships. Relationships changed for twenty-two (61.1%) participants. Seventeen participants reported being in a relationship at the time of their stroke, either married or living with a de-facto partner. Of these participants, seven (41%) reported a change because of the stroke in the relationships they had with their spouse/partner with a relationship ending in separation for one participant. Relationship changes were also reported with friends (31%, $n = 11$) and other family members (28%, $n = 10$). Medical records indicated that twenty-one (58.3%) participants who participated in the survey were diagnosed with CCD during their hospital admission. Self-reported perceptions of communication on the *Communication* items of the IR subscale revealed that only 10 of these participants felt that their communication had changed because of the stroke, ranging from a little or some change (70%, $n = 7$) to moderate change (30%, $n = 3$).

Independent Living Skills (LS). Twenty-nine participants (80.6%) reported changes in one or more areas related to their living skills. *Social skills* and *Personal habits* were reported to have

changed with a similar frequency for 27.7% and 24.9% of participants respectively. Three participants (8.3%) reported that they experienced a moderate to a lot of difficulty interacting with other people with a further seven (19.4%) noting some changes in their social skills or comfort in social situations. Personal habits such as requiring help with dressing or house work changed only a little for eight participants (22.2%). Only one participant (2.7%) reported that a lot of assistance and reminders were required. Responses to the *Community travel* and *Accommodation* items indicated that 25 participants (69%) reported changes in community access and the change was considered extreme for seven, who were unable to use their own or public transport following hospital discharge. The participants were all described as independent prior to the onset of stroke and most (94%, $n = 34$) were living independently in the community with only two from low care residential settings. Three participants reported that they experienced more than a little change in their accommodation (living situation) post stroke, and that they were not able to continue to live in the same residence (8.3%). The remaining participants felt that they either had no change to their living situation (70%, $n = 23$) or that they required only a little support from others following the stroke. Despite reporting no or only a little change to living situation, seven participants (19%) reported that they would not be confident on their own for more than a two-week period.

Changes in social participation: influence of a cognitive communication disorder

A significant difference in social participation change was found when comparing SPRS-2 Total scores ($p = .002$) and each of the domain scores for participants with CCD ($n = 21$) to participants without CCD ($n = 15$)(refer to Table 4).

Occupational Activities. OA (participation at work and leisure) was the participation domain in which the greatest difference in perceived change occurred between the two groups, which was statistically significant ($p = .002$). Though both groups reported changes related to *vocational roles and duties* these changes occurred with greater frequency in the group with a communication impairment (83.3%) than in the group without (42.8%) when looking at participants who were employed prior to stroke.

The groups were also different in reported changes in *leisure types and frequency* with 85.7% ($n = 18$) of people with CCD reporting reductions in the frequency and amount of activities engaged in compared to 40% ($n = 6$) of those without CCD. A similar trend was found in

Table 4.2:

Social participation reported by people with and without CCD post RH stroke

SPRS-2 ¹ domain scores and total scores	All participants <i>N</i> = 36	CCD present <i>n</i> = 21	CCD absent <i>n</i> = 15	Between group difference <i>p</i> < .05
Occupational activity				
Mean (SD)	11.44 (3.66)	9.90 (3.44)	13.60 (2.84)	.002 ³
Median (range) ²	12.00 (2-16)	10.00 (2-16)	16.00 (6-16)	
Interpersonal relationships				
Mean (SD)	14.25 (2.24)	13.52 (2.54)	15.26 (1.22)	.019 ³
Median (range) ²	15.00 (8-16)	14.00 (8-16)	16.00 (12-16)	
Independent living				
Mean (SD)	13.47 (2.64)	12.38 (2.90)	15.00 (1.06)	.002 ³
Median (range) ²	14.00 (4-16)	13.00 (4-16)	15.00 (13-16)	
SPRS-2 Total				
Mean (SD)	39.16 (7.57)	35.80 (7.90)	43.86 (3.68)	.002 ³
Median (range) ²	40.00 (15-48)	37.00 (15-47)	45.00 (36-48)	
Logit Scores	63.25	59.14	73.84	

Note: ¹SPRS-2 = Sydney Psychosocial Reintegration Scale. ²Highest subscale score = 16, highest total score = 48 with higher scores indicating higher levels of occupational activity, interpersonal functioning or independent living. ³Statistically significant difference between group 1 CCD present and group 2 CCD absent.

organising skills, where 80.9% (*n* = 17) of those with CCD reported change in their organising skills compared to 26.6% (*n* = 4) in those without CCD.

Interpersonal Relationships. A statistically significant difference was found in the IR domain which looks at relationships with a spouse/partner, with family members and with friends (*p* = .019). There was a greater frequency of reported change in relationships with friends in people with CCD (47.6%, *n* = 10) compared to only one participant without CCD (6.6%).

Independent Living Skills. A significant difference between the two groups was also present in the LS domain (*p* = .002). Changes in returning to driving was the area with the greatest variance with initial difficulty returning to driving reported by 90.4% (*n* = 19) of people with CCD and by 40% (*n* = 6) of those without CCD.

Between group differences were present not only in the frequency of reported change across SPRS-2 domains but also the degree of change (refer to Figure 4.2).

Note: Group 1 = CCD present; Group 2 = CCD absent.

Figure 4.2: Comparison of degree of social participation change on the SPRS-2 in the presence (Group 1, $n = 21$) or absence (Group 2, $n = 15$) of CCD post RH stroke.

Changes in social participation: proxy perspective

As a group, proxies, reported comparable participation levels (SPRS-2 Total logit score 61.11) to participants (SPRS-2 Total logit score 63.25). When comparing proxy reports for the two participant groups based on presence or absence of CCD a significant difference emerged on all three domains and the SPRS-2 Total score (see Table 5).

Proxies of participants with CCD reported levels of participation on OA ($M = 10.15$, $SD = 3.27$), IR ($M = 13.21$, $SD = 2.37$) and LS ($M = 11.31$, $SD = 3.12$) that were significantly lower than proxies of participants without CCD (OA: $M = 13.78$, $SD = 3.16$; LS: $M = 14.42$, $SD = 1.65$) with significance levels of $p = .003$ for OA, $p = .035$ for IR and $p = .002$ for LS.

A comparison between the two groups in terms of the degree of change that they have observed in their family member or friend indicates that a moderate to extreme change was reported more frequently when CCD was present (refer to Figure 4.3).

Table 4.3

Social participation in the presence or absence of CCD post RH stroke: Proxy report

SPRS-2 ¹ domain scores and total scores	All proxies <i>N</i> = 33	CCD present: Proxy report <i>n</i> = 19	CCD absent: Proxy report <i>n</i> = 14	Between group difference <i>p</i> < .05
Occupational activity				
Mean (SD)	11.69 (3.66)	10.15 (3.27)	13.78 (3.16)	.003³
Median (range) ²	12.00 (4-16)	10.00 (4-14)	14.00 (5-16)	
Interpersonal relationships				
Mean (SD)	13.87 (2.14)	13.21 (2.37)	14.42 (1.65)	.035³
Median (range) ²	15.00 (8-16)	14.00 (8-16)	15.00 (11-16)	
Independent living				
Mean (SD)	12.63 (3.00)	11.31 (3.12)	14.42 (1.65)	.002³
Median (range) ²	14.00 (5-16)	12.00 (5-16)	15.00 (11-16)	
SPRS-2 Total				
Mean (SD)	38.21 (8.23)	34.68 (8.00)	43.00 (5.92)	.003³
Median (range) ²	40.00 (22-48)	37.00 (22-45)	45.00 (27-48)	
Logit Scores	61.77	56.96	71.04	

Note: ¹SPRS-2 = Sydney Psychosocial Reintegration Scale. ²Highest subscale score = 16, highest total score = 48 with higher scores indicating higher levels of occupational activity, interpersonal functioning or independent living. ³Statistically significant difference between group 1 CCD present and group 2 CCD absent.

Note: Group 1 = CCD present: Proxy report; Group 2 = CCD absent: Proxy report.

Figure 4.3: Proxy report of social participation change on the SPRS-2: Report by proxies of participants with CCD (*n* = 19) and proxies of people without CCD (*n* = 14).

Fifty-eight percent ($n = 11$) of proxies of participants with CCD felt that they had experienced a moderate to extreme change in OA compared to 14% ($n = 2$) of proxies for participants without CCD. Similar patterns of greater degree of change reported by proxies of participants with CCD compared to proxies of participants without CCD were present for IR and LS.

Participant-proxy agreement

Agreement was examined at the SPRS-2 Total score and domain level with difference scores, percent agreement and Kappa coefficient presented in Table 4.4 for both the CCD present and CCD absent groups.

The participant-proxy mean difference score on the Total SPRS-2 and domain scores were smaller for the group without CCD compared to the group with CCD. As a group, proxies of participants with CCD rated their family member/friend lower across all domains than what the participants rated themselves, resulting in negative difference scores on all domains, OA: -0.12; IR: -0.24; LS: -0.35.

Table 4.4

Participant-proxy agreement on the SPRS-2 in the presence and absence of CCD

	Difference score ¹ <i>M (SD)</i>		Percent agreement %		Kappa coefficient (ICC)	
	CCD present <i>n</i> = 19	CCD absent <i>n</i> = 14	CCD present <i>n</i> = 19	CCD absent <i>n</i> = 14	CCD present <i>n</i> = 19	CCD absent <i>n</i> = 14
Total SPRS-2	-0.27(0.4)	0.08(0.4)	57.89	64.28	.37 ⁵	.39 ⁵
OA ²	-0.12(0.5)	0.07(0.5)	57.89	71.42	.37 ⁵	.42 ⁶
IR ³	-0.24(0.4)	0.00(0.4)	52.63	78.57	.35 ⁵	.44 ⁶
LS ⁴	-0.35(0.4)	-0.02(0.3)	57.89	78.57	.37 ⁵	.44 ⁶

¹Difference score = proxy – participant score; ²OA: Occupational Activities; ³IR: Interpersonal relationships; ⁴LS: Independent Living Skills; ⁵Fair agreement (.21-.4); ⁶Moderate agreement (.41-.6)

Percent agreement indicated between group differences and a trend of participant-proxy dyads in the group with CCD (SPRS-2 Total score agreement 57.89%) achieving lower levels of agreement than the group without CCD (SPRS-2 Total score agreement 64.28%), a trend which was also found across all domain scores. IR was the domain that achieved the lowest percent agreement between participants and their proxies in the group with CCD.

The inter-rater reliability for participant-proxy dyads in the group with CCD found a fair agreement across OA ($\kappa = 0.37, p < .001$); IR ($\kappa = 0.35, p < .001$) and LS ($\kappa = 0.37, p < .001$). Participant-proxy dyads in the group without CCD reached moderate agreement across OA ($\kappa = 0.42, p < .001$); IR ($\kappa = 0.44, p < .001$); and LS ($\kappa = 0.44, p < .001$).

Sixty-eight-percent ($n = 13$) of the participants with CCD rated themselves higher than their proxies, as per the SPRS-2 Total score, compared to 35.7% ($n = 5$) of participants without CCD. Nine of the thirteen participants with CCD who rated themselves higher than their proxies had a moderate-severe communication impairment on discharge from hospital.

The four items on which the least agreement occurred between participants and proxies in the CCD present group ($n = 19$) were in IR and LS. In all of these cases the participants with CCD rated themselves higher (greater degree of participation or psychosocial functioning) than their proxies. Firstly, relationship with friends, where 42.1% ($n = 8$) of participants with CCD indicated that a relationship change had occurred compared to 57.9% ($n = 11$) of their proxies. Secondly, 52.6% ($n = 10$) of participants with CCD denied any change in their communication in instances where their proxies reported change. A further 36.5% ($n = 7$) reporting a smaller degree of change in their communication caused by the stroke than their proxies. Thirdly, a change in social skills and behaviour in public was reported by 42.1% ($n = 8$) of participants with CCD compared to 68.4% ($n = 13$) of their proxies. The fourth item with low levels of participant-proxy agreement for the group with CCD was personal habits (care in cleanliness, tidiness and dressing) where 36.8% ($n = 7$) of participants reported a change compared to 68.4% ($n = 13$) of their proxies.

Discussion

This paper provides an initial exploration of social participation in people following a RH stroke, on the variable influence of communication disorder and on the degree of agreement about social participation change between participants and proxies. Social participation change was reported across all three areas of the SPRS-2 in a group of people who were randomly selected based on the presence of a confirmed unilateral RH stroke. The use of a telephone interview method to administer the SPRS-2, was guided by findings that the SPRS-2 was not well suited to mail-out administration with resulting reported response rates around 44% and at 60% for proxies in a study by Kuipers et al. (2004). The 90% participation rate in the current study increases confidence that the study explored social participation in a representative sample of people with confirmed first onset RH stroke.

Thirty-four of the 36 participants with RH stroke reported changes in at least one of the three SPRS-2 domains of social participation with varying degrees of change across OA, IR and LS. OA was the social participation domain that was reported to have changed with the greatest frequency (change reported by 83.3% of participants) in the study population as a whole. Half of all employed participants could not return to employment and a further 21% required changes to work roles and tasks. Vocational role change post stroke, was similarly reported by Egbert, Koch, Coeling and Ayers (2006) following interviews with 12 people with RH strokes however the variable influence of CCD was not explored. Changes in social participation were reported in the current study, with greater frequency and degree where a CCD was present across all SPRS-2 domains by both participants and their proxies.

When comparing participants based on the presence or absence of CCD, the current study found greater levels of vocational change in the group with a communication impairment (83.3%) than in the group without (42.8%). Literature is currently not available on the variable influence of severity or characteristics of CCD on the ability to return to employment. However, the current study indicates that even a mild communication impairment may create vocational challenges as seven of the 12 participants with CCD who were unable to return to employment presented with a mild CCD at the point of hospital discharge. Mackenzie and colleagues (2001) similarly cautioned that low levels of impairment may still be sufficient to create significant changes in vocational and also social roles in this population. The current study is also in line with past research that report changes in relationships with friends following acquired communication impairment such as aphasia (Cruice et al., 2006; Hilari & Northcott, 2006). Participants with CCD and their proxies reported more frequent and greater degrees of change in relationships than participants without CCD.

The impact of mobility on social participation was not explored in the current study; however, given the low levels of physical dependency in the total sample (8%, $n = 3$), it is unlikely to have been the primary factor in ability to resume social roles. Sixty-eight percent of participants with CCD who reported changes in ability to access the community with a car had received medical clearance to resume driving; however, they reported ongoing challenges related to planning a trip and in the ability to concentrate on the activity of driving. Only two participants with CCD reported that the change in their ability to drive was the reason for the change in their vocational and social activities. The other participants with CCD denied a causal link between driving ability and restriction in community access, often stating that

community access had not changed due to the support of a spouse or family member. This finding is in line with a study by Northcott and Hilari (2011) that impaired mobility is not necessarily the primary reason for reduced social interactions reported by PWA, stating that the variable impact of communication impairment on ability to resume social activities need to be considered.

The use of the SPRS-2 with the addition of proxy perspective offered an initial insight into agreement about social participation change between participants with CCD and their family members or friends. While a moderate level of participant-proxy agreement was present for the group without CCD, only fair agreement was found for the group with CCD and in particular on some items in the IR and LS domains. Participants with CCD rated themselves higher (greater degree of participation or psychosocial functioning) than their proxies on the IR and LS domains but not the OA domain. The current study found that nine of the 13 participants who rated themselves higher than their proxies had a more severe CCD. The variable influence of CCD severity on social participation requires further exploration.

The participant-proxy difference in perceptions of change that emerged highlights potential impaired awareness in the study population (CCD present group) which has been reported in the literature following a RH stroke (Dai et al., 2014). Previous research has indicated that impaired awareness may be a consequence of acquired brain injury with different patterns of either under- or over-reporting of impairments occurring due to neuropsychological and psychological factors (Ownsworth, Fleming, Strong, Radel, Chan, & Clare, 2007). People with neuropsychologically-based awareness deficits may not achieve comparable levels of psychosocial recovery as those with good awareness (Ownsworth, et al., 2007). The use of proxy report in this study provided a valuable supplement and highlights the need to include significant other perspectives during goal identification.

Ten (47.6%) of the 21 participants with CCD denied any stroke related change in their communication, which again may indicate anosognosia. This study did not allow for exploration of why awareness of changes on particular items in the IR and LS domains appear to be disproportionately different to proxy reports, in CCD present group, compared to awareness of changes in ability to for example return to work, leisure activities and driving. In a study that explored participant-proxy agreement on three outcome measures following TBI, it was found that the strongest agreement occurred on items related to concrete, observable information (Cusick, Gerhart, & Mellick, 2000). The findings in the current study are in line with Cusick and colleagues' (2001) findings, that a discrepancy is present between

participants' ability to gauge the success of social interactions and relationships compared to judging the success of more concrete and visible tasks related to work and driving. Brookshire and McNeil (2014) highlight the importance of utilising proxy reports in people with severe CCD post acquired brain injury. Participant-proxy agreement on social participation outcomes, as measured by the SPRS-2, has not been explored for people with CCD post RH stroke.

A limitation of this study was the use of a single measure of self-reported change in participation which was supplemented by proxy reports to account for potential reductions in awareness of participation change due to stroke. Although information is provided on how social participation has changed, a combination of subjective and objective measures, as recommended by Sander and colleagues (Sander, et al., 2010) would have allowed for identification of particular facilitators and barriers to participation. Social participation is a complex concept to research and is best explored in a multi-dimensional framework such as the ICF (WHO, 2001). The ICF framework would allow for exploration of facilitators and barriers to social participation in relation to impairment, environmental and personal variables. A consideration of the extent to which routinely used rehabilitation outcome measures can predict future social participation is warranted.

A potential limitation of the self-report survey method used in this study is that amount of time since stroke onset may have added recall bias to the survey responses as the participants were between six and 33-months post stroke. Structured questions and the rating scale of the SPRS-2 would have reduced the impact of interviewer bias; however, as the interviewer is a speech-language pathologist the potential of interviewer bias has to be acknowledged. A further limitation is that this study does not provide insight into adaptation or altered perceptions of the significance of social participation change that occurred in relation to time post stroke. A longitudinal study would identify if changes in the severity and/or characteristics of CCD over time correlates with improved social participation, which in turn provides a motivation for therapy that would reduce the communication impairment.

Further research is required to identify protective and risk factors inherent in not only the impairment level but also at the environmental level, and therefore to what extent the presence of a family member supported community access. The presence of family and close friends have been identified as an important environmental determinant of social participation and reported community integration in people with a TBI (Reistetter & Abreu, 2005; Lefebvre, Pelchat, Swaine, Glinas, & Levert, 2005). Sixty-six percent of the current study sample were

living with a spouse/partner or family member at the time of the survey, with the remaining 34% living on their own. A comparison of perceptions of social participation for those returning home to family versus those living on their own would provide insights into the influence of a family network on a person's ability to resume and maintain social activities and roles.

Research is required to determine if the presence of particular impairments, such as social cognition deficits create challenges in judging the success of social interactions and relationships compared to judging the success of more concrete and visible tasks, and if this might have been a source of the low participant-proxy agreement found on some items in the current study. Impairment in emotion perception post stroke in general was found to be significantly correlated with social participation in a study by Cooper and colleagues (Cooper et al., 2014). Similar findings are reported for people with social cognition impairments post TBI, that poor social inferential reasoning is a source of interpersonal difficulty (McDonald, et al., 2014). Emotion processing difficulties related to poor facial expression recognition and receptive aprosodia may be underlying causes of deficits in social cognition. The inability to understand and predict the thoughts, actions and motivations of others (Macrae & Bodenhausen, 2000) has the potential to influence interpersonal interactions (Borod, Bloom, Brickman, Nakhutina, & Curko, 2002).

Exploration of particular determinants of social participation change and satisfaction with return to social activities and roles will add evidence to better understand the variable risk for social isolation in people with CCD following a RH stroke. Altered social participation can lead to feelings of social isolation and can negatively affect both the person who has sustained a stroke as well as people within their social network (Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000). In particular, changes in ability to participate in highly-valued roles have been found to be predictive of self-reported quality of life (Haley, Roth, Kissela, Perkins, & Howard, 2011). The extent of restrictions on participation in social, recreational or vocational contexts has been found to be a strong predictor of health-related quality of life, which highlights the importance of goal setting that addresses successful community reintegration (Hilari & Northcott, 2006). Goal management training is an approach used with people with TBI and has been postulated as potentially valuable for others with impaired executive functions, an impairment that often occurs in those with a RH stroke (Ownsworth & Shum, 2008). Given similarities in the nature of CCD across the RH stroke and TBI populations there may be value in determining the efficacy of use of approaches found

beneficial in those with TBI to support goal identification related to return to social participation. Rehabilitation approaches that focus on the provision of education about psychosocial adjustment, that identifies valued social activities and roles and that includes significant others as partners in rehabilitation hold promise for this population.

This study found that the presence of CCD appears to create a risk for social participation restrictions, which is greater than reported following a RH stroke where communication remained unchanged. The majority of our daily activities and our interaction with others require communication. Altered communication and cognitive skills may be less visible than post-stroke physical impairments; however, the impact on social participation is significant. Future research is required to explore the impact that specific communication and cognitive profiles, and personal and environmental factors, may have on the life outcomes of people who have RH stroke.

Bridging statement

The results presented in the above paper allowed for three hypotheses to be tested in relation to *Aim 1* of this thesis. All three hypotheses were supported. People with a RH stroke report changes in their social participation with varying degrees across occupational activities, interpersonal relationships and independent living skills. The variability can partly be explained when comparing people with a CCD to people without a CCD. The presence of a CCD emerged as predictive of social participation change. The difference in participant-proxy perceptions of change that emerged confirmed that under-reporting of need for support to resume roles and relationships may be present post RH stroke if proxy reports are not included. This paper allowed for exploration of one impairment level variable that is hypothesised to influence participation, namely the presence of CCD. At an impairment level, particular aspects and/or severity of CCD may emerge as predictive as impaired cognition, given the frequent co-occurrence of communication and cognition impairments post RH stroke. Environmental (formal support such as access to rehabilitation and informal support related to social network characteristics) and personal variables (relationship status and change) that are known to influence participation in the presence of other acquired communication impairments such as aphasia will also be considered in Chapter Five.

Chapter 5

Aim 2 - Predicting Social Participation Change

“What annoys me most these days is that I think they should have spent more time on other things in rehab. I know they wanted him to get stronger in his arm and better with his balance, but it is as if they didn’t pick up on all the other stuff on the very first day leaving the hospital a lady got into a waiting taxi ahead of us and he said 'wow she is fat' out loud and I could just hide somewhere for the embarrassment. I had to warn all our friends about this. He is so reluctant to socialise now. Not really reluctant, I mean he would go along, but he looks so bored that conversations just pass him by” (Wife of a 64-year-old participant who spent 17 days in in-patient rehabilitation accessing five speech pathology sessions. Moderate CCD, MMSE: 23/30).

Chapter Four demonstrated that social participation change occurs in a large proportion of people with RH stroke, and that the degree of change is greater when a CCD is present. In *Chapter Five* the possibility of predicting, during the acute stage post stroke, who will be at risk for social participation change and isolation is explored. The chapter consists of two sections (studies) addressing two hypotheses towards addressing the aim of exploring: A risk profile for social participation restriction of people returning to community living following a RH stroke.

Study one considers impairment, personal and environmental risk factors for social participation that have been identified in prior literature (refer to Chapter Two). In particular this study considered how prevalent risk factors are related to i) the presence and severity of impairment in communication, and ii) lack of access to formal rehabilitation for people with RH stroke in comparison to a group of people with aphasia. The following hypothesis was tested: At the point of discharge from an acute or rehabilitation setting, persons with CCD would have a risk profile (that includes environmental, and impairment level information) for social participation restriction similar to people with aphasia.

Study two explores if future social participation could have been predicted during hospitalisation in the acute-stage following a stroke based on results obtained from routinely administered screens of cognition and communication. The following hypothesis was tested: Routinely administered screens of cognition and communication would not be able to predict future social participation change in people with RH stroke.

Study One: Exploring Risk Factors for Social Participation Restriction

A published manuscript has been inserted as *study one* of Chapter Five with minor wording changes and formatting according to APA style guidelines.

Hewetson, R., Cornwell, P., & Shum, D. (2017). Cognitive-communication disorder following right hemisphere stroke: Exploring rehabilitation access and outcomes. *Topics in Stroke Rehabilitation*, 24(5), 330-336.

Introduction

Fifteen million people experience a stroke annually, with higher income countries reporting increasing overall numbers of strokes in the presence of declining stroke mortality rates and increasing population age (Thrift et al., 2014). Globally, five million people are left with permanent disability post stroke. Stroke related changes in physical, cognitive and communication ability negatively influence return to vocational and social roles, with improved participation outcomes reported for those who access rehabilitation (Obembe & Eng, 2016). Rehabilitation outcomes, or the change in functioning that occur over a period of time during which a person receives therapy, was traditionally based on change at an impairment level. However, more recently an increase in a persons' ability to participate in life roles and complete activities independently is being considered as outcomes (WHO, 2011). While improved participation following rehabilitation is documented for people with the communication impairment of aphasia, (Le Dorze, et al., 2014; Simmons-Mackie & Damico, 2007), less is known about rehabilitation outcomes for people with a cognitive-communication disorder (CCD) after a right hemisphere (RH) stroke (Blake, 2016). One method to determine rehabilitation need is by considering prevalence data of particular health conditions that have a potential to restrict participation, and that would benefit from rehabilitation (WHO, 2011).

The communication impairments characterizing CCD, recently reported as present in 78% of people post RH stroke, are different to aphasia (Ferré, 2009). Aphasia is a language-level disorder typically resulting from a focal brain lesion in the language-dominant hemisphere, that can affect comprehension and use of language across written, spoken and auditory modalities (Papathanasiou, Coppens, & Potagas, 2013). Access and use of the building blocks of language related to vocabulary and syntax remains largely intact in CCD, but difficulties emerge in establishing a relationship between language and the context in which it is used thus affecting communication despite relatively intact linguistic ability (Ferré & Joannette, 2016). CCD following a RH stroke results in a diversity of presentation with impairment profiles now emerging that document changes in communication areas of lexical-semantics, pragmatics, receptive and expressive prosody, and/or discourse, as well as in cognitive functions that support communication (Abusamra, Côté, Joannette, & Ferreres, 2009; Ferré & Joannette, 2016; Tompkins, et al., 2000). The term cognitive-communication disorder was first used to define communication impairments arising following traumatic brain injury to highlight the interplay of impairments in communication and cognition, an interplay of impairments that also occurs following a right hemispheric stroke (Togher, McDonald, Coelho & Byom, 2014).

Positive health and wellbeing outcomes associated with access to rehabilitation justifies the longer hospital admission times that has been reported for people with more severe physical and cognitive impairments and more severe aphasia (Berkman, Glass, Brissette, & Seeman, 2000; Gialanella, Bertolinelli, Lissi, & Prometti, 2011). The severity of aphasia is also related to participation restriction experienced when returning to social roles post rehabilitation. (Hilari & Northcott, 2006; Hilari, et al., 2010; Simmons-Mackie & Damico, 2007). Rehabilitation outcomes such as change in independence in completing activities related to mobility, self-care and problem solving for people with a RH stroke are generally reported in aggregate, thus the variable influence of the presence, severity and characteristics of CCD on rehabilitation outcomes and how these outcomes relate to social participation is as yet not known.

Removing the influence of communication disorder, inferior physical recovery is reported following a RH stroke compared to a left hemispheric (LH) stroke. Inferior rehabilitation outcomes in the RH stroke population has been postulated to relate to cognitive and perceptual deficits such as unilateral spatial neglect (USN), however, methodological limitations are acknowledged for studies considering the influence of USN on functional outcomes (Cherney, Halper, Kwasnica, Harvey, & Zhang, 2001; Katz, Harman-Maeir, Ring, & Soroker, 2000; Robertson, Ridgeway, Greenfield, & Parr, 1997; Stein, Kilbride, & Reynolds, 2016). Cognitive deficits occur frequently, with up to 96% of people with RH stroke in a rehabilitation unit reported to have at least one cognitive process impaired (Blake, Duffy, Myers, & Tompkins, 2002). The incidence of cognitive deficits is important to consider as cognitive skills, in particular executive functions, support effective communication.

The number of people needing rehabilitation, based on the incidence of stroke-related impairments, is an important consideration in the planning and budgeting of rehabilitation programs as the financial cost of stroke rehabilitation can be significant (National Stroke Foundation, 2013). The incidence of CCD following first onset right hemispheric stroke still remains unclear, ranging from 50% in early research, to more recent estimates of up to 80% Benton, & Bryan, 1996; Joannette, & Goulet, 1994). Literature describing rehabilitation access for people with CCD is also limited. One study reported referral rates to speech pathology of 45% of people admitted to rehabilitation with RH stroke, surprisingly low considering the high incidence of communication impairments described for this population (Blake et al., 2002). The sensitivity of acute neurologic examination stroke scales in identifying people with mild CCD post RH stroke compared to people with aphasia has been questioned, (Blake, 2016), which may account for potential low referral rates. A paucity of acute phase screening tools

that consider the range of communication domains that may be impaired following a RH stroke creates a further challenge in standardised speech pathology assessment procedures across different services (Blake, 2016).

Rehabilitation has known advantages of supporting return to community roles and activities for people with aphasia, however, little is known about the likely need for access to and rehabilitation outcomes for people with CCD (Davidson, Howe, Worrall, Hickson, & Togher, 2008). Stroke-related physical impairment, USN and age at time of stroke onset have been associated with rehabilitation outcomes following a RH stroke, however, the severity of CCD has not been considered as another potential determinant of rehabilitation outcomes, as has been shown for aphasia following left hemispheric strokes. This exploratory study (1) describes rehabilitation need (based on the presence of a communication impairment), rehabilitation access and outcomes for people with CCD following in-patient rehabilitation; (2) compares rehabilitation access and outcomes in people with aphasia (PWA), and people with no communication impairment post stroke; and (3) identifies factors that are predictive of functional outcome at rehabilitation discharge in people with CCD.

Materials and Methods

Following ethical clearance from the relevant hospital Human Research Ethics Committee HREC/15/QPCH/13, a retrospective chart audit was completed for patients admitted consecutively over 24-months at a single hospital. Inclusion criteria were 1) unilateral first onset stroke diagnosed as per radiological imaging, 2) hospital length of stay (LOS) of at least 2 days, and 3) with documented results of screening assessments of cognition and communication by an occupational therapist and speech pathologist respectively. Exclusion criteria were 1) cerebellar, brainstem or bilateral strokes 2) prior acquired brain injury, diagnosed dementia or psychiatric illness, and 3) those deceased during admission. Charts were reviewed across acute and in-patient rehabilitation settings to address sampling bias related to patients not admitted to in-patient rehabilitation. Quality control and reviewer accuracy was ensured through a second reviewer for 10% of randomly selected charts.

Assessment and outcome measures

The presence of CCD and aphasia was determined by speech pathologists, using screening procedures comprising both formal and informal measures and severity ratings were based on the Australian Therapy Outcome Measures, AusTOM (Perry, et al., 2004). Patients with LH stroke were assessed on areas of auditory and reading comprehension and verbal and written expression using either the Bedside Western Aphasia Battery-Revised (Kertesz, 2007) or an informal screen of language that was routinely used with patients within 24 hours of admission in this study's audit site. The screening procedure for patients with RH stroke included a combination of subtests from the Measure of Cognitive-Linguistic Abilities (MCLA; Ellmo, Graser, Krchnavek, Hauck, & Calabrese, 1995) and Comprehensive Aphasia Battery (Swinburn, Porter, & Howard, 2004) as well as informal tools to evaluate lexical-semantics (verbal fluency with phonemic constraint, verbal reasoning and figurative language, complex sentence comprehension), discourse production (procedural and conversational), pragmatics (clinician observations and reports by family members), prosody (receptive and expressive affective prosody), and reading comprehension requiring written responses to questions with a combination of stated and inferred meanings. Post-stroke cognitive deficits were recorded based on occupational therapist and/or neuropsychologist reports and for the purpose of this study, included information about attention, reasoning and problem solving, awareness of deficits, and visuospatial perception which was determined using a range of tools including the Standardized Mini-Mental State Examination (Vertesi et al., 2001) and the Kitchen Task Assessment (Baum & Edwards, 1993). Results from the above assessment procedures and tools were included in this study as these tools were routinely used in the stroke and in-patient rehabilitation units of the recruitment site of this study and thus they were not selected by the investigators.

Rehabilitation gains, or functional outcomes, were evaluated for patients with aphasia, CCD and those without a communication impairment post stroke, who participated in in-patient rehabilitation using the Functional Independence Measure (FIM, Guide for the Uniform Data Set for Medical Rehabilitation, 1997) that measures level of independence across self-care, sphincter control, transfers, locomotion, and cognition (comprehension, expression, social interaction, problem solving, and memory). A seven-point scale represents amount of observed assistance required from 1 (total assistance) to 7 (total independence). The FIM has demonstrated reliability and validity as a rehabilitation outcome measure, however, it is

acknowledged that communicative and cognitive functioning are not comprehensively evaluated (Frymark, 2004; Ottenbacher, Hsu, Granger, & Fiedler, 1996). A FIM Gain score (change in FIM Total scores from admission to discharge) and FIM Efficiency (change in FIM Total scores in relation to LOS) was determined for each participant who accessed rehabilitation. For the purpose of this study a FIM Independence score was calculated (FIM Total score divided by the number of FIM items) to identify patients who required ongoing assistance to complete activities by discharge from rehabilitation, that is, a score below 6.

Data analysis

Statistical analysis was performed using Statistical Package for the Social Sciences (SPSS V22.0), with $p < .05$ considered significant. Descriptive statistics are provided for socio-demographic and clinical characteristics. Within group change and between group differences were analysed using Student's t -test, Chi-square test for independence, and one-way ANOVA. Linear multiple regression was performed to assess the impact of theoretically selected factors on functional outcomes for patients with CCD (dependent variable: FIM Total score at discharge). Factors considered in the model were based on prior literature considering potential predictors of functional outcomes following stroke and for the purpose of this study included 1) severity of the communication impairment (CCD), 2) FIM Motor score on admission to in-patient rehabilitation, 3) presence of USN and 4) age at time of stroke. The relationship among the factors were investigated using Pearson's r and Spearman's Rho correlations prior to undertaking the regression analysis.

Results

Over the two-year chart audit period, 387 people were admitted with stroke of whom 115 met the inclusion criteria. Communication impairment was recorded to be present for two-thirds of the 115 patients, comprising both left- and right-hemispheric strokes. Aphasia was diagnosed in 39 cases (68% of LH stroke group, $n=57$) and CCD in 38 cases (66% of RH stroke group, $n = 58$).

The groups were comparable on socio-demographic variables with approximately a fifth ($n = 27$, 21.6%) employed at the time of stroke and all were reported to be independent in mobility and self-care prior to admission. The severity of communication impairments on admission differed significantly between the two groups, $\chi^2(1, 77) = 5.7, p = .017$. Individuals

with CCD were more likely to be rated as mild in severity of communication impairment 63.2% ($n = 24$) than PWA who had a more even distribution of severity of communication impairment from mild to severe as shown in Table 5.1.

Table 5.1

Participant demographics

	CCD present <i>n</i> =38	Aphasia present <i>n</i> =39	No communication impairment <i>n</i> =38	<i>p</i> -value
<i>Socio-demographic characteristics</i>	% (<i>n</i>)	% (<i>n</i>)	% (<i>n</i>)	
Female	52.6 (20)	48.7 (19)	50.0 (19)	.94
Age (years): Mean $\pm$ <i>SD</i>	68.23 $\pm$ 14.4	73.79 $\pm$ 14.5	74.47 $\pm$ 11.4	.09
Age group: $\leq$ 65 years of age	34.2 (13)	25.6 (10)	26.3 (10)	.66
Married or de-facto relationship	50.0 (19)	48.7 (19)	60.5 (23)	.53
Employed prior to stroke	23.7 (9)	20.5 (8)	21.1 (8)	.94
Residential setting prior to stroke				
Independent, living on own	23.7 (9)	33.3 (13)	28.9 (11)	.86
Independent, living with family	71.1 (27)	61.5 (24)	68.4 (26)	.86
Supported, low care	5.2 (2)	5.1 (2)	2.6 (1)	.86
<i>Clinical characteristics</i>				
Stroke type, ischemic	84.2 (32)	84.6 (33)	84.2 (32)	.99
Stroke location, cortical only	73.7 (28)	79.5 (31)	50.0 (19)	.047
Access to rehabilitation	73.7 (28)	64.1 (25)	39.8 (15)	.005
Rehabilitation LOS: Mean $\pm$ <i>SD</i> ¹	27.8 $\pm$ 21.7	30.6 $\pm$ 16.4	23.9 $\pm$ 13.1	.54
Severity of communication impairment on admission ²				
Mild	63.2 (24)	30.8 (12)	-	.017
Moderate	26.3 (10)	35.9 (14)	-	.37
Moderate-severe or Severe	10.5 (4)	33.3 (13)	-	.09
Unilateral spatial neglect present	52.6 (20)	-	13.2 (5)	

¹ Rehabilitation LOS: CCD group $n = 28$, aphasia group $n = 25$, no communication impairment group $n = 15$. ²Severity of communication impairment based on AusTOM Cognitive-Communication scale for RH stroke group and AusTOM Language impairment scale for LH stroke group.

In-patient rehabilitation access and length of stay

Fifty-three of the seventy-seven patients with communication impairment were transferred from an acute stroke unit to an in-patient rehabilitation unit (refer to Table 5.2). No difference was found in access to in-patient rehabilitation between the group with CCD and the group with aphasia, $\chi^2(1, 77) = .44, p = .50$. Only 10% ($n=1$) of patients with CCD discharged from the acute stroke unit were referred for community-based rehabilitation (in-home), compared to 53% ($n=8$) of PWA. The reason for discharge with no further inpatient rehabilitation was most often stated to be that impairments were mild and unlikely to impact on return to independent activity.

For the sixty-eight patients who accessed in-patient rehabilitation there was no significant difference in rehabilitation LOS across the three groups, $F(2, 65) = .63, p = .54$. Similarly, no difference was found in rehabilitation LOS when comparing patients with CCD ($M = 27.8$ days, $SD = 21.7$) and PWA ($M = 30.6$ days, $SD = 16.4$; $t(51) = -.54, p = .59$).

Outcomes following in-patient rehabilitation

A paired-samples t -test revealed a statistically significant within group increase in FIM Total scores from admission to discharge for all three groups: CCD ($t = -7.41, p < .001$), PWA ($t = -7.80, p < .001$), and no communication impairment ($t = -6.06, p < .001$), with a large effect size for all three groups: .67, .62 and .72 respectively (refer to Table 8). All three groups demonstrated improvements in independence across a range of tasks as evaluated on the FIM scale from admission to discharge from in-patient rehabilitation.

There was no significant difference in FIM Gain ($F(2, 68) = 1.4, p = .25$) nor FIM Efficiency ($F(2, 68) = 1.2, p = .32$), based on the presence or absence of a communication impairment. By rehabilitation discharge, 53.6% ($n=15$) of patients with CCD, and 52.0% ($n=13$) of PWA required the presence of another person to provide direction, prompting or assistance based on a FIM Independence score, compared to 26.7% ($n=4$) of people without communication impairment, however, this difference was not significant, $F(2, 67) = 1.6, p = .21$. Reasons for ongoing direction, prompting or assistance required by these patients are difficult to interpret from the audit data, however, descriptively physical impairment related to mobility (walking) was severe for 7 patients with CCD, 8 PWA and all of the patients without communication impairment resulting in an inability to walk on discharge. The level of supervision during mobilisation that other patients required who were able to walk cannot be

Table 5.2:

Outcomes following in-patient rehabilitation

	CCD present		Aphasia present		No communication impairment		Within group change	Between group difference	
	<i>n</i> =28		<i>n</i> =25		<i>n</i> =15		<i>p</i> -value	<i>p</i> -value	
	Admission	Discharge	Admission	Discharge	Admission	Discharge		Admission	Discharge
<i>Functional Independence Measure</i>	<i>Mean ± SD</i>		<i>Mean ± SD</i>		<i>Mean ± SD</i>				
FIM Total Score ¹	71.5 ± 33.4	93.4 ± 30.1	72.9 ± 28.6	102.4 ± 18.7	79.8 ± 29.5	105.3 ± 27.7	< .001	.692	.274
FIM Motor Score ²	49.4 ± 27.6	66.2 ± 26.0	52.2 ± 25.7	75.1 ± 17.9	51.5 ± 23.6	74.0 ± 22.2	< .001	.922	.313
FIM Cognitive Score ³	22.3 ± 7.7	27.1 ± 5.3	18.9 ± 7.4	25.0 ± 6.8	28.3 ± 6.7	31.3 ± 5.7	< .001	.001	.008
FIM Gain	-	21.8 ± 15.6	-	29.5 ± 18.9	-	25.5 ± 14.9	-	-	.255
FIM Efficiency	-	1.06 ± 1.03	-	1.12 ± .89	-	1.60 ± 1.62	-	-	.322
<i>Australian Therapy Outcome Measure</i>	% (<i>n</i>)		% (<i>n</i>)		% (<i>n</i>)				
No impairment	-	14.3 (4)	-	8.0 (2)	100 (15)	100 (15)	-	-	-
Mild impairment	57.1 (16)	53.6 (15)	20.0 (5)	48.0 (12)	-	-	-	-	-
Moderate impairment	28.6 (8)	32.1 (9)	40.0 (10)	32.0 (8)	-	-	-	-	-
Moderate-severe or severe	14.3 (4)	-	40.0 (10)	12.0 (3)	-	-	-	-	-
Improved in AusTOM rating	-	50.0 (14)	-	72.0 (18)	-	-	-	-	.17
Discharged to pre-admission residence	-	78.6 (22)	-	76.0 (19)	-	86.6 (13)	-	-	.95
FIM Independence Score ⁴	-	56.4 (13)	-	48.0 (12)	-	73.3 (11)	-	-	.21

Note: ¹FIM Total scores range 18 – 126. ²FIM Motor scores range 13 – 91. ³FIM Cognitive scores range 5 – 35; higher FIM scores denoting greater levels of independence. ⁴Independent or modified independence-no helper based on FIM Total average score of 6 or higher

extrapolated, thus ongoing direction or prompting may reflect impairments in cognition or USN rather than physical impairment.

No significant difference was found in the number of people with CCD and PWA who improved in their communication ability ($\chi^2 (1, 53) = 1.8, p = .17$) based on a change in communication severity rating on the AusTOM scale. Despite improvements in communication, a high proportion of people with CCD (85.7%, $n=24$) and PWA (92%, $n=25$) were discharged from in-patient rehabilitation with ongoing communication impairments, of whom ten people with CCD (41.7%) and thirteen PWA (52%) were referred for further community-based rehabilitation.

When comparing the ability to return to home or to the same setting (e.g. home on own, home with others, residential care) on discharge from in-patient rehabilitation, no significant difference was found $\chi^2 (2, 68) = .09, p = .95$ between the group with CCD compared to PWA. Descriptively more people with CCD who were discharged to a residential care setting, required a high level of care (four of five) than PWA (one of five).

CCD severity as a predictor of functional outcome as measured on the FIM

Medium to large correlations were found between FIM Total score at discharge and three variables: CCD severity ($r = -.385, p = .020$), presence of USN ($r_s = .374, p = .024$), and FIM Motor score on admission ($r = .882, p < .001$) with age not strongly correlated and thus excluded in the model. No violations were found of the assumption of normality, multicollinearity nor homoscedasticity. The total variance explained by the model, containing three predictors (CCD severity, FIM Motor on admission, presence of USN), was 86.4%, $F (3, 32) = 31.47, p < .001$. CCD severity appears to be a clinical predictor of functional outcome post stroke, a predictive relationship that has previously been shown for USN and motor impairment in the RH stroke population and for the severity of aphasia following a LH stroke. FIM Motor on admission ($\beta = .80, p < .001$) was the most important independent predictor of functional outcome by discharge from rehabilitation.

Discussion

Communication post RH stroke remains an important area of inquiry as much remains to be explored about the frequency and severity of impairments and rehabilitation outcomes. The findings demonstrate that CCD occurs with comparable frequency to aphasia within acute and

in-patient rehabilitation settings, and that comparable rehabilitation gains may be expected following in-patient rehabilitation.

Prevalence data on stroke-related communication impairments with a potential to restrict participation, provide insight into rehabilitation needs and thus an estimate of people with stroke who would benefit from access to in-patient rehabilitation and referral to speech pathology. The frequency of CCD in this audit (66%), was higher than original estimates of 50% yet lower than more recent reports of 78% (Ferré, 2009). Variance in incidence has been attributed to inconsistency in terminology and assessment practices and sample selection of patients within rehabilitation settings alone where impairment may be more frequent and severe than for people with stroke who are discharged from an acute setting (Brookshire & McNeil, 2014). The current audit included patients discharged from both acute and rehabilitation settings and also from a single hospital, which increases consistency of assessment procedures. Despite the use of a routine screening procedure that resulted in consistently used diagnostic terminology related to impairments the screening procedure used by clinicians in this audit included a combination of formal and informal tools and was not a validated tool. The absence of a validated screening tool is a study limitation. Acute stroke screening tools to diagnose aphasia are in the literature, however a routinely used, standardised acute screening tool that considers all aspects of CCD and profiles of communication impairment is still not available to speech pathologists.

Despite CCD being diagnosed with similar frequency to aphasia, notable differences in the severity of communication impairment was found. This study found that 62.3% of people with CCD were rated as having a mild impairment. The AusTOM instrument that was used within the audit setting, which is routinely used in Australia to determine severity of CCD, does not require from a therapist to obtain proxy reports on how communication may have changed since the stroke. It has been said that people with aphasia communicate better than they speak, whereas those with RH CCD speak better than how they communicate, which reflects relatively intact basic linguistic skills following a RH stroke with a potential change in the style of communication (Myers, 1999). It is therefore possible that, without a familiar conversational partner's input on potential changes to communication style, therapists may have incorrectly estimated the degree of change in communication caused by the stroke. Acute phase screening procedures should include routine input from familiar conversational partners to ensure that changes in communication post stroke are diagnosed as CCD and not attributed to pre-stroke communication style differences.

Although communication impairments of CCD have been described as less obvious than aphasia, the presence of mild impairments may nevertheless influence social participation (Mackenzie & Brady, 2008). Wozniak and colleagues, (Wozniak, Kitner, Price, Hebel, Sloan & Gardner, 1999) illustrated this with comparable challenges in returning to vocational roles for people with LH and RH strokes despite milder communication impairments in the RH stroke group. Within the literature that considers participation outcomes for people with CCD following traumatic brain injuries (TBI) it has also been demonstrated that participation can be affected even in the presence of mild impairments (Togher, et al., 2014).

The potentially large group of people with CCD who would benefit from access to rehabilitation, motivates consideration of why prior reports of referral to speech pathology is comparatively low. Fewer published accounts of CCD are available compared to other acquired communication impairments, and current stroke scales may not be sensitive to detecting mild CCD, which may reduce rehabilitation professionals' awareness of the need for speech pathology intervention (Foerch, et al., 2005; Blake, et al., 2002). In addition to the risk of under-referral there is also a risk of under-diagnosis by speech pathologists due to a paucity of acute phase screening assessment tools that are sensitive and specific enough to detect mild impairments across all domains that may be affected. As has been highlighted for CCD following TBI, more sensitive and ecologically valid measures that consider complex cognitive-communication demands of communication across diverse roles and activities is needed (Togher, et al., 2014).

This audit found that the presence of communication impairment did not result in a statistically significant difference in LOS nor in functional gains. Patients with CCD (not controlling for severity of CCD) demonstrated FIM Gain and FIM Efficiency comparable to PWA. Furthermore, FIM scores on discharge were not dissimilar to what has been reported for a stroke population in general (Inouye, Hashimoto, Mio, & Sumino, 2001; National Stroke Audit, 2014). Similar to prior reports on the association between the severity and nature of aphasia and rehabilitation outcomes, the severity of CCD was correlated to FIM Total scores by discharge from rehabilitation.

Seventy-nine percent of people with CCD, and 76% of PWA, were discharged to their pre-admission residence following in-patient rehabilitation, which is in line with prior reports, on ability to return home post stroke rehabilitation (National Stroke Audit, 2014). The high proportion of people discharged home with ongoing CCD (85.7%), requires exploration of post-rehabilitation support needs and access. Unmet rehabilitation needs can limit activities

and restrict participation across vocational and social roles with potential negative outcomes related to social isolation, increased dependency on others and decrease quality of life (WHO, 2011).

This study extends findings on outcomes after stroke, in particular the influence of severity of communication impairments on rehabilitation outcomes. Despite extending knowledge on functional outcomes, the findings do not provide guidance on the likely ability of people with CCD to participate in social roles and activities. A number of features of the CCD that arises post traumatic brain injury have been identified as prognostic of participation restrictions, a prognostic relationship that also requires exploration in people with CCD post RH stroke.

Relatively small audit numbers create limitations in interpretation of the findings. A further limitation relates to the outcome measures, chosen because of routine use, as these measures may not adequately have identified disability (Oczkowski & Barreca, 1993). The restricted number of communication items and ratings in both the FIM and AusTOM scales may not have provided an accurate representation of independence in communication-related activities nor small improvements achieved during rehabilitation. Outcome measure scores are based on observations made within a rehabilitation unit, which may not be predictive of participation in situations requiring complex communication such as returning to prior social and vocational roles (Nichol, Higgins, Gabbe, Murray, Cooper & Cameron, 2011). Outcome measures that are ecologically valid and therefore relevant to the setting of future communication exchanges, are required to predict participation restrictions (Simmons-Mackie & Damico, 2001).

Conclusions

This audit provides rehabilitation providers with data to aid review of rehabilitation access for people with CCD post RH stroke. An exploration of the impact of mild CCD on the ability to return to social and vocational roles is required, as this audit found that a large number of people may be discharged from rehabilitation with ongoing CCD. A predictive model of social participation based on aspects such as CCD severity and characteristics would assist rehabilitation professionals to identify those most at risk for social participation restriction, which in turn will inform the provision of rehabilitation services.

Bridging statement

Study one considered impairment (presence and severity of communication impairment) and environmental (lack of access to rehabilitation) risk factors for social participation restriction present in a group of people with CCD compared to people with aphasia. Changes in social participation have been shown to be associated with a more severe aphasia and also when formal supports (including access to rehabilitation) are not present. In particular this study established if, at the point of discharge from an acute or rehabilitation setting, persons with CCD will have a risk profile (that includes environmental, and impairment level factors) for social participation restriction similar to people with aphasia.

The hypothesis that communication impairment would be present with similar frequency across the two groups was supported. CCD occurred with similar frequency to aphasia supporting the notion that people with LH and RH strokes face a similar risk for social participation restriction due to the presence of a communication impairment. However, there was a difference in severity which was seen in CCD being rated as mild more often than aphasia.

A concerning trend emerged, with more people with mild CCD being discharged from an acute setting without community-based rehabilitation than people with aphasia. Statements alluding to unlikely long-term impact of a mild CCD on ability to resume activities and roles were noted on review of charted discharge summaries. This trend supported further exploration of factors that might influence the decision to discharge without further support. *Study two* therefore considers to what extent routinely used assessment results can predict future support needs to resume social activities and roles.

Study two: Predicting Social Participation Restriction

Study two examined the hypothesis that differences in sensitivity would emerge when comparing routinely administered screens of cognition and communication in terms of their ability to predict future social participation in people with RH stroke. This section presents and elaborates on data presented at the Australasian Association for the Study of Brain Impairment, 2018 on “*Early prediction of social participation following right hemisphere stroke*” as a poster presentation.

Introduction

Stroke rehabilitation aims to reduce impairment and improve functional independence. A focus beyond improvement of function during activities of daily living, to improved participation upon discharge from hospital is increasingly considered to be an essential component of rehabilitation (Wolf, Baum & Connor, 2009). In fact, satisfaction with hospital-based stroke rehabilitation has been shown to be influenced by more than achievement of functional gains, with greater satisfaction reported by patients who perceive improvements in community-based participation and quality of life (Bölsche, Hasenbein, Reissberg & Wallesch, 2004).

Between 75% - 85% of people with stroke are discharged to their pre-admission residential setting following a period of rehabilitation (Oczkowski & Barreca, 1993). Despite aiming for functional independence many people are discharged home with ongoing stroke-related physical, cognitive or communication changes that influence the return to social activities and roles. More than 85% of people with a RH stroke were discharged from rehabilitation with ongoing communication impairment in a study exploring the rehabilitation outcomes of this population (Hewetson, Cornwell, & Shum, 2018). Assessment of ability to resume and maintain social roles and relationships post stroke allows for the evaluation of effectiveness of rehabilitation beyond the impairment level, and for identification of risk of future social isolation. Routinely administered screening measures are used during the acute stroke phase, to identify the presence of neuropsychological impairment and to aid determination of candidacy for rehabilitation access. However, it is not clear if these measures can predict long-term stroke outcomes, in particular a social participation restriction.

Literature to date highlights stroke-related clinical variables, socio-demographic and environmental factors that have a unique contribution to future participation in people with stroke. Severity of initial physical impairment (D'Alisa, Baudo, Mauro, & Miscio, 2005), sensory difficulties (Doyle, Bennett, Fasoli, & McKenna, 2010), impaired cognition (Viscogliosi, Desrosiers et al, 2011), impaired communication (Dickson, Barbour, Brady, Clark and Paton, 2008; Hewetson, Cornwell & Shum, 2018; Shadden & Agan, 2004; Viscogliosi, Desrosiers, et al, 2011), age (Ekstam, Uppgard, von Koch, & Tham, 2007; Viscogliosi, et al, 2011; Fleming, Kuipers, Foster, Smith & Doig, 2009; Geyh et al, 2011), relationship and employment status (Baumann, et al., 2012), and environmental factors related to access to rehabilitation (Baumann, et al., 2012) and support through a social network (Hilari, Northcott, Roy, Marshall, Wiggins, Chataway & Ames, 2010) have been identified as potential factors influencing successful community re-integration. The majority of research report risk factors for poor future social participation following a stroke in aggregate, irrespective of lesion location. It therefore remains unclear to what extent social participation restriction risk factors are present in people with a RH stroke, and furthermore in the presence of a CCD.

The impact of the stroke-related language impairment of aphasia on rehabilitation outcomes and participation has been shown. It is not only the presence of aphasia but particular features such as severity and impaired comprehension that has been related to compromised social participation (Tsouli, Kyritsis, Tsagalis, Virvidaki, & Vemmos, 2009). Patients with impaired comprehension in the presence of aphasia, had a five-fold greater risk of poor response to rehabilitation than when comprehension remained intact (Gialanella, 2011). Communication impairment has now also been shown to be predictive of stroke-related outcomes following a RH stroke with CCD severity emerging as a clinical predictor of functional outcome post stroke (Hewetson, et al., 2018).

Cognition can also impact rehabilitation outcomes following stroke in general, evident in the decreased likelihood of being discharged home following a period of rehabilitation when a low admission Cognitive Function score (5 to 20) on the FIM was obtained (Canadian Inst of Health outcomes, 2009). Differences in cognitive functions accounted for 13% to 27% of the variance in participation on discharge from rehabilitation in people with a range of pathological conditions (Jette et al., 2005). With respect to RH strokes, domain-specific cognitive impairments such as USN, anosognosia, and impaired executive function are considered to

hold prognostic value for functional outcomes (Cherney, Halper, Kwasnica, Harvey, & Zhang, 2001). Where USN was present, it was found to be a major predictor of performance in activities of daily living (ADL) and instrumental activities of daily living (IADL). However, in the absence of neglect other cognitive deficits such as impaired executive function skills were similarly significantly related to functional outcomes (Katz, Harman-Maeir, Ring, & Soroker, 2000; Robertson, et al., 1997). Executive functions, or higher-level cognitive abilities, appear to be especially important for complex behaviours post stroke such as successful community integration (Hanks, Rapport, Millis, & Deshpande, 1999).

A growing body of research suggests, however, that specific links between RH damage and extent of cognitive impairment may be less convincing than commonly believed. Brookshire and McNeil (2014) point out that because a left hemisphere brain damage control group is rarely included in RH damage studies, it is not possible to differentiate the general effects of brain injury from hemisphere specific effects. Gillespie, Bowen and Foster's (2006) meta-analysis of memory impairment in RH stroke found performance to be superior to that of participants with left hemisphere stroke for verbal recall and recognition tasks. It is therefore possible that some cognitive domains may be more significantly impacted than others, such as memory, following a RH stroke. A further consideration is that performance on neuropsychological measures may not predict performance in situations that are cognitively demanding compared to a standardised assessment context (Cahn-Weiner, Malloy, Boyle, Marran, & Salloway, 2000).

Depending on lesion location, stroke can produce a broad range of neuropsychological deficits. Existing cognitive screeners do not appear to have the scope to assess the wide range of cognitive domains often affected by stroke (Stolwyk, 2016). Van Heugten, Walton, and Hentschel (2015) in a recent systematic literature review found that no screening measures assessed all commonly affected cognitive functions following stroke. While the Montreal Cognitive Assessment (MoCA; Nasreddine, et al., 1996) most closely approached this criterion, it failed to measure a commonly impaired domain of information processing speed. A concern is that some patients may present with domain specific cognitive impairments, which are overlooked in favour of a composite cognitive score. Chan and colleagues (2017) reported that the MoCA may under-estimate cognitive impairment in RH stroke. In their study the RH patient group, with intact cognition as assessed by the MoCA, showed impairments in information processing speed (57%), executive function (46%) and non-verbal memory (31%) on neuropsychological assessment (Chan, Altendorff, Healy, Werring, Cipolotti, 2017). While

the MoCA has more items assessing executive functions than the MMSE, impairment in executive function was not detected in 46% of their RH patient group. A comparison of acute-phase stroke patient performance on The Oxford Cognitive Screen (OCS; Demeyere, et al., 2015), a domain specific assessment, versus generalized cognitive assessments (MoCA) revealed that close to 30% of patients were passing the MoCA in the presence of an impairment in one cognitive domain (Demeyere, Riddoch, Slavkova, Jones, Reckless, Mathieson, & Humphreys, 2016). The authors also reported under-representation of patients with RH stroke in the group found to present with cognitive impairment when a screen of global or generalized cognition was used (Demeyere et al., 2015). In clinical settings, under-identification of the need for additional assessment which in turn might more accurately identify impairments in cognition and communication, may negatively impact access to rehabilitation in RH strokes. Equity of access to rehabilitation for all patients with stroke is promoted in the Australian Clinical Guidelines for Stroke Management (2017).

It is unclear to what extent results on cognitive screening tools that determine global cognitive functioning are being used to determine candidacy for rehabilitation in this population. Screening and assessment measures that lack the sensitivity to identify functionally significant communication and cognitive deficits may result in under-identification of need for rehabilitation (Blyth, Scott, Bond & Paul, 2012). Research in the area of RH CCD suggests a disproportionate focus in referral processes and care-pathways on swallowing and motor speech deficits may exclude communications needs from provision of services. It had been estimated that less than half of those requiring evidence based SLP intervention receive referral for service (Blake, Frymark, & Venedictov, 2013; Hinckley, 2014; Tompkins, 2012).

In a study by the current authors it was found that social participation change is a frequent outcome following RH stroke (Hewetson, Cornwell, & Shum, 2018). Hewetson and colleagues (2018) reported 34 of 36 participants with RH stroke recorded changes in at least one of three SPRS-2 domains for social participation. Half of all participants employed prior to stroke could not return to work, and for a further 21% alterations to work tasks and roles were required. Social participation changes were reported more frequently and as being more severe, by participant-proxy dyads when CCD was present. Vocational change was greater for participants with CCD (83.3%) compared to participants without CCD (42.8%). Additionally, on discharge from hospital, seven of 12 participants with CCD who could not return to

employment, presented with a mild CCD, indicating participation restrictions can result from even mild impairment (Hewetson et al., 2018).

At present, it is not known if the risk for social participation change can be predicted during the acute stroke phase following a RH stroke. This study compared routinely administered acute stroke screens of communication and cognition with future reported social participation for people with RH stroke. The overall objective of this study was therefore to explore if routinely completed screening tools of communication and cognition, administered during the acute stroke stage, can predict long term social participation in those with RH stroke. The hypotheses were that 1) an impairment in cognition, as determined by a composite screening tool of cognition, will not accurately predict social participation, 2) an impairment in cognition related to a measure of executive function would predict social participation, 3) an impairment in communication would predict social participation with greater accuracy than both measures of cognition.

Method

This observational study is presenting an analysis of data that were gathered during a retrospective chart audit (Chapter 5, Study one) of consecutively admitted patients with stroke which was part of a larger study with ethical approval from the relevant hospital Human Research Ethics Committee HREC/15/QPCH/13.

Participants

Inclusion criteria for the study were 1) unilateral first onset RH stroke diagnosed per radiological imaging, 2) a hospital length of stay of at least 2 days, and 3) English proficiency at a level that would not warrant an interpreter during communication and cognition assessments. Exclusion criteria were pre-existing impairment or history that might influence cognitive or communication function, including history of prior neurological events, drug-dependence, psychiatric illness, dementia or reported cognitive decline preceding stroke onset.

Data collection procedure and instruments

Socio-demographic and acute-phase stroke assessment data of communication and cognition was gathered from medical records based on Occupational Therapist, Speech Pathologist, and/or Neuropsychologist reports. Results from three assessments were included, namely the

Mini Mental State Exam (MMSE; Folstein et al., 1975), Controlled Oral Word Association Test (COWAT), and an informal communication screen.

A global rating of cognition was based on the MMSE, a 30-point questionnaire where a score less than 24 indicates the presence of cognitive impairment. The MMSE was included as it was routinely used within the current study's data collection site, however low levels of sensitivity among those with mild cognitive impairment following a RH stroke has been reported in addition to being affected by age and level of education (Tombaugh & McIntyre, 1992).

Executive function was based on results from the COWAT. The term executive function is used as an umbrella for various complex cognitive processes such as task-switching, planning, and inhibition and is understood to be multidimensional (de Frias, Rixon, & Strauss, 2006). The COWAT, in particular verbal fluency with phonemic constraint (F-A-S), was selected as a screening task that is likely to provide insight into executive function (Ettenhofer, et al., 2006). Executive ability has been found to be more strongly reflected in performance on verbal fluency with phonemic constraint tasks than in category or verbal fluency with semantic constraint tasks (Shao, Janse, Visser & Meyer, 2014). The selection was further influenced by screening assessment tasks routinely administered at the site where data collection occurred. COWAT: F-A-S has been used as a test of executive control ability in adults with Parkinson Disease (Henry & Crawford, 2004) and those with damage to frontal brain areas (Schwartz & Baldo, 2001) and secondary to TBI (Hanks, Rapport, Millis, & Deshpande, 1999). It is acknowledged that COWAT: F-A-S performance may reflect a number of cognitive aspects such as inhibition, self-initiation, and switching ability (Hirshorn & Thompson-Schill, 2006). COWAT: F-A-S norms are available to reflect differences in performance related to age and education (Loonstra, Tarolow, & Sellers, 2010) and these were similarly considered when interpreting the scores of this study.

The presence and severity of a communication impairment was based on a routine screening assessment completed by Speech Pathologists at the study site. Assessment occurred across communication domains of i) lexical-semantics involving verbal fluency with phonemic constraint (COWAT F-A-S), interpretation of figurative language (MCLA; Elmo, et al., 1995) and comprehension of sentences (CAT; Comprehensive Aphasia Test), ii), oral discourse production and written discourse comprehension (MCLA, Elmo, et al., 1995), iii) pragmatics

(based on significant other reports and observations), and iv) prosody (informal assessment of receptive and expressive linguistic and affective prosody). CCD was determined as present by Speech Pathologists based on impairment of at least one of the four communication domains, and within lexical-semantics at least two of three tasks. No cut-off scores were used, and the tasks were weighted equally.

Stroke services within Australian hospitals make use of discipline specific impairment level scales such as the Australian Therapy Outcome Measure Scales (AusTOMS). The AusTOMS is an outcome measure with an ordinal scale that allows for descriptions based on severity of presenting communication changes from 0 (most severe, profound) to 5 (no difficulty) (Morris et al, 2004; Perry and Skeat, 2004; Unsworth and Duncombe, 2004). Severity of communication impairment was based on ratings made on the AusTOM Cognitive-Communication Scale (Enderby & John, 1997; Enderby et al, 1998). The AusTOM has been found to have excellent content, face, and construct validity (Morris, Perry, Unsworth, et al., 2005) and is able to measure change over time (Unsworth & Duncombe, 2005).

The SPRS-2 (Tate, 2011) Form A (Change in participation) was used to determine social participation, which was rated by a significant other. The SPRS-2, a 12-item rating scale, was developed for use with people who have sustained a brain injury and who are living in the community. Items are grouped across Occupational Activities (work and leisure), Interpersonal Relationships and Independent Living skills.

Data analysis

Statistical analyses were performed using Statistical Package for the Social Sciences (SPSS V22.0), with $p < .05$ considered significant. Descriptive statistics were used to describe all participants based on socio-demographic and clinical characteristics and to document reported change in social participation as per the SPRS-2. Total SPRS-2 raw scores were converted to logit scores as per the SPRS-2 scoring procedure.

Cut off scores for the MMSE are 1) cognition intact: score of 24 – 30, and 2) cognition impaired: < 24 . In line with the criteria outlined by Petersen and Morris (2005) an impairment on the COWAT: F-A-S test was determined to be present if a score greater than 1.5 SD below age and educationally determined norms were obtained. The F-A-S norms contained within the MCLA were used (Ellmo, et al., 1995). Participants were stratified based on global cognition score (group 1: score of 24 – 30, group 2: score < 24), executive function task score (group 1:

within norm, group 2: 1.5 SD below norm), and communication assessment (group 1: absence of CCD, group 2: presence of CCD). Independent group comparison tests (independent *t*-tests) were used to compare reported social participation (SPRS-2 logit scores) across the groups, viz CCD: present or CCD: absent, MMSE: impaired or MMSE: intact, and F-A-S: impaired or F-A-S: intact. Simple correlations examining the associations between individual screening tests and the outcome measure (SPRS-2 Logit) were conducted using Pearson's *r* and Spearman's Rho correlations. Sensitivity (impairment present and change in social participation) and specificity (impairment absent and no change in social participation) data is presented. A linear regression was performed to assess the ability of the three measures to predict social participation outcomes for patients with RH stroke (dependent variable: SPRS-2 Logit score). Factors considered in the model were 1) presence of CCD, 2) impaired cognition as determined on the MMSE, 3) COWAT: F-A-S 1.5SD below the norm.

Results

All RH stroke participants ($n = 36$, $M = 65.5$ years of age) were mobile and the majority ($n = 35$) discharged home. The demographical and clinical variables are presented in Table 5.3.

Table 5.3

Participant (N = 36) demographic and clinical variables

Demographic variables		Mean $\pm$ SD	n (%)
Age	In years	65.5 $\pm$ 13.5	-
Gender	Male	-	21 (58.3)
Marital status	With a partner	-	14 (38.9)
Education	>17 years	-	9 (25.0)
	13-17 years	-	15 (41.7)
	<13 years	-	12 (33.3)
Clinical variables		Mean $\pm$ SD	n (%)
Stoke type	Ischemic	-	32 (88.8)
MMSE ¹	Score	23.9 $\pm$ 4.4	-
CCD ²	Present	-	21 (58.3)
CCD severity based on admission AusTOM ³	Moderate-severe	-	2 (5.5)
	Moderate	-	6 (16.7)
	Mild	-	13 (36.1)
LOS ⁴	In days	20.7 $\pm$ 22.7	-
Mobility on discharge	Independent	-	36 (100)
Discharge destination	Unchanged	-	35 (97.0)
SPRS-2 ⁵	Score	68.3 $\pm$ 16.3	-

Note: ¹MMSE: Mini-Mental State Examination, ²CCD: Cognitive-communication deficits, ³AusTOMs Cog Com: Australian Therapy Outcome Measures Cognitive-Communication scale, ⁴LOS: Hospital length of stay in days, ⁵SPRS: Sydney Psychosocial Reintegration Scale.

Impaired cognition as a predictor of future social participation

Global measure of cognition (MMSE)

There was no significant difference on SPRS-2 mean scores when comparing participants with intact ($M=72.36$, $SD=15.0$) versus impaired cognition ($M=61.84$, $SD=16.72$) as per the MMSE groupings of intact (24 – 30 score) versus impaired (< 24 score) ($t(36)=1.962$, $p=0.6$). The magnitude of difference in the SPRS-2 mean scores (mean difference = 10.52, 95% CI: -.376 to 21.42) between groups was moderate to large (eta squared = .1). Refer to Table 5.4. There was a non-significant trend of patients with lower MMSE scores reporting lower social participation as measured on the SPRS-2.

Table 5.4

Between group comparison of social participation

		<i>n</i>	SPRS-2 ¹ Mean (SD)	<i>t</i>	<i>p</i>	η^2
Global measure of cognition (MMSE ²)	Intact	22	72.36 (15.00)	1.962	0.6	.1
	Impaired	14	61.84 (16.72)			
Executive function task (COWAT: F-A-S ³)	Intact	22	73.91 (16.58)	2.59	0.007	.16
	Impaired	14	59.40 (11.54)			
Communication impairment (CCD ⁴)	Absent	15	80.79 (14.31)	-5.091	0.000	.43
	Present	21	59.33 (10.99)			

Note: ¹SPRS-2: Sydney Psychosocial Reintegration Scale-2, higher score indicates better reintegration; ²MMSE: Mini-Mental State Examination; ³COWAT: F-A-S: verbal fluency with phonemic constraint; ⁴CCD: Cognitive-communication deficits

Executive function task (COWAT: F-A-S)

There was a significant difference on SPRS-2 mean scores for patients with intact executive function skills as measured on the F-A-S ($M=73.91$, $SD=16.58$) and patients 1.5 SD below norm based on age and education ($M=59.40$, $SD=11.54$; $t(36)=2.59$, $p=0.007$). The magnitude of difference in the SPRS-2 means (mean difference = 14.52, 95% CI: 4.19 to 24.82) was large (eta squared = 0.16).

Impaired communication as a predictor of future social participation*Communication impairment (CCD)*

There was a significant difference on SPRS-2 scores between the group of patients with CCD ($M=59.33$, $SD=10.99$) compared to the group without a diagnosis of CCD ($M=80.79$, $SD=14.31$; $t(36)=-5.091$, $p=0.000$). The magnitude of difference in the SPRS-2 means (mean difference = -21.45, 95% CI: -30.02 to -12.89) was large (eta squared = .43).

Communication or cognition as predictors of social participation outcomes

Descriptive correlations between screening measures and social participation as determined on the SPRS-2 is presented in Table 5.5. No violations were found of the assumption of normality, multicollinearity nor homoscedasticity. The total variance explained by the model, containing three predictors (CCD, MMSE, F-A-S), was R squared 44.0%, $F(3, 32) = 8.395$, $p < .001$. CCD presence versus absence ($\beta = .595$, $p = .001$) was the only variable making a statistically significant unique contribution to the model. The presence or absence of an impairment on the MMSE ($\beta = .013$, $p = .933$) as well as F-A-S within norm or 1.5 SD below norm ($\beta = .103$, $p = .535$) did not make statistically significant contributions to the prediction model.

Table 5.5

Correlations between acute-stroke screening data and social participation change (SPRS-2)

Variables	1	2	3
1. SPRS-2 mean score	-		
2. MMSE < 24	-.319	-	
3. COWAT: FAS 1.5 SD below norm	-.440 [†]	.416 [‡]	-
4. CCD: present	-.658 [‡]	.443 [‡]	.559 [‡]

Note: [†] $p < .01$, [‡] $p < .05$

Sensitivity and specificity

The sensitivity and specificity of the three acute-stage screening tasks were compared in terms of the ability to correctly identify someone with social participation change, reported in at least one SPRS-2 domain. Change within a domain was based on a domain mean score of 0 – 3, with 4 denoting no change.

Table 5.6 provides an overview of the findings. The screen for CCD was most sensitive amounting to 17 of 22 (77%) people with social participation change correctly identified and having the fewest false negatives (i.e. no CCD but altered social participation reported). The COWAT: F-A-S and MMSE were comparable at 0.54 and 0.5 sensitivity respectively. Specificity was highest for the COWAT: F-A-S (0.86) screen, which correctly identified 12 of 14 people without social participation change, followed by the MMSE (0.79) and CCD (0.71).

Table 5.6

Predicting social participation, sensitivity and specificity of acute screens

Measures	Social participation change			
	True positive n, %	False positive n, %	True negative n, %	False negative n, %
Impaired global cognition (MMSE < 24)	11, 50.0	3, 21.4	11, 78.6	11, 50.0
Impaired executive function (COWAT 1.5 SD below norm)	12, 54.5	2, 14.3	12, 85.7	10, 45.5
Impaired communication (CCD present)	17, 77.3	4, 28.5	10, 71.4	5, 22.7

Discussion

In response to poor participation and health outcomes for persons with RH stroke, recent studies have attempted to increase awareness of the need for rehabilitation that supports community integration by facilitating return to social roles, and maintenance of social networks and relationships (Hewetson, et al., 2018). The absence of a means to identify people who require rehabilitation has been raised as a potential barrier to efficacy and equity of rehabilitation (Blake, Frymark, & Venedictov, 2013; Hickley, 2014; MacDonald 2017). This study addressed a concern that under-identification of rehabilitation need for people with RH stroke may be present. It considers tools that may improve identification, already in use within clinical settings and that would therefore be a cost-effective way of risk identification. The use of a communication screening tool was found to be more sensitive in identifying future social participation challenges than either a global cognition score (MMSE), or executive function task performance (COWAT: F-A-S). This study found that communication and cognition screening tools, routinely used in acute stroke units in Australia, might not be equally sensitive as a means to predict future social participation challenges.

The ability to participate or engage in life situations, as defined in the ICF framework, may be influenced by a range of stroke related impairments including the ability to communicate. Communication underpins interactions with others in our community and stroke-related impaired communication in turn may influence participation in social roles and activities. The

National Stroke Guidelines (2017) requires from professionals to identify the presence of impairments in communication and/or cognition using appropriate tools and to ensure equity of access to rehabilitation for people who would benefit from rehabilitation.

The ability of some screening measures, such as the MMSE, to identify cognitive impairment following RH stroke in acute-phase stroke contexts has been questioned (Tombaugh & McIntyre, 1992). Notwithstanding known limitations of the MMSE, it remains a frequently used screening tool in acute stroke units in Australia. Under-identification of mild cognitive impairment or domain specific cognitive impairment may impact on access to rehabilitation services and potential under-referral to speech pathology services. This is particularly relevant in people with RH strokes, where it is understood that their need for speech pathology services is based on the presence of a combination of cognition and communication impairments, however a bias towards identification of those with left hemispheric strokes appear to be present (Blake, 2016). General stroke scales such as the National Institutes of Health Stroke Scale (NIHSS; Brott et al., 1989) have also been found to be biased toward identification of LH over RH strokes. The NIHSS appears less sensitive to mild symptoms of RH brain damage and also to people with RH stroke who do not present with neglect (Fink et al, 2002; Gottesman, Kleinman, Davis, Heidler-Gary, Newhart & Hillis, 2010). Neglect occurs in only 25% of the RH stroke population. The presence of aprosodia, the difficulty using or interpreting prosodic features of speech, has been suggested to be more sensitive of RH stroke (Dara, et al, 2014; Foerch, et al, 2005). Considering the three screening measures evaluated in the current study, only the screen of communication would have detected aprosodia. Screening tools, designed to detect specific impairments in cognition that may occur following a RH stroke, may demonstrate a greater association with future social participation outcomes. The MMSE provides a global or composite score of cognition while the COWAT could be considered domain specific (executive function). In the current study, changes in reported social participation was not associated with a global score of cognition based on the MMSE cut off score of < 24. This finding supports careful consideration of how the MMSE is used to inform decisions about referral for rehabilitation post RH stroke. A strong case can be made for the routine use of a communication screener that considers all domains that are known to be vulnerable to change in the presence of RH damage.

Irrespective of the ability of acute screening measures to identify impaired cognition and/or communication, the relevance of such impairments for successful return to and maintenance of social roles and relationships warrants future exploration. Various studies have

investigated stroke recovery trajectories by measuring functional gains achieved during rehabilitation while others consider subjective experiences as reported by people with stroke. The complexity of meaning-making processes for people with stroke requires a consideration of the extent to which a stroke disrupts perceptions of ability to resume and maintain meaningful tasks, roles and relationships (Arntzen, 2015). The current study demonstrated that when impairment level data is used to make decisions about community-based support needs, careful consideration should be given to the likelihood of particular data (results) to be associated with future participation restrictions. For rehabilitation clinicians to understand such associations, consideration must be given to self and proxy reports of long-term stroke outcomes related to participation.

A potential limitation of this study was that the presence and severity of CCD was determined with an informal screening measure rather than a standardised and validated tool. A battery of assessment subtests and informal assessment tasks tapping into lexical semantics, prosody, pragmatics, discourse and functional reading and writing were used in this study. Standardised screening assessments of CCD post RH stroke, that are ecologically valid, are limited and is an area of speech pathology that requires development. The results also represent routine screening practices within a single hospital in Australia, which might not be representative of all acute stroke units. The inclusion of proxy reports, and a focus on social participation change rather than activity levels (e.g. frequency of contact with social network members) were strengths of the current study.

The findings of this study challenge rehabilitation professionals to consider how access to rehabilitation services are determined during the acute-stroke phase of hospitalisation. Without sensitive means to identify rehabilitation need, people may be denied an opportunity to improve their stroke-related outcome of resuming and maintaining social participation.

Bridging statement

In *Chapter Five* the possibility of predicting risk for social participation change was explored. A few factors emerged that could be included in a risk profile for social participation restriction of people returning to community living following a RH stroke.

Study one described a group of people with RH stroke, admitted consecutively and randomly selected in terms of the presence of risk factors that have been identified in prior literature as relevant for social participation (refer to Chapter Two). In particular this study considered how prevalent risk factors related to the presence of impairment in communication, and a lack of access to formal support (rehabilitation) are in people with RH stroke in comparison to a group of people with aphasia. It was found that RH strokes created a comparable risk that communication impairment may be present than what is found in the presence of LH strokes. This was an important starting point to highlight frequency of need for rehabilitation post RH stroke and challenges current low speech pathology caseload numbers for this population. A reassuring finding, based on this single recruitment site, was that access to in-patient rehabilitation was comparable for people with CCD and PWA. However, a concerning finding was that only 10% of people with CCD were referred for ongoing speech pathology services on discharge which was significantly lower than referral rates for people with aphasia (52%). Reduced access to rehabilitation for communication impairment creates a risk for restricted social participation. Study one further provided support for access to rehabilitation by demonstrating comparable activity level gains and improvement in communication ability for those with CCD compared to aphasia, albeit with a slightly longer period of access to rehabilitation.

Study two considered how health professions, who make decisions concerning access to rehabilitation, may be supported in identifying rehabilitation needs based on risk for social participation restriction. Routine practice was explored to identify frequently used screening tools that may contribute to referral decisions. Study two demonstrated that acute-stroke administer screens may not equally predict future social participation change. In particular the value of using a global cognition score is challenged, and questions emerged regarding use of domain specific tasks that have been demonstrated to be impaired secondary to RH damage as a more sensitive measure. Determining if CCD was present, again emerged as an important aspect of a risk profile, however, questions again arose as to the aspect of CCD that might be most predictive of social participation. Chapter Six offers a detailed exploration of social participation outcomes in people with a particular impairment post RH stroke, as an initial exploration of domain specific impairments that might be informative of rehabilitation need.

Chapter 6

Aim 3 – The Impact of Social Participation Change

“His emotions and communication definitely changed. It was like living with a toddler who didn't understand human emotions and how to respond. I remember sitting on the couch crying one day and he just looked at me and changed the subject, as if he didn't even realise that I was sad I still have to remind him not to cut people off in conversations and make excuses for him when he is rude ... He seems to go well with old friends as long as it is just one or two mates but add their partners to the mix with unfamiliar topics and he is lost - he then tends to just change the topic and can say embarrassing things.”

(Wife of a 67-year-old retired man admitted for 23 days to in-patient rehabilitation with a mild CCD and MMSE score of 23/30)

Chapter Five demonstrated that careful consideration is needed when using acute-stroke screening assessment data as a means to make decisions about rehabilitation and to predict future social participation. It appeared that communication impairment, determined through screening assessment tasks, during the acute-stroke phase of recovery holds value to be considered within a predictive model of social participation. At this point in the thesis information has also been presented on the frequent reporting of social participation change by self-and proxy report in people with CCD post RH stroke.

Chapter Six considers a group of people who share a characteristic feature of CCD post RH stroke, that being impaired social cognition. The information presented in Chapter six aims to demonstrate the impact social participation change had on people with CCD. This exploration involving consideration of reported relationship and social network change, role loss, and perceptions of quality of life that have occurred since onset of RH stroke. The following constitutes a manuscript that is yet to be submitted for publication, titled “*Quality of life and social networks in the presence of social cognition impairment following a right hemisphere stroke: a multiple case study.*”

Introduction

Impairments in communication and neurocognitive domains can influence the ability to return to social roles and relationships in people with stroke and traumatic brain injury (Brown, Gordon, & Spielman, 2003; Cruice, Worrall & Hickson, 2006; Dalemans, De Witte, Beurskens, Van Den Heuvel, & Wade, 2010; Turner, Fleming, Cornwell, Haines, & Ownsworth, 2009). Social participation change has been described for people with a RH stroke, and the presence of a cognitive-communication deficit (CCD) found to be predictive of the extent of participation change (Hewetson, Cornwell, & Shum, 2018). Unmet social participation needs may result in negative psychological and health-related outcomes following stroke, and influence perceptions of quality of life (Berkman, Glass, Brissette, & Seeman, 2000). Quality of life and maintenance of a social network have not been explored for people with CCD following a RH stroke. It is furthermore not known if particular impairments across cognition and communication may create a risk for social isolation and poor quality of life.

Longer term outcomes related to maintenance of group membership and social roles have been identified as challenging for people with cognitive and communication impairments (Hilari & Northcott, 2006; Northcott & Hilari, 2011). With regards to frequency of

communication-based activities, people with the language impairment of aphasia have fewer telephone conversations and attend fewer social activities than aged matched controls (Davidson, Worrall, & Hickson, 2003). Similarly, a group of people with CCD reported reduced social participation more often than people without a communication impairment post RH stroke (Hewetson, et al., 2018). In addition to reduced quantity of communication activities, people with aphasia (PWA) after LH stroke, report a reduction in the size of their social networks and lower satisfaction with social engagements (Cruice et al., 2006; Hilari & Northcott, 2006; Hilari, 2011). Social isolation risk emerges where social networks change (Boden-Albala, Litwak, Elkind, Rundek, & Sacco, 2005).

Change over time in social networks is one way to explore the process of involuntary isolation that can occur following acquired brain injury. The impact of social isolation may however be under-reported in people with reduced insight, as could occur following a RH stroke. Low scores on cognitive tasks, including awareness of impairment, have been noted in up to 68% of those with a RH stroke (Cherney, Halper, Kwasnica, Harvey, & Zhang, 2001). CCD also occur often, in 63 to 78% of cases with RH stroke (Hewetson, Cornwell & Shum, 2017; Blake, 2017; Myers, 1999). The co-occurrence of communication and cognitive deficits is important to consider as cognitive skills support effective communication and may account for a number of communication features associated with CCD. CCD is most evident during complex communication tasks, and likely due to an interplay of communication, neurocognitive and social cognition impairments.

This study focussed specifically on a group of people with impaired social cognition after a RH stroke. Social cognition has been described as “pivotal to successful interpersonal interactions” (McDonald, Togher, & Code, 2014, pg. 145). We relate to others by way of social cognition and an impairment in social cognition may influence the way in which communicate with others (McDonald, et al., 2014; Reis & Downey, 1999). One aim of this study was to consider relationship change. This focus necessitated including impaired social cognition as a potential source of relationship vulnerability. Our ability to communicate effectively is essential not only to the establishment of relationships but also the maintenance of such relationships and our participation in social roles (McDonald, et al., 2014). Social cognition allows for recognition and interpretation of interpersonal cues which is essential for effective communication. Impaired social cognition may arise due to difficulty processing emotion and impairments in Theory of Mind (ToM) or difficulty inferring intentions, thoughts and beliefs held by others (McDonald, Honan, Kelly, Byom, & Rushby, 2014).

Evidence considering social cognition impairment after TBI supports the notion that poor emotion perception and social inferential reasoning are sources of interpersonal difficulty (McDonald, et al., 2014). In people with TBI, difficulty on The Awareness of Social Inference Test (TASIT-R), an ecologically valid assessment of social cognition, was particularly evident when a mismatch occurred between words and non-verbal expressions across both first-order ToM tasks (judging speakers' emotions and beliefs) and second-order ToM tasks (what a speaker intended their conversational partner to believe) (McDonald & Flanagan, 2004; McDonald, Flanagan, Rollins, & Kinch, 2003). Impaired ToM has similarly been identified following RH stroke and proposed as an underlying cause of communication breakdown (Borod, Bloom, Brickman, Nakhutina, & Curko, 2002; Dara, Bang, Gottesman, & Hillis, 2014).

Determining the presence and nature of social cognition continues to be an area of debate as ecological validity is challenging to ensure, and stimulus material requires consideration in those with concomitant communication impairments (Martin & McDonald, 2003). It remains unclear to what extent emotion perception and ToM contribute individually to social understanding. It has however been found that difficulties on the Emotion Evaluation subtest of the TASIT-R may occur in isolation from difficulties on the inferencing tasks in a group of people with TBI. This dissociation across TASIT-R tasks was postulated to reflect differences in underlying pathology and the heterogeneous nature of TBI by the authors (McDonald & Flanagan, 2004). Dissociations based on lesion locations have also been identified when comparing affective ToM (bearing some resemblance to emotion perception) and cognitive ToM, as well as the valence of emotion cues, that being positive as opposed to negative emotions (Mitchell & Phillips, 2015).

The exploration of social network and relationship change following a RH stroke in the current study required a multifaceted approach that considered the nature and purpose of communication. Most communication is transactional in nature and impaired social cognition may impact this transaction. The transactional dimension of participation can be explored through the Social Convoy Model of social relations that contends that individuals interact with others who move with them through their life course and experiences of health conditions (Antonucci, Ajrouch, & Birditt, 2014). Social network analysis, as approached in the current study, therefore explored experiences of both the person with stroke as well as a significant other. Furthermore, involvement in a social network can be understood by considering a taxonomy of social activities as proposed by Levasseur and colleagues (2010). The taxonomy

allows for description of communication-based activities that includes interaction with others across a continuum in which the person may be passive to very active and the goals of activities range from being orientated to basic needs, socially oriented, task oriented, oriented towards helping others and being society oriented (Levasseur, Richard, Gauvin, & Raymond, 2010).

The importance of relationships in maintaining satisfaction with QoL following stroke emerged as a key theme in a meta-synthesis of qualitative studies about quality of life post stroke (Salter, Hellings, Foley, & Teasell, 2008). Positive gains in physical function, psychological resilience and overall perception of quality of life has been documented for those who have access to a large social network that offer interactions perceived to be supportive in nature (Hilari & Northcott, 2006; Hilari et al., 2010). Health related quality of life in PWA has been found to be more severely affected compared to people without a communication impairment. In chronic aphasia, reported low levels of QoL was associated with severity of aphasia (Hilari, Wiggins, Roy, Byng, & Smith, 2003). In terms of social cognition impairments, Cooper and colleagues found a significant correlation between stroke related impaired emotion perception and QoL (Cooper, Phillips, Johnston, Radlak, Hamilton, & McLeod, 2014). Two factors emerged as strongly predictive of health-related QoL, that being extent of restriction on social participation and ability to participate in highly valued roles (Hilari & Northcott, 2006; Kersten, Low, Ashburn, George, & McLellan, 2002).

The maintenance of social networks, relationships and roles have not been documented as long-term outcomes for people with a social cognition impairment following RH stroke. The lack of evidence is surprising given the frequency of occurrence of CCD as well as evidence that altered interpersonal communication can create a social isolation risk. Social functioning and communication-based participation are dependent on social cognition skills, making this an important concept to explore (Malle, Moses, & Baldwin, 2001). The aims of this study were therefore to (1) describe change in social networks, roles and relationships, and, (2) determine if the reported changes are related to reduced quality of life in the presence of social cognition impairment after RH stroke.

Method

A multiple case study methodology incorporating qualitative and quantitative data was utilised to allow exploration of differences within and between cases (Yin, 2014). The multiple case

study design is appropriate due to the contextual and multifaceted nature of long term stroke outcomes for people with communication impairments. Ethical clearance was obtained through the relevant hospital and university ethical committees.

The unit of analysis was participant-proxy dyad descriptions of experiences of returning to and maintaining social roles, relationships and social networks in the presence of varying degrees of social cognitive impairment. Boundaries, as defined by Yin (2014), related to activity, time and definition were determined. The activity of interest was returning to and maintaining social roles, relationships and networks. The time frame was 8 to 13 months post stroke onset. Social participation was narrowed and defined in this study as the engagement in social roles, relationships and networks that require transactional communication between individuals, who interact with each other toward a particular goal (Antonucci, et al., 2014; Levasseur, et al., 2010).

Case sampling

The cases are participant-proxy dyads, who were purposively sampled based on set criteria. Participants were selected as they were experiencing the phenomena of returning to social roles and relationships in the presence of a CCD characterised by social cognition impairment. This approach allowed for the description of a group in depth which is similar to homogeneous sampling described by Patton (1990). Sample size in the multiple case study approach is determined by the number of cases needed to reach a point of data saturation, which generally is achieved through the inclusion of six to ten cases (Yin, 2014).

Participants were identified, and consent to contact obtained by speech pathologists working in a stroke and rehabilitation unit at a single recruiting hospital. Eligible participants met the following criteria, i) first onset unilateral RH stroke determined through radiological evaluation, ii) no prior neurological events nor psychiatric history, iii) diagnosed CCD following a speech pathology assessment, iv) presence of impaired social cognition as determined on the TASIT-R, and v) return to pre-stroke residential setting on discharge from hospital. Proxy participants met the inclusion criteria of, i) living with or in daily contact with the participant, and ii) identified by the participant as someone who knows them well currently and prior to stroke onset.

Theoretical propositions

Propositions, as defined by Yin (2014), were theoretically developed in reviewing the literature about social network change, social cognition and QoL in the presence of a communication impairment post stroke and TBI. Three propositions were tested in this study, namely that: i) people with social cognition impairment post RH stroke would experience social network change evident in a reduction of the size of the network and the frequency of contact with network members, ii) relationship change following a RH stroke, would be more significant in the presence of a more severe impairment in social cognition, and iii) valued roles would be lost in the presence of impaired social cognition post RH stroke and where valued roles were lost a greater reduction in quality of life would be reported.

Data sources and instruments

Multiple data sources were utilised, including quantitative questionnaires, archival records and interviews. Data was collected and analysed concurrently to enhance credibility and to reach a holistic understanding of the phenomenon (Yin, 2014).

Archival records. Records were accessed to gather sociodemographic and clinical data related to age at time of stroke onset, education, occupation and marital status as well as stroke location and onset, and discharge destination. Data about the presence of a CCD and social cognition impairment, inclusion criteria to the study, were also collected from records. The presence of CCD was determined during hospital admission by speech pathologists, using a screening assessment protocol that considered lexical-semantics, discourse production, pragmatics, receptive and expressive prosody, and functional reading and writing. Impaired social cognition was based on the TASIT-R (McDonald, et al., 2003) results gathered during hospital admission or within a few weeks after discharge from hospital.

Questionnaires. Reported change in social participation was determined by the 12-item SPRS-2 (Tate et al., 2012). The SPRS-2, developed for use with people with brain injury, explores community-based participation across three domains; that being Occupational Activities, Interpersonal Relationships and Independent Living Skills. Total scores range from 0 to 48 with a higher score indicating greater levels of participation or psychosocial functioning. The SPRS-2 was administered during a face to face interview with both the participant and a proxy simultaneously, during which they were asked to select from a 5-point

scale with 0 = extreme degree of change to 4 = no change. Participant-proxy agreement has been found to be fair to moderate across the three SPRS-2 domains for people with a RH stroke, with participants with more severe CCD tending to rate themselves as experiencing less change in participation than their proxies (Hewetson, et al., 2018). The simultaneous completion of the SPRS-2 allowed for participant-proxy discussion, leading to a consensus on each item.

Perceptions of importance of different social roles and the extent to which changes to these roles are considered as negative, were established using the Role Checklist (Oakley, Kielhofner, Barris, & Reichler, 1986). The Role Checklist is not specific to any diagnostic population and explores past, present and planned roles; and secondly, asks participants to assign a significance or value to each role. The Role Checklist was completed during a face-to-face interview with participant-proxy dyads.

Perceived QoL was determined using the SS-QOL (Williams, et al., 1999), which has been described in Chapter Three of this thesis. The SS-QOL was completed in an interview format with participant-proxy dyads in which they were asked to rank each item on a 5-point Likert scale where higher scores indicate better function or less change since stroke. An SS-QOL domain scores of < 4 is reflective of impaired QoL. The use of a participant-proxy consensus process on the SS-QOL was again used as a preferable approach to excluding participants with reduced insight post stroke. Participant-proxy agreement on scales of QoL has been found to be moderate to substantial in the post-acute stroke period with overestimation of impairments by proxies more prevalent during the acute period (Oczkowski & O'Donnell, 2010). No participants were in the acute phase of stroke recovery in the current study. To further increase participant-proxy agreement, as recommended when proxy report is used on the SS-QOL, all proxies were living with the participants and in daily contact with them (Lynn Snow, Cook, Lin, Morgan & Magaziner, 2005; Muus, Petzold & Ringsberg, 2009)

Semi-structured interview. Analysis of social networks entailed a face to face semi-structured interview with each participant-proxy dyad in which a visual representation of the social network was co-constructed. A script (Appendix A), adapted from the National Social Life, Health and Aging project guided the interview and data gathered was furthermore based on Levasseur and colleagues' taxonomy (Cornwell, Schumm, Laumann & Graber, 2009, Levasseur, et al, 2010). Measuring the frequency of performing pre-determined activities and roles brings challenges as this may not capture pre-morbid participation levels and makes assumptions of the degree of participation that may be common across all people. Participants

were therefore asked how their social network would have been different prior to the stroke related to network composition, viz (i) the size of the network and (ii) the relationships with people within the network. Further data was collected on change in (iii) frequency of contact with members of the network; (iv) purpose of interactions (basic needs oriented, socially oriented, task oriented, oriented toward helping others); and (v) perceptions of changes in relationships. Interviews were digitally recorded, and recordings were transcribed verbatim.

Direct observation of communication. The Measure of Participation in Conversation (MPC) scale, which forms part of the Adapted MPC and MSC Scales (Togher, Power, Tate, McDonald, & Rietdijk, 2010) was used to describe the communication of participants observed during the interviews. The MPC consists of two subscales, namely Interaction and Transaction with items scored on a Likert scale in 0.5 levels ranging from 0 (no participation), 2 (some participation) to 4 (full participation in conversation). The MPC was developed to assess communication interaction in real-life contexts, and in particular in the presence of CCD.

Data management and analysis

An evidence database was created to organise and store case data, ensuring a chain of evidence was maintained to allow tracking of assertions back to their original evidence sources (Yin, 2014). Descriptive statistical analyses allowed for an overview, with tabulated frequency data; means; and standard deviations.

As proposed by Yin (2014) each data source was initially analysed independently. Data collected using the TASIT-R, SPRS-2, Role Checklist and SS-QOL were scored and analysed according to the standard scoring and interpretation procedures of these measures. Impairment on individual parts of the TASIT-R was determined to be present, if the scores were ≤ 1.5 SD based on the norms published by McDonald and Flanagan (2004). The cut off scores across the three parts were therefore: 21.5 for the Emotion Evaluation Test, 46.9 for Social Inference – Minimal (SI-M), and 44.9 for Social Inference - Enriched (SI-E). Potential unique contributions of emotion evaluation as opposed to ToM on social inferential reasoning and therefore relationship maintenance has been acknowledged, and thus, interpreted separately in this study. A severe impairment in social cognition, for the purposes of this study was based on scores 3.5 SD below the norm, that being a score of ≤ 17 on the Emotion Evaluation Test, ≤ 38.4 on SI-M, and , ≤ 32.9 on SI-E.

The SS-QOL yields both domain and an SS-QOL summary score. Domain scores are unweighted averages of the items in each domain and the SS-QOL summary score is an unweighted average of all domain scores. In addition to the mean and standard deviation of SS-QOL summary score, a rank score between 1 to 5 is provided for each participant's SS-QOL domain score with scores of ≥ 4 considered to indicate relatively good QoL. The inclusion of the rank score allowed for easier interpretation of the data and relates directly to the scoring used on the SS-QOL where 4 indicates only 'a little help / a little trouble / moderately disagree (that a change has occurred)' and a score of 5 indicates 'no help needed / no trouble at all / strongly disagree (that a change has occurred)'. Inductive thematic analysis was used as the analytic strategy for the qualitative data (Baun, 2003).

Analysed data sets were converged and linked to each of the three propositions to ensure focussed analysis based on the scope of the research (Yin, 2014). Analysis techniques included pattern matching and cross-case synthesis where rival interpretations are considered based on supporting and challenging data (Yin, 2014). The process of pattern matching involved stating the propositions, testing the pattern found from each data source against the predicted pattern, and offering explanations. Dependability was ensured through triangulation with multiple sources of data and analysis procedures. Direct quotations of participant interviews are offered to further increase dependability. Pseudonyms are used to ensure confidentiality.

Results

Case descriptions

A summary of socio-demographic and clinical features of each case is presented in Table 6.1. The cases represent seven participant-proxy dyads. Participants ranged in age from 54 to 80 years (mean 66 years). All participants had a radiologically diagnosed, first onset, ischemic RH stroke that occurred between 8 to 13 months prior to participation in the study. More male stroke participants were recruited ($n = 5$, 71%) and participants were predominantly married and living with a spouse both prior to and after stroke onset ($n = 6$, 86%). At the time of stroke, three participants were employed (43%), two in a part-time capacity and the third in a home-based business. All participants were independent in all activities of daily living prior to the

Table 6.1

Case demographic and clinical details for participant-proxy dyads

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
Participant							
Age	54	62	61	80	79	67	69
Gender	Male	Male	Female	Male	Male	Female	Male
Marital status	Widowed	Married	Married	Married	Married	Married	Married
Children	2	3	6	2	2	3	2
Employment, at time of stroke	Part time manual labourer	Retired aged care worker	Full time home industry, foster carer	Retired truck driver	Retired electrician	Part time bookkeeper	Retired manager
Employment, current	Unemployed	Retired	Unemployed	Retired	Retired	Retired	Retired
Stroke type	Ischemic subcortical	Ischemic cortical & subcortical	Ischemic cortical	Ischemic cortical	Ischemic cortical & subcortical	Ischemic cortical	Ischemic cortical
Rehabilitation length	Nil	7 weeks	2 weeks	8 weeks	Nil	1 week	2 weeks
Time post stroke	12 months	13 months	11 months	8 months	13 months	12 months	13 months
CCD ² severity at discharge	Mild	Mild-moderate	Moderate	Moderate	Mild	Mild	Mild
Mobility at discharge	No support	Wheelchair	No support	Support with stairs	No support	No support	No support
Proxy							
Relationship to participant	Adult daughter	Wife	Husband	Wife	Wife	Husband	Wife
Employment status, current	Part time retail assistant	Part time bookkeeper	Full time engineer	home maker	Retired teacher	Retired clerical	home maker

stroke. Five of the seven participants (71%) were independently mobile at the time of hospital discharge. Case 2 required a wheelchair for mobilisation outside of the home and assistance to walk short distances in the home. Case 4 was described as independently mobile however supervision was required with stairs due to impaired balance. Proxies were predominantly spouses ($n = 6$, 86%) with one adult daughter acting as proxy in Case 1. The daughter had been living with the 54-year old participant for four years at the time of data collection and was in daily contact with the participant. She was identified by the participant as someone who knew him well.

All participants were diagnosed with a CCD. All participants were also identified as having impaired social cognition (refer to Table 6.2) based on below norm performance in at least one part of the TASIT-R, with most participants demonstrating impairment across two parts that were 1.5 SD or more below the norm. Case 2, 4 and 7 were identified as having a severe impairment on the Emotion Evaluation test (≤ 3.5 SD below norm). Three participants were identified as having a severe impairment on the Social Inference subtests (≤ 3.5 SD below norm), that being, Cases 3 and 4 on SI-E and Case 4 on SI-E.

Table 6.2:

Participant clinical / questionnaire data

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
TASIT-R ¹ Total score	112	113	95	76	104	97	109
Part 1 ²	20 ¹³	15	20	13	19	20	16
Part 2 ³	47	49	38	33	48	40	47
Part 3 ⁴	45	49	37	30	37	37	46
MPC ⁵ Interaction	4.0	2.5	3.5	1.5	3.0	4.0	4.0
Transaction	3.0	2.0	3.0	1.5	3.0	3.5	4.0
SPRS-R ⁶ Logit score	52.06	38.50	55.91	34.03	71.04	73.84	77.25
OA domain ⁷	2.0 ¹⁴	0.7	2.0	0.2	3.2	3.0	3.5
IR domain ⁸	2.2	1.0	3.0	1.5	3.7	3.7	3.7
IL domain ⁹	3.0	1.5	3.2	0.5	3.7	4.0	4.0
SS-QOL ¹⁰ Total score	192	134	195	153	187	198	234
Total scale score ¹¹	3.9	2.7	3.9	3.1	3.8	4.0	4.7
Domain scale scores							
<i>Energy</i>	4.0	2.0	3.3	2.3	1.0	1.0	4.7
<i>Family roles</i>	3.7	2.0	3.7	3.3	3.0	2.0	5.0
<i>Language</i>	4.4	2.4	5.0	3.8	5.0	4.0	4.6
<i>Mobility</i>	4.0	3.2	4.7	3.6	4.5	4.3	4.7
<i>Mood</i>	3.0	2.8	4.0	3.8	3.8	4.2	5.0
<i>Personality</i>	3.0	2.7	2.0	2.0	1.3	5.0	3.7
<i>Self-care</i>	4.2	3.4	4.4	3.6	5.0	4.8	5.0
<i>Social roles</i>	4.4	2.2	4.0	3.8	4.2	4.6	4.8
<i>Thinking</i>	3.3	2.7	1.3	2.0	3.0	4.3	4.8
<i>Upper extremity</i>	3.6	3.4	5.0	3.0	5.0	4.2	5.0
<i>Vision</i>	5.0	2.3	5.0	3.3	4.0	5.0	5.0
<i>Productivity</i>	4.3	3.0	2.7	2.3	3.0	3.7	5.0

¹TASIT-R: The Awareness of Social Inference Test; ²Part 1: Emotion evaluation test, maximum score 28; ³Part 2: Social Inference – Minimal response, maximum score 60; ⁴Part 3: Social Inference – Enriched Response, maximum score 64; ⁵MPC: The Measure of Participation in Conversation Scale, range 0 – 4 with higher number indicating greater participation in conversation; ⁶SPRS-2: Sydney Psychosocial Reintegration Scale; ⁷OA: Occupational Activities, range 0 – 4 with 4 indicating no change; ⁸IR: Interpersonal Relationships, range 0 – 4 with 4 indicating no change; ⁹IL: Independent Living Skills, range 0 – 4 with 4 indicating no change; ¹⁰SS-QOL: Stroke Specific Quality of Life Scale, range 49 – 245; ¹¹SS-QOL Total Scale score: range 1 – 5 with higher number indicating less difficulty/less help needed; ¹²SS-QOL Domain scale scores: range 1 – 5 with higher number indicating less difficulty/less help needed; ¹³Bold and italics: 1.5 standard deviation below norm; ¹⁴Bold and italics: change since stroke.

Study propositions

The results are presented for each of the three propositions. In addition to confirming or disputing the propositional patterns, explanations of why the pattern was confirmed or disputed is offered and linked to the relevant data source.

Proposition one: people with impaired social cognition post RH stroke would experience social network change, evident in a reduction of the size of the network and the frequency of contact with network members.

The size of the social network reduced in 71.4% ($n = 5$) of the cases (Cases 1, 2, 3, 4 and 6) as depicted in Table 6.3. Frequency of contact with network members was more variable and related to the relationship that the person with stroke had with particular network members, that being family versus friends.

Table 6.3:

Social network analysis

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
Network size	D ¹	D	D	D	No C ²	D	No C
Frequency of contact							
Family	D	No C	I ³	No C	No C	No C	No C
Friends	D	D	No C	D	D	No C	No C
Relationship change							
Family	-C ⁴	-C	-C/+C ⁵	-C	-C	No C	-C
Friends	-C	-C	No C	-C	No C	No C	No C
Role change							
Basic needs oriented	No C	I	I	I	No C	No C	No C
Task oriented	No C	D	D	D	D	D	D
Socially oriented	D	D	No C	D	No C	No C	No C
Oriented to helping	D	D	D	D	D	D	No C

¹D: Decrease; ²No C: No Change; ³I: Increase; ⁴-C: Negative change; ⁵+C: Positive change

From the social network analysis data, cases that experienced employment status change (Cases 1, 3 and 6) experienced a relatively immediate reduction in network size because of the loss of contact with work colleagues. A slower pattern of network size reduction was evident when looking at network members identified as friends. Loss of contact with friends accounted for the greatest reduction in size of the networks.

The interviews revealed potential reasons for network size reduction. The first factor that emerged as a contributor was that of motivation or interest in spending time with others. This pattern was most evident in Case 1 and Case 4, who both had awareness of their network reducing in size, however denied concern about the change.

“There are a lot of people on that picture [visual representation of social network] that I used to make an effort to see or speak to, but now they should be taken off the picture.”

(Case 1, participant)

Case 1, a 54-year-old man, acknowledged that he avoids answering phone calls from friends and family members, and that he does not want to *‘listen to their silly stories anymore’*. Of interest was that both Case 1 and Case 4 reported an overall reduced quality of life on the SS-QOL, however, neither reported a reduction in QoL in the SS-QOL social roles domain despite a loss of contact with friends. Both Cases 1 and 4 were also characterised by a low Interpersonal Relationship domain score on the SPRS-R, again confirming reduced contact with friends (refer to Table 6.2.).

In addition to reduction in network size, Case 1 also reported a decrease in the frequency of contact he had with friends and family and noted that this did not cause him concern. His daughter, a 33-year-old mother of two, expressed a lack of understanding of why the change was occurring in her father.

Participant: *“I suppose I would have phoned them more before the stroke. A lot of times their numbers come up on the phone and I just let it ring now ... Before the stroke I would have been right into everything. Listening to people’s problems. But now I am not into them. My cousin would ring up every week with some drama. Now I don’t take her calls, maybe only once a month.”* Interviewer: *“How do you think they feel about it?”*

Participant: *“I don’t know, I never really thought about it”*. Proxy: *“He is very different now, can’t tell why”* [frowns and shakes her head]

(Case 1, participant and proxy)

In Case 2, the proxy stated that for her husband, a 62-year old retired aged care worker, the reduction of contact with friends was an ongoing source of distress for him. She continued to offer a second potential cause of network size reduction, that being altered communication style following the stroke.

“One friend cannot cope with it at all. He just did not know what to do or what to say to Nick [after the stroke] ... Nick sometimes struggles with reading between the lines. It is so hard sometimes. When we go out to see our friends, and these are friends who we have known all our lives, he doesn’t speak to them. He would sit on the side.”

(Case 2, proxy)

Evidence was found across all cases that communication style was different after stroke, and for many, this appeared to be a cause of not only network size reduction but also a change in frequency of contact with network members. Post-stroke communication was described as reduced in information quantity “... he didn’t talk much like on the phone. He just did not have much of a conversation” (Case 5, proxy); inability to remain focussed on the conversational partner or topic “I would talk to her but she would seem to be lost in her thoughts” (Case 6, proxy); as well as in the general communication style that seemed out of character for the person “... I used to yell my orders and make sure that things got done. Now I am more laid back. I just sit down and shut up in groups” (Case 1, participant). Difficulties participating during group-based conversations were occurring even when the conversation partners were well known:

“It is harder when we are in a larger group, but this is family, and Nick knows them all well. He knows them all, but it does not always seem like it. As if they are strangers to him now.”

(Case 2, proxy)

This theme of the potential impact of post-stroke communication impairment on network size and frequency of contact with network members, again emerged when analysing the MPC data (refer to Table 6.2). Participant communication skills observed during the interviews, were considered impaired with varying degrees on the MPC for all but Case 7. Despite not being observed during the interview, the proxy in Case 7 reported that her husband was responding more abruptly and with less patience when interacting with her. This communication style change was considered the most significant post-stroke change by the proxy in Case 7.

A third pattern, that could account for network size and frequency of contact reduction, was a lack of understanding about the changes that occur following a stroke, in particular changes in communication “It astounded me [observing her husband during a communication

assessment], *but we just assumed it is age*” (Case 7, proxy). Provision of education about the potential impact of communication changes on ability to maintain roles and relationships, did not occur in all cases.

“We never really got information on thinking and communication and things such as knowing which direction you are heading into or if it is normal to be disorientated after a stroke. ... It was more just the physical stuff that they did when we were there” [in-patient rehabilitation]. (Case 5, proxy)

Contrary to what might be expected, impaired mobilisation did not result in a reduction in network size for all participants who could not return to driving post stroke. Case 4, reported that the size of his network was being maintained because of his wife’s initiation of contact with friends and frequent family gatherings. Case 2 on the other hand considered his physical impairment as a barrier to engaging with network members. His reliance on his spouse to access the community was a challenge for both him and his wife.

“it is up to me to take him to visit this mate” (Case 2, proxy).

Case 2 reported more leisure-based social roles that were performed independently of his wife prior to the stroke, such as fishing and playing golf with a particular friend. Shared interests were more common in Case 4 than Case 2, which might account for some of the differences between these two cases.

“He loves going into [shop name] and he can spend hours in there. I don’t enjoy it, but will take him sometimes. In my mind, there is too much else that need to be taken care of to spend time wandering around in one store.” (Case 2, proxy)

The facilitator role of a spouse in network size maintenance was highly prevalent and is the fourth significant pattern related to network size and frequency of contact across all cases.

“It has been a change but, I will get us back out there again. Our son up north has twins. We have only seen them once and have not been able to since the stroke. I really want us to get up there to see them. I have already checked with the doctor and he said flying would be quite alright.” (Case 4, proxy)

Despite denying network size reduction during completion of the social network analysis task, the below quote from Case 5, illustrates network maintenance being supported by his spouse.

“There is a group of us who catch up for aqua gym and a lunch. But when Ben first had his stroke he did not want to socialise anyway. He was just happy to stay at home unless I take him.”

(Case 5, proxy)

An increase in the social network size or frequency of contact with network members did not occur in the majority of the cases, despite attempts by the wife in Case 4, who reported that they were relatively new to the area and that she wished to expand their group of friends. Case 3 reported an increase frequency of contact with family, which was due to a change in living arrangements with her grown daughter deciding to move back home to support her mother.

“I am trying to get him into some sort of group or rehab so that we can meet people. We tried the stroke group get-together at the tavern. I found it very interesting because I like talking to other people. Henry would fall asleep after a while and if I woke him, he would not even realise that it was a bit rude”.

(Case 4, proxy)

Case 7, a 69-year old retired manager was the only case in which network change in terms of size and frequency did not occur. Both participant and proxy agreed that he appeared able to see as many network members, and as often as prior to the stroke without support. This finding was in line with results obtained on his SPRS-R where only limited change in Occupational Activities and Interpersonal Relationships occurred. Case 7 also reported the highest quality of life score on the SS-QOL, with limited change in both family and social roles. Potential reasons for Case 7 not confirming proposition one, may be a large number of participant-proxy shared interests and friends, independence with mobility, and strong communication skills post stroke reflected in the MPC despite impaired social cognition.

Proposition two. Relationships change following a RH stroke, and with greater frequency in the presence of a more severe social cognition impairment.

As per Table 6.3, interpersonal relationship change was reported often ($n = 6$, 85.7%), and with greater frequency when considering family relationships as opposed to friendships. The most frequent and greatest degree of relationship change was reported for the relationship with a spouse *“He is different. So much frustration. We have been fighting”* (Case 2, proxy). Cases

2 and 4 reported extreme change, Case 1 reported moderate difficulty maintaining a new romantic relationship, while Cases 3, 5 and 7 reported a little change stating that they are still maintaining a good relationship but that it definitely was “*not the same*” as prior to the stroke.

Perceived change in personality emerged as one contributor to relationship change, mentioned in six cases, and exemplified in the following quote:

“This is the biggest difference. He can say some very nasty, hurtful things whereas he never would have before. And it is just with me. The rest of the family and his friends don’t notice it. And even you will find him lovely today.” (Case 7, proxy)

The perceived personality change was furthermore confirmed in the questionnaire data. Personality was the second lowest domain score on the SS-QOL with an average score across cases of 2.8, which equates to a moderate degree of change in quality of life (< 4 indicates impaired quality of life). Proxies described changes that they felt were out of character related to task completion “*He used to stick with things*” (Case 5, proxy); impatience “*He is so impatient now when he is driving. He will have something to say about everyone, look at that idiot, did you see what he did? Get moving!*” (Case 7, proxy); and orientation to others “*He had a thing about colour and off course in the hospital the staff were multi-cultural, and he would always point it out ... That was very embarrassing.*” (Case 2, proxy).

A second contributor to spousal relationship change was a change in the role of a spouse from equal partner to what they felt was more in line with being a caregiver. The stories reflected an increased focus on physical support and verbal prompts that were needed for everyday routines.

“It is hard for me to feel confident about leaving him at home alone for too long. It is sad to say it but it really has taken his independence from him.” (Case 4, proxy)

A change in the relationship with other family members also occurred ($n = 4$, 57.14%)

“He also used to have a real good relationship with our grandchildren, but now they don’t know what to say to him anymore. Even our teenage grandchildren they just don’t know what to say. So, they say less and less to him. And Nick used to have a lot to say to them.” (Case 2, proxy)

The above quotation reflects a change in the relationship with grandchildren which emerged with similar frequency to relationship change with friends. Case 1, 2 and 4 reported relationship change with grandchildren occurred due to reduced initiation of contact with them, increase in difficulty communicating with young people, and responding with less patience. Analysis of the interviews also demonstrated evidence of relationship change with friends ($n = 4$, 57.14%) with Case 2 and 4 reporting a lot of change in the relationship with friends and Cases 1 and 3 reporting moderate change.

The first part of proposition two is confirmed with evidence across cases and data sources indicating that relationships do change following a RH stroke. The second part of the proposition considers if such variation was associated with severity of social cognitive impairment. The SPRS-2 Interpersonal Relationships Domain score confirmed variability in the degree of relationship change across the Cases, a variability which was similarly evident in the social network analysis data (Table 6.3).

Cases 2, 4, and 7 were identified as having severe impairments on the Emotion Perception Test. Cases 2 and 4 obtained the lowest scores out of the seven cases on the SPRS-2 Interpersonal Relationships Domain score as well as the SS-QOL Social Roles domain. Both Cases also reported negative change in relationships with family members as well as friends. Case 7 did not however support the observed pattern with relatively high scores on the SPRS-2, SS-QOL and no negative change in relationships with friends.

Considering the cases with more severe impairments on the Social Inference subtests (SI-M and SI-E) one of the two Cases emerged with a clear pattern, that being Case 4. Case 3 denied significant negative relationship change with friends and only with some family members.

The number of severe cases is extremely small making interpretations challenging. It is however of interest that Cases 2 and 4 represented the cases with the lowest overall scores on the satisfaction with social roles, interpersonal relationships and participation during conversations (MPC). Extreme change was reported on the Social skills subtest for Case 2 (has difficulty interacting appropriately with other people), while Case 4 reported moderate change (is not as tactful or sensitive to other people's needs).

Considering Case 2, a 62-year-old retired aged care worker, in more detail. Case 2 presented with the highest Total TASIT-R score, however a severe impairment on the Emotion

Perception Test. A low score representing significant change post stroke, was reported on the SPRS-2 Interpersonal Relationship domain representing “a lot of change”. Case 2 also experienced the greatest degree of physical impairment requiring spousal support and reported ongoing fatigue. The combination of these impairments may well have increased the risk for relationship change, even in the presence of intact social inferential reasoning as per SI-M and SI-E. An alternate explanation may be that the low Emotion Evaluate Test score, which reflects difficulty processing emotion as conveyed in prosodic speech features and facial expressions, in and of itself created a risk to relationship maintenance. It was particularly relationships with grandchildren that seemed to be impacted for Case 2, which may indicate that there is a difference in how younger people communicate and in turn how their thoughts and intentions are interpreted. Another potential interpretation might be that the SI-M and SI-E subtests did not detect this particular difficulty related to inter-generational communication as demonstrated in the following quote:

“I don’t know what to say. I can’t always make out where they [grandchildren] are going with, what they are saying. So, I just keep quiet. I don’t know what they are saying or even thinking, makes no sense. Yeah, different to before.” (Case 2, participant)

Other evidence that may support the presence of social cognition impairment, not detected on the TASIT-R emerged when analysing the interview data for Case 7 who appeared to present with strong communication skills on the day of the interview based on the MPC:

“He sometimes will just say something, and I will think to myself that I have no idea what he is talking about, because he thinks it and he thinks that you know what he is thinking. He thinks that I am thinking with him, and doesn’t give the whole picture. He just jumps in with a thought and gets frustrated that you are not on the same page.” (Case 7, proxy)

Not detecting subtleties and being less perceptive than before the stroke was also mentioned by proxies:

Participant: *“You say to me: did you notice so and so? I didn’t notice it, because noticing things is a female thing. I have always been like this.”* Proxy: *“Just a lot more so [since the stroke]. The subtleties are hard, and he is not aware of it.”*

(Case 5, participant and proxy)

Proposition three: valued roles would be lost in the presence of social cognition impairment post RH stroke and, where valued roles are lost a greater reduction in QoL will be reported.

The Role Checklist identified a pattern of loss of social roles. Based on Levaseur and colleagues' taxonomy, roles oriented toward helping others and task orientated roles, such as being an employee, changed most often ($n = 6$, 85.7%). An empowering effect was again implied by the role of the spouse who facilitated access to community-based activities. There was however, also evidence of times when support was not considered helpful:

Proxy: *"I would get impatient and just do it."* Participant: *"I remember that day. You had to start the mower for me, and that upset me. I just did the front edges, and then later was going to come back to finish the lot, but then you went and did it."*

(Case 5, participant and proxy)

"Sometimes I get so angry. I used to tell him [husband]: why did you take that away from me, that was something that I was able to do for myself? Now you have taken that independence away from me".

(Case 3, participant)

A theme from proposition one that can be seen to repeat here was the impact of reduced concern about role change resulting in reduced interest in maintaining prior roles:

"I have sort of lost interest in doing stuff. I thought it would just come back to me, the wish to do stuff. I used to like cooking up a meal for the kids. I don't miss it. Oh, I sort of think about, like I think about wanting to do it."

(Case 1, participant)

In terms of most valued roles that altered following stroke, the role of provider or caregiver was mentioned most often. Case 2 and 4 were either unable or only able with support to continue in the role of caregiver for grandchildren, for a child with a disability (Case 6), or in the role of foster parent (Case 3). There seemed to be two distinct reasons for the loss of the role, firstly related to difficulty communicating with younger people as discussed under proposition two, and secondly related to concerns about caregiving ability:

Proxy: *"We have always enjoyed having little ones running around and like to share in being their parents".* Participant: *"We have looked after three foster children in the past. I used to like taking them to school on the bus. But I am sad to say that we*

had to let them go. It was just not safe for us to keep them you know, I do not think that I can take the bus on my own". (Case 3, proxy and participant)

Further pattern matching identified another potential reason for role loss when comparing interview data and questionnaire data. Responses on the SPRS-2 Occupational Activities domain, indicated change in ability to return to work and leisure-based activities as well as an impaired ability to plan activities related to work or leisure. Impaired organisational ability was identified as a particular challenge post stroke ranging from moderate to extreme in five Cases.

Another influencing factor in role loss was that of physical or cognitive support, with Case 2 and 4 requiring support with activities of daily living such as dressing. This change created an increased engagement in basic needs-oriented tasks, and consequently as outlined under proposition two, may have contributed to relationship change. Roles related to being a community member, with participation in structured events or activities within the community, were independently maintained by Case 7, whereas Case 2 and 4 required support from a spouse to continue engaging in community-based activities.

Pre-stroke personality traits may also have played a protective function in maintaining roles. This is not to suggest that role maintenance is assured in the presence of particular traits, however themes emerged in three interviews where participants' spoke about their approach to life changing events:

"When I had the stroke, I used to lay around a lot, and that after being used to working ten hours a day. I had to force myself up out of bed back then. I tell myself, don't break your rule. No going back to bed. I am a pretty simple bloke. When something bad happens to you then you make the best of it. I am sort of one of those people."

(Case 1, participant)

"When I was in hospital. I used to go around talking to the other people. I used to say to them, do you not want to get up and walk around a bit? But they would say: no, I am happy to stay in bed. That is not the way to get better. I believe that you must help yourself."

(Case 7, participant)

Case 3 was not able to continue with home-based employment resulting in a loss of income as well as causing distress at the loss of a valued role. Inability to return to employment following the stroke was also reported by Case 1 and 6. However both participants indicated

that they were ready to retire and that the role of being an employee was not prized nor missed. In the current study, there was a pattern that the loss of valued roles, rather than total number of roles, is more likely to influence perceptions of QoL.

As presented in Table 14, SS-QOL summary scale scores ranged from 2.7 to 4.8. All participants reported that their QoL was worse after the onset of stroke. Energy, personality, thinking and family roles were the domains reported to be most affected. Family roles, on the SS-QOL, was identified to have changed and the change influenced perceptions of QoL in six cases, with “a lot of help/a lot of trouble” selected by Case 2 and 6. Case 2 was found to have the lowest perception of QoL post stroke, with all SS-QOL domains affected. Case 2 also reported the loss of many valued roles and additionally expressed distress at the role loss. Case 1, on the other hand, reported initiating community based and socially orientated activities less frequently, however these were not valued roles and no distress at the loss was reported. A pattern therefore was confirmed that QoL appears most affected when a higher value was placed on a lost role.

Discussion

This research offers an exploratory insight into living with CCD and impaired social cognition post RH stroke, based on three propositions of long-term social outcomes. The propositions were found to be noteworthy. The final empirical patterns discussed here reflects adaptations that were made to initial propositions to ensure that all emerging themes were represented.

The first empirical pattern was that people with social cognition impairment post RH stroke experience social network change, evident in a reduction of network size and frequency of contact with network members. Furthermore, the facilitation role of a family member appears to be protective, while an altered style of communication, reduced motivation and for some potentially a reduced insight into the impact of communication impairment on relationship change emerged as risk factors for social network change.

In line with research on social integration in the presence of TBI and aphasia, this study found that people with RH stroke experience social network change, which was significant in some cases (Northcott & Hilari, 2011; Ponsford, et al., 2014). Friends accounted for the greatest reduction in overall network size. Reduced motivation to remain in contact, an altered communication style, insufficient education about stroke-related changes, and physical impairments were noted as potential reasons for the loss of friendships. Data in the current

study was collected at a single point, between 8- and 13-months post stroke onset. Of concern, is a trend found in a longitudinal study by Ponsford and colleagues (2014), that personal relationships may continue to deteriorate over time, in particular when a more severe brain injury is present.

The frequency of contact and size of the social network reduced or was at risk of reducing if it was not for the facilitator role of a spouse in 85.71% ($n = 6$) of the Cases. The presence of family has been identified as an important environmental determinant of social participation in people with TBI and stroke. Egbert and colleagues (2006) reported that community integration appears less dependent on the level of disability post RH stroke, not controlling for presence or absence of a communication impairment, and more on the presence of resources including support from family (Egbert, Koch, Coeling & Ayers, 2006).

Reduced motivation to engage with network members and altered communication style were also noteworthy as influencing social network maintenance. Family members indicated only mild changes when responding to questions about changes in using or understanding language as per the SPRS-2 and SS-QOL questions. However, during interviews family members revealed examples of a range of communication impairments and how these were influencing social connectedness. It is possible that understatement of language changes post RH stroke arises due to a narrow understanding about communication. This is in line with Mackenzie (2001), who found that family members reported mild changes in communication, that these changes seemed situation specific (e.g. “being part of a conversation where it is fast and there are a number of people involved”), which nevertheless posed a challenge to social participation.

Considering proposition two, this study found relationship change to be a frequent and almost universal theme across the Cases. Potential contributors to relationship change emerged, including altered personality, altered communication style and a change in spousal role. The proposed pattern, that relationship change would be greatest for those with more severe social cognitive impairments as per the TASIT-R subtests, was partly supported. Two of three participants with the most severe impairments in Emotion Recognition and Social Inference were found to report change in relationships with friends and family, and to also present with reduced participation during conversations. This pattern was not present for the third participant. However, evidence of the impact of altered communication style that would be in line with what might be expected in the presence of impaired social cognition featured

prominently. The empirical pattern that emerged in this study is therefore, that relationship change occurs frequently following a RH stroke, and altered communication style in line with social cognitive impairments, create a risk to relationship maintenance.

The current study purposefully recruited participants with confirmed CCD and social cognitive impairment following RH stroke. This decision was guided by prior research (Chapter Five) that the presence of CCD post RH stroke is predictive of social participation as found on the SPRS-2 (Hewetson et al., 2018). The study compared social participation of thirty-six people with and without CCD following a RH stroke, and found a significant between group difference in reported relationship change with friends (CCD present 47.6%; CCD absent 6.6%), however relationship change with a spouse was not significantly different across groups (CCD present 33.3%; CCD absent 14.2%)(Hewetson et al, 2018). The presence of a communication impairment was not identified by Egbert and colleagues (2004); thus, it is difficult to compare current findings with their high rate of relationship change in 11 or 12 participants with RH stroke. Relationship change was reported in all seven Cases of the current study, and more frequently with a family member than friends which is in contrast to the previous study by Hewetson and colleagues (2017). Participants in the current study were all diagnosed with CCD as well as impaired social cognition, which might have accounted for greater spousal relationship change. Another potential reason may be related to the use of interview data in addition to the SPRS-R, which allowed for exploration of experiences from both the participant and proxy perspective.

The current study did not find a clear pattern that a more severe social cognitive impairment would result in more significant relationship change, however evidence emerged that social cognition impairments were creating a risk to network and relationship maintenance. Reduced perceptiveness, insensitivity and disinterest emerged in the current study, observed by family members who knew the participants well prior to and subsequent to the stroke. A disorder of social perceptiveness, as an underlying cause of perceived personality change post TBI, was noted by Lezak in 1978. Similar deficits in social reasoning and interpersonal interactions have subsequently been documented post TBI, and that such deficits may be interpreted by communication partners as egocentric, lacking an interest in others, and inappropriate in communication style (McDonald, et al., 2014). In a study by Knox and Douglas (2000) a significant association was found between a person's ability to interpret facial expressions post TBI and their reported social integration, which was present even when controlling the effect

of cognition. The results from the current study adds support to previous research demonstrating that individuals with impaired social cognition may experience difficulties maintaining relationships.

Proposition three is supported as the pattern of findings across data sources and cases matched the predicted pattern. The empirical pattern is therefore that valued roles are lost in the presence of social cognition impairment post RH stroke and, where valued roles have been lost a greater reduction in QoL is reported. Role loss, related to being a caregiver to children and grandchildren, vocation and leisure activities, was evident in the current study which was in line with findings from other studies considering social participation in the presence of RH stroke (Egbert, et al, 2006; Hewetson et al, 2018).

Return to vocational roles and ability to complete activities associated with social participation in PWA and following TBI, have been shown to be dependent on factors such as social support from friends and family members but also from formal support offered through speech pathology rehabilitation (Rath, Hennessy, & Leonard, 2003; Sarno, 1997). Conversely, limited access to rehabilitation post stroke has been identified as a barrier to social participation in those living with aphasia (Le Dorze, et al., 2014). This study found variable access to speech pathology services across the seven cases of people diagnosed with CCD, ranging from no rehabilitation to 8-weeks of in-patient rehabilitation. It is beyond the scope of this paper to identify causal links for the extensive loss of roles that were experienced by some participants, however the variable access to speech pathology services raises concerns that some participants may have been discharged prematurely or that a social isolation risk was not identified during hospital admission.

Role loss was reported by all participants in the presence of an impairment in social cognition. In line with existing literature, it appeared to be the loss of valued roles in particular that influenced perceptions of QoL (Haley, Roth, Kissela, Perkins, & Howard, 2011; Kersten, et al., 2002). The appraisal of QoL, or life satisfaction, has been linked to satisfaction in any life domain or role that are most relevant to an individual (Dijkers, 2004). This pattern of influence on perceptions of quality of life was confirmed in the current study.

Methodological considerations and research recommendations

Social network and relationship maintenance as well as and QoL in the presence of impaired social cognition following a RH stroke is multifaceted, and thus, required investigation through multiple methods and perspectives.

A strength of this study was the selection of an analytic pattern-matching technique to analyse data sources within and across cases. The methodological approach chosen allowed for testing of propositional patterns, and also for building explanations of why patterns were confirmed or disputed. The inclusion of familiar communication partners added to the strength of the approach. The use of proxy report ensured that communication style changes that were reported reflected a change in communication because of stroke rather than communication features that may also be found in non-brain damaged people, in particular when considering age-related changes to communication (Mackenzie & Brady, 2008).

The timing post stroke was carefully selected, and the range kept narrow, thereby increasing confidence that the experiences of returning to and maintaining social roles and relationships across the Cases could be comparable. Data collection occurred between 8 and 13 months post stroke onset, a time frame that was based on patterns of perceived recovery and improvement reported by family members of people with RH stroke. Family ratings of communication improvement have been found to reflect an initial positive trend, followed by a reversal in the direction of change reported by families between 6 and 12 months post stroke. This pattern has been attributed to familiar communication partners becoming more aware of communication difficulties as the person with stroke is observed in a greater range of situations and as they return to prior vocational and social roles in the community (Mackenzie, et al., 2001).

The challenge in conducting research that requires participants with cognitive and communication impairments to reflect on and rate long term stroke related outcomes is acknowledged in this study. Neuropsychological deficits related to neglect, anosognosia, impaired emotion interpretation, anosodiaphoria and deficits of magnitude estimation may have been present in varying degrees in the current study as these have been identified to be present in people with RH stroke (Adair, Schwartz & Barrett, 2003; Barrett, 2009). The presence of such impairments, in addition to factors such as post stroke depression, may result in underestimation of stroke related disability and impact on QoL. In a study by Dai and colleagues (2014) a pattern of underestimation on the SS-QOL in people with RH stroke was noted when anosognosia was present. Potential underestimation of social participation change has been discussed by the current researchers in a study of people with RH stroke, in which it was found that participant-proxy agreement on a scale of social participation was lower when a more severe CCD was present and that some domains appeared more affected than others (Hewetson, et al, 2018). Validity of findings was increased in the current study by obtaining

self-report and proxy-report simultaneously, and, in a manner that allowed for reaching of consensus. In this regard, the current research was influenced by the Social Convoy Model and therefore a shared experience of stroke was appropriate. Thus, the inclusion of a communication partner, familiar with the person with stroke, both currently and prior to stroke onset, was deemed essential to address potential under-reporting.

Research recommendations

This exploratory study is necessarily limited in that the data is derived from a series of seven cases only. Diversity of the cases are acknowledged. Within this diversity clear themes and patterns were present while others will require future testing, potentially with comparison groups and purposive sampling based on profiles of cognitive-communication impairments. However, this analysis suggests a number of significant themes about the lives of people with impaired social cognition following a RH stroke as well as those who share that life with them. Consequently, this study has demonstrated that evaluation and interventions required that consider social network, role and relationship maintenance, as important factors that may influence perceptions of quality of life. In particular an exploration of the ability to influence the maintenance of social connectedness over time would add insight into the social focus that is required to supplement impairment-based therapy goals. An exploration of social network maintenance in people with different profiles of CCD, where social cognition is not necessarily impacted, would allow for a comparison with the experiences of the cases included in this thesis.

The relationship between severity of social cognition impairment and relationship maintenance requires further exploration to determine if specific aspects of social cognition, that being emotion interpretation versus social inferential reasoning, may create different risk patterns. Until a comparison occurs across groups with impaired versus intact social cognition skills the proposition should not be fully discounted due to the frequent statements in the interview data that reflected the impact of social cognition impairments.

The experiences of being a spouse of a person who returns to social roles and relationships in the presence of impaired social cognition, and how this process may be supported emerged as an unintentional theme of this study that requires exploration. The communication disorder that emerges following RH stroke impacts the social network and relationships of not only the person with stroke, but may also cause an unintentional isolation in those who are closest to them. The need for the development of couple-focussed interventions, with a particular

emphasis on interpersonal communication and targeted education about social cognition change post RH stroke is required. A similar need for couple-centred interventions have been highlighted for people with TBI (Knox, Douglas, & Bigby, 2015).

Clinical implications

A number of clinical implications are apparent. The overall finding highlights the importance of promoting social participation in those with CCD following a RH stroke. Impairments in social cognition should be identified and intervention provided to improve the ability of people with RH stroke to interpret and predict the intentions and emotions of the people within their social networks. Current identification and prioritisation procedures that determine access to speech pathology intervention for people who are at risk of social isolation, require consideration. Research demonstrates that social participation restriction may occur even when a mild CCD is present, and that routinely used outcome measures may not reflect communication competence upon return to social roles and relationships (Hewetson, et al., 2018; McDonald & Johnson, 2005). In the current study, participants received on average three weeks of speech pathology intervention with two participants receiving no intervention. This finding is significant as, universally the participants and proxies reported ongoing difficulties related to communication. Premature discharge may be occurring when evaluation of communicative competence does not reflect real-world communication and when the risk of social isolation is not apparent at the point of hospital discharge. The routine identification of protective and risk factors inherent in the person and their environment holds promise for supporting future social relationships and roles in people with RH stroke.

The focus of post-acute stroke rehabilitation is often on the individual and on the individual's impairments, however communication and social engagement is collaborative. Research considering successful social engagement in PWA challenge assessment practices and interventions that focus only on the person with aphasia (Simmons-Mackie & Damico, 2007). Communication is collaborative and communication partners have been shown to increase social inclusion in the current study. The clinical relevance of this finding highlights the need for speech pathology intervention that is inclusive of communication partners and aimed at communication exchanges as would be required to maintain relationships and personally relevant social roles following a RH stroke.

People with CCD following a RH stroke have historically, and likely continue to face under identification of their need to access support that would facilitate maintenance of social roles and relationships (Blake, 2017). One proposed reason for under-identification is a lack of understanding of CCD as well as the interplay between cognitive impairments and effective communication. The model of cognitive-communication competence proposed by McDonald (2017) offers a framework to bring key variables required for effective communication to the forefront. The model is recommended as an aid to the identification of impaired communication competence, and in provision of education on the multifactorial nature of CCD, and how a range of impairments and protective factors may impact communication competence in real-world settings. The current study offers some insight into the lives of people with impaired social cognition post RH stroke which is one of the cognitive processes with a potential to impact dynamic and interactive communication exchanges, identified within the model of cognitive-communication competence (McDonald, 2017).

This study demonstrated that the loss of valued social roles holds significant consequences for perceived QoL. Contextual factors unique to each person, and directly related to the communication demands unique to particular valued roles should be explored and supported as rehabilitation goals. Creating and maintaining meaningful roles emerged as a theme related to long term needs of people with communication impairment (excluding CCD) post stroke (Wray, & Clarke, 2017). The nature of a particular role may result in a different communicative performance than what may be found when evaluating communication during a structured activity within a standardised setting. Identification and development of role-specific or relationship-specific communication coping strategies may hold promise as an intervention approach. Recent research on an intervention that would reduce non-productive interactions and increase productive communication-strategies in people with TBI, may hold transferrable value to those with RH stroke (Douglas, 2017).

Conclusion

The results from this study do not answer questions about causal relationships. Rather, the study highlights observations that are clinically relevant to guide education provision, identification of potential risk of poor long-term outcomes, and therefore to aid prioritisation and access to rehabilitation for people with CCD post RH stroke. Impaired social cognition emerged as one potential variable that may hold consequences for the ability to maintain relationships. This study supports the need for education and therapy that focus on collaborative communication, occurring at the level of the social network and in particular with

network members who are facilitators of social engagement to reduce social participation restriction risk post RH stroke.

Chapter 7

Discussion

“Everything changed for him, he could not return to work even if he wanted, not just his physical difficulties, his way of thinking through problems is shocking and of course the way he views a situation is strange to say the least. They only looked at the physical stuff but if your brain is not thinking clearly about what it needs to do, what sense does it make to be able to walk over to it? His speech was always clear, and he could understand what he heard and read and could write but his communication was completely different - does that make sense? He would just go quiet in a group of people, he cannot participate ... he doesn't seem able to come up with new topics. A lack of communication about stroke, and what changes, and what they can and can't offer was a significant problem for me as a family member.”

(Wife of a 55-year-old man with moderate-severe CCD and 13/30 on the MMSE. Unable to return to employment after 64 days in rehabilitation during which time 12 speech pathology sessions were accessed)

Each chapter of this thesis opened with a quotation from a participant with RH stroke or a significant other (proxy participant). Their words were followed by a brief summary of impairment-based findings, including the presence of CCD and a score obtained on a screen of cognition. Lastly, access to rehabilitation was summarised, in particular access to speech pathology services. Each of these statements tell the story of this thesis. In their words, we are offered a frank account of the social participation restrictions that may be created by a RH stroke. Lives were altered, relationships changed, roles were lost, and questions emerged about stroke rehabilitation services for people with RH stroke. Their stories are compelling and prompt us to reflect on current speech pathology practice. This chapter summarises key findings of this thesis and offer recommendations for the future.

Summary of Key Findings

Prevalence and nature of social participation change following a RH stroke

The first aim addressed in this thesis related to change in social participation as reported by people with a RH stroke (self-report) and a significant other (proxy-report). Social participation change following a RH stroke was found to be prevalent (94.4%, $n = 36$). The presence of a CCD created a risk to social participation, which was greater than when communication remained intact following a RH stroke. People with CCD reported more frequent and greater degrees of change across occupational activities, interpersonal relationships and independent living skills than people without CCD. This difference was significant when comparing SPRS-2 Total scores and SPRS-2 Domain scores for participants with CCD to participants without CCD. The difference was most evident when looking at frequency of reported change related to vocational roles and duties (CCD present: 83.3%, CCD absent: 42.8%), leisure activities (CCD present: 85.7%, CCD absent 40.4%), organisational skills (CCD present: 80.9%, CCD absent: 26.6%), and relationships with friends (CCD present: 47.6%, CCD absent: 6.6%). Perceptions of social participation change varied when considering self and proxy reports, with only fair participant-proxy dyad agreement in the presence of CCD ($\kappa = 0.36$). More than half (65%, $n = 20$) of people with CCD rated themselves as having better social participation outcomes than their proxies. All three hypotheses related to Aim 1 of this thesis were supported, that being, 1) people living with a RH stroke report changes in social participation, 2) social participation change is reported with greater frequency and as being more severe in

people with a CCD compared to people without a communication impairment following RH stroke, and 3) lower participant-proxy agreement about social participation change is evident when CCD is present.

Predicting social participation support needs in people with CCD post RH stroke

It is reported that people with RH stroke make up a small portion of speech pathology caseloads. This finding is surprising given a similar occurrence of CCD (66% of RH stroke group, $n = 58$) to Aphasia (68% of LH stroke group, $n = 57$) found following a chart audit of 115 consecutively admitted patients with confirmed, first onset stroke in this thesis. At the point of hospital discharge, people with CCD post RH stroke did not enjoy parity of referral for ongoing community-based rehabilitation compared to PWA. This is again surprising when considered in light of the frequent reports of difficulties resuming and maintaining relationships and roles in the presence of CCD noted in this thesis. The group with Aphasia was on the whole considered more severe in their communication impairment than those with CCD; however, an important finding was that even a mild CCD can result in reported social participation restrictions.

In addition to the presence and severity of a communication impairment, acute hospital administered screening measures of cognition might influence decisions about rehabilitation access. Performance on a global cognitive screen (Mini Mental State Examination) was found to be insensitive to predicting future social participation change. A key finding was that the presence of CCD identified during the acute-stroke phase by evaluating lexical semantics, prosody, discourse and pragmatics, is a sensitive measure to predict future social participation change (77% of people with altered social participation correctly identified).

Aim 2 of this thesis considered two hypotheses. The first explored risk factors that have been shown to impact participation, that being presence of a communication impairment (impairment level risk factor) and secondly access to rehabilitation (environmental risk factor). Results confirmed that people with RH stroke and LH stroke face a similar risk to social participation based on comparable frequency of communication impairments. However, referral rates to community-based rehabilitation services were lower for people with CCD compared to PWA, which in turn may indicate that they faced a greater risk of social participation restriction. The second hypothesis was also confirmed. Routinely administered screens of cognition and communication were not equally able to predict future social participation change in people with RH stroke. This finding holds significance for acute-stroke

management when triage decisions are influenced by screening tools of cognition, reinforcing the importance of inclusion of routine communication screens.

The significance of social participation change for people with CCD post RH stroke

The third aim of this thesis was to determine the significance of social participation change in terms of relationship maintenance, social network change and quality of life in those living with a CCD characterised by impaired social cognition. Social network change, evident in a reduction of network size and frequency of contact with network members was prevalent in people with CCD. Relationship change was a frequent and almost universal theme reported in 85.7% of a small sample, based on strict inclusion criteria to reflect people with confirmed social cognition impairment post RH stroke ($n = 7$). Potential contributors to relationship change included altered personality, altered communication style and a change in spousal role from equal partner to carer. The relationship between severity of impaired social cognition (as per the TASIT-R) and relationship maintenance requires further exploration. Based on a very small sample, two of three participants with more severe social cognition impairment reported greater relationship change than when impaired social cognition was mild.

Perceptions of reduced QoL in the presence of impaired social cognition was reported by all seven participant-proxy dyads in this thesis. Valued roles were lost in the presence of impaired social cognition and the loss of these valued social roles was likely a key factor influencing perceptions of QoL.

The three propositions that were considered in relation to Aim 3 of this thesis were largely supported. Altered relationships, social network change, social role loss and reduced QoL were prevalent in people with CCD characterised by impaired social cognition. Family members emerged as playing a protective role in facilitating social network contact, while an altered style of communication post RH stroke, reduced motivation and insight into change, and insufficient education about communication post stroke, emerged as risk factors for social network change.

Synthesis

The overarching premise of stroke rehabilitation is to support the return to prior and valued activities, roles and relationships (National Stroke Foundation, 2013). Where stroke-related impairments are severe, stroke rehabilitation assists the person with stroke to renegotiate life goals, as modifications may be required to roles and activities and the residential setting. Rehabilitation professionals are motivated to support people to resume roles and activities successfully. Furthermore, rehabilitation triage decisions are influenced by service provision models and current evidence. This thesis adds evidence to support professionals in both acute and rehabilitation contexts who make decisions about access to hospital- and community-based services. Most notably, data was presented on the incidence of CCD following RH stroke that may be more representative than prior estimates. The findings presented here were obtained through strict inclusion criteria that ensured that the 155 included patients represented people with first onset, unilateral stroke as determined by neuroimaging and who did not have a history of prior neurological or psychological events. The incidence data included patients who were not referred to rehabilitation (acute care only) and those receiving inpatient rehabilitation, thus making the sample more representative than prior data collected from rehabilitation caseloads only. Ninety-two percent of all patients admitted with RH stroke over the two-year period were assessed by speech pathologists, which provides support for the data being representative of likely incidence. In this regard, CCD post RH stroke was present with similar frequency to Aphasia post LH stroke. This finding allows the speech pathology profession to reflect on why CCD post RH stroke may represent a smaller part of clinical caseloads, as reported in prior research (Blake, et al, 2002).

A question that emerged when considering prior reports of low referral rates, and for ongoing rehabilitation as reported in the current study, was why issues of identification of rehabilitation need exist for this population. A lack of formal communication screening tools, that are sensitive to detect the need for further assessment and rehabilitation could partly explain reported low referral rates. This is in line with concerns raised by Blake (2016) about the sensitivity of acute neurological examination stroke scales in identifying people with mild RH stroke. This thesis furthermore demonstrated the importance of including screening measures of communication, in addition to screens of cognition and mobility to guide acute-stroke triage decisions. A number of participants with CCD in this thesis reported altered social participation in the absence of impaired mobility and cognition. This finding was in line with prior research that the extent of activity limitation does not necessarily predict participation

restrictions following a RH stroke (Cooper et al., 2014; Egbert, 2006; Hamzat et al., 2014). The choice of screening tool for cognition may also require consideration to ensure that the broad range of neuropsychological deficits that may arise post RH is assessed. The prior reported concern that some patients may present with domain specific cognitive impairments, which are overlooked in favour of a composite cognitive score, is reflected in findings within this thesis (Chan, 2017).

The Speech Pathology profession has commendable service provision recommendations for people with Aphasia. The impact of Aphasia on role and relationship maintenance is known. Longitudinal studies describe the experience of living successfully with Aphasia with numerous studies considering facilitators and/or barriers (e.g. Brown, Worrall, Davidson, & Howe, 2010; Grohn, Worrall, Simmons-Mackie, & Hudson, 2014; Hinckley, 2006). Aphasia rehabilitation options have been developed, replicated and refined at an impairment as well as at the activity and participation level. Much more slowly in comparison to Aphasia or CCD post TBI, evidence is emerging about CCD in the RH stroke population. At present, the speech pathology profession lacks clear guidelines that would ensure equity of access to rehabilitation and inform timing and intensity of rehabilitation following a RH stroke. Data reported in this thesis strongly supports the need to develop service provision recommendations for people with CCD post RH stroke.

Firstly, referral rates for community-based rehabilitation should be reviewed to address potential disparity of access to services. Only 10% of people with CCD who were discharged from the acute setting were referred for community-based rehabilitation compared to 53% of PWA. Furthermore, 85.7% ($n = 24$) of people with CCD who accessed in-patient rehabilitation, were discharged with no further community-based rehabilitation despite ongoing communication impairments noted by the discharging speech pathologist. Secondly, the use of the AusTOMS, in isolation, to determine severity of CCD requires consideration. Missing data precluded an exploration of all discharge decisions in this data set. However, where stated, the decision that further rehabilitation may not be required was often supported by a statement that the presenting CCD was mild and therefore unlikely to impact on return to independent activity. This thesis presented findings that demonstrates that current methods for establishing severity were not sensitive in predicting future support needs. On discharge from hospital without further rehabilitation, seven of 12 people with a mild CCD, could not return to employment despite being independently mobile. Considering the dose and focus of speech

pathology therapy is also beyond the scope of this thesis, however a number of statements by proxies raised concerns that the focus of therapy might not have met the needs of patients and their families (Proxy participant quote: *They only looked at the physical stuff but if your brain is not thinking clearly about what it needs to do, what sense does it make to be able to walk over to it?*).

To better understand the need for rehabilitation this thesis highlighted the experiences of people with CCD post RH stroke on resuming or maintaining roles and relationships. People's experience of returning to their community following a stroke has been described as a transition through a series of goals. The initial focus on re-establishing independence is followed by a period where expectations may need to be readjusted. The last goal in the series is resuming meaningful activities associated with, what Wood and colleagues term, "real living" (p. 1048, 2010). The profound realisation from this statement is that "real living" is likely negatively impacted when this final goal of resuming meaningful roles is not achievable. It was when valued roles were lost that participants reported increased dissatisfaction with post-stroke QoL in this thesis. The findings from this thesis are thus in line with authors who have demonstrated the importance of participation in meaningful activities as a valued long-term stroke outcome for PWA, and therefore an important goal for rehabilitation teams (Grohn, et al., 2014; Holland, 2006).

The Social Convey Model was selected as a means to conceptualise the shared experience of transitioning through life events for those with RH stroke and their families. A recurring theme in this thesis was the facilitating role of family members in supporting role and relationship maintenance for their family member. This theme has also been demonstrated for people with TBI and those with Aphasia, with Holland (2006) stating that living well with aphasia requires a family focus. In comparison to Aphasia, CCD in the RH stroke population may create reduced awareness of difficulty or stroke-related restrictions. This was evident in the participant-proxy interviews and when comparing evaluations across participant and proxy groups on the SPRS-2. The Social Convey Model therefore emerged as a relevant framework, as inclusion of a family member in exploring social participation change addressed potential under-reporting of change due to reduced insight.

The inclusion of both participants and proxies also enabled an exploration of relationship change as experienced by both parties. Prior to this research, the variable influence of CCD arising following RH stroke on relationship maintenance has not received research attention.

Egbert and colleagues (2004) found that 11 of 12 participants with RH stroke experienced changes in their relationships, however the presence or absence of CCD in their sample was not specified. In comparison, strong evidence guides our understanding about long-term outcomes in terms of relationship maintenance with spouses and friends for PWA (e.g. Le Dorze & Brassard, 1995; Northcott & Hilari, 2011) and those with CCD post TBI (e.g. Godwin, Chappell, & Kreutzer, 2014; Shorland & Douglas, 2010). This thesis provided evidence of frequently reported relationship change following a RH stroke. This change was significantly greater in the presence of CCD for relationship maintenance with friends (CCD present 47.6%; CCD absent 6.6%, $n = 36$). When considering a smaller group ($n = 7$) of people with CCD characterised by impaired social cognition, spousal relationship change emerged more frequently than relationship change with friends. Findings are also in line with reports that people with impaired social cognition may experience difficulties maintaining relationships post TBI (Northcott & Hilari, 2011; Ponsford, et al., 2014). Spousal comments in this thesis, such as *“It was like living with a toddler who didn't understand human emotions and how to respond. I remember sitting on the couch crying one day and he just looked at me and changed the subject”*, resonate with a theme of “Loss of [emotional] connectivity” identified by Godwin and colleagues (2014). Whereas the theme of “Changes to conversational skill” identified in a study by Shorland and Douglas (2010), also emerged as a factor that likely impacted maintenance of friendships as demonstrated in this thesis (proxy: *“Nick sometimes struggles with reading between the lines. It is so hard sometimes. When we go out to see our friends, and these are friends who we have known all our lives, he doesn't speak to them.”*)

The voices of participants and proxies are brought to the forefront by including direct quotations throughout this thesis. Insights arise about service provision during hospitalisation, including concerning statements related to education about RH stroke and CCD. An important finding was that proxies reported only mild changes when responding to questions about changes in using or understanding language as per the SPRS-2 and SS-QOL questions. However, during interviews family members revealed examples of a range of communication impairments and how these were influencing social connectedness. It is possible that the understatement of changes arose due to a narrow understanding about communication. This is in line with Mackenzie (2001), who found that family members reported mild changes in communication, which nevertheless posed a challenge to social participation.

The experience of navigating the return to roles and relationships as experienced by participant-proxy dyads in the presence of CCD characterised by social cognition impairment

has not been reported before. Through the use of multiple data sources, and in the words of participants, hints emerged as to potential contributors to social participation change. The facilitation role of a family member appeared to be protective, a finding similarly reported by Arntzen in participants with RH stroke (2015). An altered style of communication, the presence of CCD as well as social cognition impairment, reduced motivation to engage with network members, and insight into stroke-related change emerged as risk factors for social network and relationship maintenance. All dyads reported reduced perceptions of QoL, many reported challenges in returning to or maintaining roles and relationships. Relationships with a spouse as well as friends altered, which was in line with Taule and Raheim in their participants with RH stroke (2015). The exploratory nature of this thesis generated many clinical and research implications. The most salient implications are summarised below.

Recommendations

Clinical implications

In terms of stroke management, implications are twofold. Firstly, acute stroke management requires consideration of how risk of social participation restriction is determined. Findings in this thesis highlight that some routinely used screens may not be sensitive to predict future participation support needs. The utility of such tools to guide decision making about rehabilitation referral is questioned. Secondly, as the presence of CCD emerged as a sensitive way to predict long-term participation outcomes, referral in acute-stroke units, to speech pathology for communication assessment post RH stroke is indicated.

A number of clinical implications emerged with relevance to speech pathology practices, including the need to address low caseload numbers, provision of education about CCD, determining the need for speech pathology services on discharge from hospital, and the focus of therapy to facilitate improved return to roles and relationships. One proposed reason for under-identification is a lack of understanding of CCD as well as the interplay between cognitive impairments and effective communication. The model of cognitive-communication competence proposed by MacDonald (2017) offers a framework to bring key variables required for effective communication to the forefront. The current study offers some insight into the lives of people with impaired social cognition post RH stroke which is one of the cognitive processes with a potential to impact dynamic and interactive communication exchanges, identified within the

model of cognitive-communication competence (MacDonald, 2017). The model is recommended as an aid to the identification of impaired communication competence, and in provision of education on the multifactorial nature of CCD, and how a range of impairments and protective factors may impact communication competence in real-world settings.

Services that experience low numbers of referrals post RH stroke may require a review of screening or formal assessment protocols used to determine the need for speech pathology in this population. Screening tools should consider lexical-semantics, prosody, discourse and pragmatics as well as significant other report of change. Recent evidence suggests that receptive aprosodia is a particularly sensitive way to identify the presence of a RH stroke during an acute phase post stroke (Darra, et al., 2014). Furthermore, aprosodia has been identified as one underlying cause of deficits in social cognition (Macrae & Bodenhausen, 2000). Such evidence should be translated to practice with inclusion of tasks that consider both expressive and receptive prosody in acute communication screening measures. Participant-proxy agreement on social participation change was relatively low in this thesis, most notably for participants with a more severe CCD. The inclusion of proxy-report is therefore essential.

For some people, the presence of CCD might only become evident during communication exchanges that requires contextual, para-linguistic and extra-linguistic interpretation. Creating naturalistic communication exchanges that require social cognition skills will likely prove challenging within acute stroke units. To reduce numbers of false negatives on current communication screening measures, speech pathologists should consider the education provided to significant others about CCD, which should enable them to identify difficulties on return to the community. The need to evaluate communication disorders in a manner that considers everyday functional communication skills rather than performance on decontextualised tests and tasks, was emphasized by Holland as far back as 1979 and should be included in comprehensive assessment protocols post RH stroke (Holland, 1979).

A concerning theme that emerged in this thesis is the impact of ongoing CCD on life participation months post stroke in participants who had accessed rehabilitation. This thesis highlighted that people discharged from hospital with ongoing CCD require support to improve social participation outcomes. Evaluating the focus of the rehabilitation sessions, and decisions to discharge without further support should be considered as relevant quality improvement initiatives across services that support people with RH stroke. On discharge from inpatient rehabilitation the majority of people with CCD in this thesis were rated as mild on the

AusTOMS Impairment Level scale. The findings from this thesis compels speech pathologists to consider successful return to valued social roles and maintenance of relationships as rehabilitation goals in people with CCD post RH stroke. The AusTOMS makes provision for rating of outcomes at both the Activity and Wellbeing levels, which may capture the true impact of CCD more accurately than utilizing only the Impairment Level scale. Furthermore, the use of not only patient subjective evaluations of their well-being, but also significant other reports, emerged as an essential component to accurately evaluate change in communication but also long-term outcomes in this population. The current study demonstrated that when impairment level data is used to make decisions about community-based support needs, careful consideration should be given to the likelihood of particular data (e.g. severity of CCD, presence of impaired cognition) to be associated with future participation restrictions. For rehabilitation clinicians to understand such associations, consideration must be given to self and proxy reports of long-term stroke outcomes related to participation.

When considering intervention approaches, a clinical implication that emerged from this thesis is that context-specific communication at a social network level should be a goal of therapy. Consideration should be given to the unique requirements of valued roles, to support return to and maintenance of these roles. Engagement in rehabilitation tasks that are ecologically valid, and directly linked to valued roles, are most likely to contribute to better QoL. Clinical service provision guidelines for PWA similarly emphasize the need to consider roles, social networks and relationships and how these can be supported (Hilari, 2011). Ecologic validity refers to the extent to which performance on therapy tasks resembles performance in a natural setting (Franzen, 2000). In stroke rehabilitation, virtual reality and virtual environments are being used for both motor and cognitive rehabilitation with promising results as is reported in a Cochrane review (Laver, George, Thomas, Deutsch, & Crotty, 2012). Less evidence is available within the field of speech pathology on the use of ecologically valid intervention approaches for people with a CCD post RH stroke.

A number of similarities in presenting communication difficulties across the TBI and RH stroke populations have been documented (Cicerone, Levin, & Malec, 2006; Blake, 2011). The overlap in cognitive-communication deficits between these two groups are at times used as a motivation for the use of treatments that have been shown to be effective in TBI with people post a RH stroke (Blake, 2011). The seminal work of Ylvisaker and Feeny (1998) on the use of everyday routines that are embedded in the context of everyday activities, is an example of

how ecologically valid intervention approaches can be used to support people with CCD. The use of such real-life tasks within rehabilitation settings for people with CCD have gained increasing attention as a means to influence participation (Renison, Ponsford, Testa, Richardson, & Brownfield, 2012). An intervention approach with the potential to consider both cognitive skills (e.g. insight, executive functions) and context, is Goal Management Training (GMT) (Levine et al., 2011). The program aims to develop participants' ability to stop and think about tasks linked to personally relevant goals and also about their performance on tasks. The use of a program such as GMT holds potential to develop skills within personally relevant, everyday communication tasks in those following a RH stroke. The efficacy of such an approach for people with RH CCD is yet to be determined.

The focus of post-acute stroke rehabilitation is often on the individual and on the individual's impairments, however, communication and social engagement is collaborative. Communication is collaborative and communication partners have been shown to increase social inclusion in the current study. The clinical relevance of this finding highlights the need for speech pathology intervention that is inclusive of communication partners and aimed at communication exchanges as would be required to maintain relationships and personally relevant social roles following a RH stroke.

Research implications

Much work remains to be done in understanding the long-term outcomes of people with CCD post RH stroke. Potential facilitators and barriers that emerged from this thesis require replication with larger samples. Given the heterogeneity of CCD post RH stroke it is recommended that long-term outcomes are evaluated based on particular profiles of impairments in communication. Available literature on long-term changes to communication following a TBI do not always offer a positive picture of improvement in communication over time (Hammond, Hart, Bushnik, Corrigan, & Sasser, 2004). At present it is not known if CCD post RH changes over time, and when such change is likely to occur or under which circumstances. Longitudinal studies that consider not only changes in profiles of impairment, but also social participation and relationship maintenance will add valuable data to support people with RH stroke to succeed in resuming roles and relationships. This thesis purposefully recruited participants who were at least six months post RH stroke with a particular

impairment, that being impaired social cognition based on literature that demonstrates relationship vulnerability when social cognition impairment is present. The small sample size, in particular small number of participants with more severe social cognition impairment, created a limitation in the interpretation of findings. Future research should ideally utilise similar measures of social cognition reported in this research, to allow for comparison of findings.

Proxy participants provided a wealth of examples of how social interactions were altered in the presence of changed communication. They furthermore offered examples of how they were acting as informal mediators and facilitators of relationship and role maintenance. Future research should explore not only the facilitation role of a family member but the nature of the communication context. Communication contexts and a diversity of communication partners will likely create variable challenges for people with CCD post RH to navigate. A starting point would be evaluating interventions that consider the nature of valued roles and knowledge held by communication partners (such as friends) about CCD, to support network maintenance.

In addition to a paucity of literature on social participation outcomes following a RH stroke, relatively few studies have evaluated communication focussed rehabilitation approaches, comparative to the literature on rehabilitation post LH stroke and aphasia. A small number of studies provide evidence for communication specific treatment approaches for people with RH stroke, focussing on coarse coding and suppression during discourse comprehension and lexical-semantic tasks, as well as the treatment of aprosodia (Blake, 2007; Blake, Tompkins, Scharp, Meigh, & Wambaugh, 2015). Slight to sizeable effects together with good maintenance were demonstrated for some treatments, however limited generalisation was evident (Tompkins, 2012). Information on the optimal timing for therapy and the intensity of intervention, is not known but generalised benefits of greater numbers of communication-focussed treatment sessions and generalised gains in communication ability have been reported in a study by Odell, Wollack and Flynn (2010). A better understanding of profiles of cognitive (including social cognition) and communication impairments, and intervention dose would improve the replication of emerging intervention approaches.

Although social participation is an area that requires inclusion in rehabilitation management programmes, there are few empirical studies describing the interventions required to improve the lived experiences of people with RH stroke. Ecologically valid intervention studies, that consider the unmet social-communication needs of people post RH stroke, are

likely able to expand current best practice. Identification and development of relationship-specific communication coping strategies may hold promise as an intervention approach, however has not been explored in people with CCD post RH stroke. An intervention aimed at reducing non-productive and increasing productive communication-strategies during communication exchanges in people with TBI may offer transferrable value to those with RH stroke (Douglas, 2017).

Relationships are at their core transactional, they do not occur between a person and a therapy activity, but between two people. Exploration of this transactional dimension of communication following a RH stroke would yield valuable insights into the interplay of CCD, including impaired social cognition, and responses or supports provided by a communication partner. The experiences of being a spouse of a person who returns to social roles and relationships in the presence of impaired social cognition, and how this process may be supported requires exploration. The communication disorder that emerges following RH stroke may cause an unintentional isolation in those who are closest to the person with CCD. The need for the development and evaluation of couple-focussed interventions post RH stroke, with a particular emphasis on education about social cognition impairment is required.

Research Limitations

To enable a systematic exploration of perceptions of social participation change as well as factors that hinder or support the return to and maintenance of social roles and relationships a mixed method approach was required. Social participation is a complex concept to research and was felt to be best served if explored in a multi-dimensional therefore drawing on the ICF framework (WHO, 2001), as well as Levasseur taxonomy and Social Convey Model.

The exploratory nature of this thesis was required as current evidence is limited that would allow identification of facilitators and barriers to social participation. The selection of an analytic pattern-matching technique to analyse multiple data sources within and across cases in chapter six was considered essential to enable exploration and preliminary theory building in an area where limited evidence exists. This research starts to provide some insight into the how and why social participation change occurs which is appropriate for exploratory studies. The researcher considered trustworthiness criteria in the planning, conducting and dissemination phases of this thesis (Patton, 2002). As examples, objectivity was achieved by demonstrating how propositions required revision based on participant experiences that were

contrary to the initial hypotheses set in Chapter six. Verbatim quotations were used in the presentation of the data to allow the reader to gain a deeper understanding of the findings, thus adding to the credibility. Transferability was increased by purposefully recruiting participants who shared the diagnosis of CCD characterised by a social cognition impairment. Furthermore, the underlying rationale for selecting the cases based on literature in related fields of acquired communication impairments was explicitly stated. The trustworthiness strategies enable extrapolation of findings to others who present with similar difficulties. However, a limitation of this approach is that CCD post RH stroke result in a diversity of impairments, which have only recently been conceptualised as representing different profiles. Further work is required that considers social participation change as reported by participants across the different profiles of CCD.

A number of limitations are evident when considering the data collection tools and methods. Firstly, recall bias is a potential limitation, as surveys were completed between six and 33-months post stroke onset, thus the amount of time between stroke onset and survey completion varied between six and 33-months. The timing post stroke was however carefully selected, and the range kept narrow, to increase confidence that the experiences of returning to and maintaining social roles and relationships could be comparable. Data collection occurred between 8- and 13-months post stroke onset, a time frame that was based on patterns of perceived recovery and improvement reported by family members of people with RH stroke. Family ratings of communication improvement have been found to reflect an initial positive trend, followed by a reversal in the direction of change reported by families between 6- and 12-months post stroke. This pattern has been attributed to familiar communication partners becoming more aware of communication difficulties as the person with stroke is observed in a greater range of situations and as they return to prior vocational and social roles in the community (Mackenzie, et al., 2001).

Secondly, the second aim of this research was to explore potential predictors of future social participation. This research met many of the recommendations outlined by Kwakkel and colleagues (2014) related to factors required for adequate prognostic research. The source population, recruitment, inclusion and exclusion criteria, baseline key characteristics of the study sample and definitions of predictors were provided. A potential limitation relates to predictor measurement, and in particular the reliability and validity of the communication screen utilised at the recruitment site. The reliability and validity of the measure was not known as it was not a formal measure developed and routinely used by the speech pathologists at the recruitment site.

The use of informal tools to identify and describe CCD in people with RH stroke is a frequent practice as few screening tools are available that represent the more recent evidence related to CCD in this population. Despite being informed by such evidence, the screening tool was not a standardised measure which will limit the potential to replicate the findings. It is however of interest that the informal screen of communication emerged as sensitive in predicting future social participation in a group of people with strengths in mobility, available family support, and for the most part not requiring support with activities of daily living. A further limitation relates to the outcome measures, chosen because of routine use, as these measures may not adequately have identified cognitive and communication impairments, nor functional limitations in communication contexts. The restricted number of communication items and ratings in both the FIM and AusTOM scales may not have provided an accurate representation of independence in communication-related activities nor small improvements achieved during rehabilitation.

Another consideration in prognostic research outlined by Kwakkel is that of sample size. The sample size across the studies within this thesis are small, however, to counter the potential limitation of sufficiency of the sample size, only a small number of variables (three) were used in the regression analyses that informed aims one and two, and participants were purposefully recruited to address aim three. The validation of the data presented in this thesis, by replication with larger samples as well as externally at a different facility is recommended.

The challenge in conducting research that required from participants with CCD to reflect on and rate long term stroke related outcomes was acknowledged in this thesis. Neuropsychological deficits related to neglect, anosognosia, impaired emotion interpretation, anosodiaphoria and deficits of magnitude estimation might have been present, and could have influenced the reported perceptions of social participation and QoL change. Validity of findings was therefore increased by obtaining self-report and proxy-report simultaneously. Thus, the inclusion of a communication partner, familiar with the person with stroke, both currently and prior to stroke onset, was deemed essential to address potential under-reporting.

Concluding statement

People with CCD following a RH stroke have historically, and likely continue to face under identification of their need to access support that would facilitate maintenance of social roles and relationships (Blake, 2017). This thesis offers an exploration of the prevalence, nature and impact of CCD on social participation. Much remains to be explored, and many clinical implications emerged that require further empirical inquiry. CCD in general, and more specifically CCD characterised by social cognition impairment emerged as a potential variable that hold consequences for the ability to maintain valued roles and relationships. This study supports the need for education and therapy that focus on collaborative communication, occurring at the level of the social network and in particular with network members who are facilitators of social engagement to reduce social participation restriction. Identification and development of role-specific or relationship-specific communication coping strategies may hold promise. While research emerges to guide our assessment practices and selection of intervention approaches, it is hoped that the stories conveyed in the data that make up this thesis will inspire a renewed focus on improving service provision to our clients with RH stroke. It is, furthermore, hoped that the experiences conveyed in this research will add towards the development of theory concerning social participation in the presence of CCD post RH stroke. The intention of this research was not to provide the final word on the phenomenon, but hopefully to increase awareness of the need for evaluation of current practices and the urgent need for research aimed at improving long-term stroke outcomes in this population.

List of references

- Abusamra, V., Côté, H., Joannette, Y. & Ferreres, A. (2009). Communication impairments in patients with right hemisphere damage. *Life span and disability*, 1, 67-82.
- Adair, J.C., Schwartz, R.L., & Barrett, A.M. (2003). Anosognosia. In K.M. Heilman and E. Valenstein eds, *Clinical Neuropsychology*, 4th Ed, Oxford University Press: New York, 184-214.
- Antonucci, T. C., Ajrouch, K. J., & Birditt, K. S. (2014). The Convoy Model: Explaining social relations from a multidisciplinary perspective. *The Gerontologist*, 54(1), 82-92.
- Arntzen, C., Borg, T., & Hamran, T. (2015). Long-term recovery trajectory after stroke: an ongoing negotiation between body, participation and self. *Disability and rehabilitation*, 37(18), 1626-1634.
- Baron-Cohen, S., Tager-Flusberg, H., & Cohen, D.J. (2000). *Understanding other minds: perspectives from developmental cognitive neuroscience (2nd ed)*. New York: OUP.
- Barrett, A.M. (2009). Rose-colored answers: Neuropsychological deficits and patient-reported outcomes after stroke. *Behavioral Neurology*, 22(17), 17-23.
- Barry, S. S., & Douglas, J. M. (2000). The social integration of individuals with aphasia. *Advances in Speech Language Pathology*, 2(2), 77-91.
- Baum, M.C., & Edwards, D. (1993). Cognitive performance in senile dementia of the Alzheimer's type: The kitchen task assessment. *American Journal of Occupational Therapy*, 47(5), 431-436.
- Baumann, M., Couffignal, S., Le Bihan, E., & Chau, N. (2012). Life satisfaction two-years after stroke onset: the effects of gender, sex occupational status, memory function and quality of life among stroke patients (NewsQol) and their family caregivers (WhoQol Bref) in Luxembourg. *BMC Neurology*, 12(1), 105.
- Baylor, C., Burns, M., Eadie, T., Britton, D. & Yorkston, K. (2011). A qualitative study of interference with communicative participation across communication disorders in adults. *American Journal of Speech-Language Pathology*, 20, 269-287
- Beeman, M. (1993). Semantic processing in the right hemisphere may contribute to drawing inferences from discourse. *Brain and language*, 44, 80-80.
- Benton, E., & Bryan, K. (1996). Right cerebral hemisphere damage: incidence of language problems. *International Journal of Rehabilitation Research*, 19, 47-54.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to

- health: Durkheim in the new millennium. *Social Science & Medicine*, 51(6), 843-857.
- Bhogal, S.K., Teasell, R.W., Foley, N.C., & Speechley, M. R. (2003). Community reintegration after stroke. *Topics in Stroke Rehabilitation*, 10(2), 107-129.
- Blake, M. (2017). *The right hemisphere and disorders of cognition and communication: Theory and clinical practice*. San Diego: Plural Publishing.
- Blake, M.L. (2016). Right hemisphere strokes. *Perspectives ASHA Special Interest Group*, (1), 63-65.
- Blake, M.L. (2011). Cognitive communication deficits associated with right hemisphere brain damage. In M. L. Kimbarow (Ed.), *Cognitive Communication Disorders*. San Diego: Plural Publishing.
- Blake, M.L. (2007). Perspectives on treatment of communication deficits associated with right hemisphere brain damage. *American Journal of Speech-Language Pathology*, 16(4), 331-342.
- Blake, M.L. (2006). Clinical relevance of discourse characteristics after right hemisphere brain damage. *American Journal of Speech-Language Pathology*, 15, 255-267.
- Blake, M., Duffy, J. R., Myers, P. S., & Tompkins, C. A. (2002). Prevalence and patterns of right hemisphere cognitive/communicative deficits: Retrospective data from an inpatient rehabilitation unit. *Aphasiology*, 16(4-6), 537-547
- Blake, M.L., Frymark, T., & Venedictov, R. (2013) An evidence-based systematic review on communication treatments for individuals with right hemisphere brain damage. *America Journal of Speech-Language Pathology*, 22(1), 146-160.
- Blyth, T., Scott, A., Bond, A., Paul, E. (2012) A comparison of two assessments of high level cognitive communication disorders in mild traumatic brain injury. *Brain Injury*, 26(3), 234-40.
- Boden-Albala, B., Litwak, E., Elkind, M.S., Rundek, T., & Sacco, R.L. (2005). Social isolation and outcomes post stroke. *Neurology*, 64(11), 1888-1892.
- Bölsche, F., Hasenbein, U., Reissberg, H., Wallesch, C.W. (2004). Expectations of stroke patients concerning in-patient or out-patient neurological rehabilitation in Phase D. *Rehabilitation*, 43(2), 65-74.
- Borod, J.C., Bloom, R.L., Brickman, A.M., Nakhutina, L., & Curko, E.A. (2002). Emotional processing deficits in individuals with unilateral brain damage. *Applied Neuropsychology* 9(1), 23-36.
- Brady, M. C., Clark, A. M., Dickson, S., Paton, G., & Barbour, R. S. (2011). The impact of stroke-related dysarthria on social participation and implications for rehabilitation.

- Disability and Rehabilitation*, 33(3), 178-186.
- Brookshire, R.H. & McNeil (2014). *Introduction to Neurogenic Communication Disorders*. 8th Ed. St Louis: Mosby Elsevier.
- Brott, T., et al (1989). Measurements of acute cerebral infarction: a clinical examination scale. *Stroke*, 20, 864-870.
- Brown, M., Gordon, W.A., & Spielman, L. (2003). Participation in social and recreational activity in the community by individuals with traumatic brain injury. *Rehabilitation Psychology*, 48, 266-274.
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010). Snapshots of success: An insider perspective on living successfully with aphasia. *Aphasiology*, 24(10), 1267-1295.
- Cahn-Weiner, D. A., Malloy, P. F., Boyle, P. A., Marran, M., & Salloway, S. (2000). Prediction of functional status from neuropsychological tests in community-dwelling elderly individuals. *Clinical Neuropsychology*, 14(2), 187–195.
- Chan, E., Altendorff, S., Healy, C. Werring, D.J., Cipolotti, L. (2017). The test accuracy of the Montreal Cognitive Assessment (MoCA) by stroke lateralisation. *Journal of the neurological sciences*, 373, 100-104.
- Cherney, L.R., Halper, A.S., Kwasnica, C.M., Harvey, R.L., & Zhang, M. (2001). Recovery of functional status after right hemisphere stroke: Relationship with unilateral neglect. *Archives of Physical Medicine and Rehabilitation*, 82(3), 322-328.
- Coelho, C., Ylvisaker, M., & Turkstra, L. S. (2005). Nonstandardized assessment approaches for individuals with traumatic brain injuries. *Seminars in Speech and Language*, 26(4), 223-241
- Cooper, C. L., Phillips, L. H., Johnston, M., Radlak, B., Hamilton, S., & McLeod, M. J. (2014). Links between emotion perception and social participation restriction following stroke. *Brain Injury*, 28(1), 122-126.
- Cornwell, B., Schumm, L.P., Laumann, E.O., Kim, J., & Kim, Y.J. (2014). Assessment of social network change in a national longitudinal survey. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 69(8), S75–S82
- Côté, H., Payer, M., Giroux, F., & Joannette, Y. (2007). Towards a description of clinical communication impairment profiles following right-hemisphere damage. *Aphasiology*, 21(6-8), 739-749.
- Cott, C.A., Wiles, R., & Devitt, R. (2007). Continuity, transition and participation: Preparing clients for life in the community post-stroke. *Disability and rehabilitation*, 29(20), 1566-1574.

- Cruice, M. (2001). Communication and quality of life in older people with aphasia and healthy older people. Unpublished Doctoral thesis, University of Queensland: Australia.
- Cruice, M., Worrall, L., & Hickson, L. (2006). Quantifying aphasic people's social lives in the context of non-aphasic peers. *Aphasiology*, 20(12), 1210-1225.
- Cusick, C.P., Gerhart, K.A., & Mellick, D.C. (2000). Participant-proxy reliability in traumatic brain injury outcome research. *Journal of head trauma rehabilitation*, 15(1), 739-749.
- Dai, C.Y., Liu, W.M., Chen, S.W., Yang, C.A., Tung, Y.C., Chou, L.W., & Lin, L.C. (2014). Anosognosia, neglect and quality of life of right hemisphere stroke survivors. *European Journal of Neurology*, 21(5), 797-801.
- D'Alisa, S., Baudo, S., Mauro, A., & Miscio, G. (2005). How does stroke restrict participation in long-term post-stroke survivors? *Acta Neurologica Scandinavica*, 112(3), 157-162.
- Dalemans, R.J.P., De Witte, L.P., Beurskens, A.J.H.M., Van Den Heuvel, W.J.A., & Wade, D.T. (2010). An investigation into the social participation of stroke survivors with aphasia. *Disability and Rehabilitation*, 32(20), 1678-1685.
- Dai, C.-Y., Liu, W.-M., Chen, S.-W., Yang, C.-A., Tung, L.-W., & Lin, L.-C. (2014). Anosognosia, neglect and quality of life of right hemisphere stroke survivors. *European Journal of Neurology*, 21, 797-801.
- Dara, C., Bang, J., Gottesman, R.F., & Hillis, A.E. (2014). Right hemisphere dysfunction is better predicted by emotional prosody impairments as compared to neglect. *Journal of neurology & translational neuroscience*, 2(1), 1037
- Davidson, B., Howe, T., Worrall, L., Hickson, L., & Togher, L. (2008). Social participation for older people with aphasia: The impact of communication disability on friendships. *Topics Stroke Rehabilitation*, 15, 325-340.
- de Frias, C.M., Dixon, R.A., & Strauss, E. (2006). Structure of four executive functioning tests in healthy older adults. *Neuropsychology*, 20(2), 206.
- Demeyere N, Riddoch MJ, Slavkova ED et al (2015) The Oxford cognitive screen (OCS): validation of a stroke-specific short cognitive screening tool. *Psychological Assessment*, 27(3):883–894
- Demeyere, N., Riddoch, M. J., Slavkova, E. D., Jones, K., Reckless, I., Mathieson, P., & Humphreys, G. W. (2016). Domain-specific versus generalized cognitive screening in acute stroke. *Journal of neurology*, 263(2), 306-315.

- Dickson, S., Barbour, R. S., Brady, M., Clark, A. M., & Paton, G. (2008). Patients' experiences of disruptions associated with post-stroke dysarthria. *International Journal of Language & Communication Disorders*, 43(2), 135-153.
- Dijkers M. P. (2004). Quality of life after traumatic brain injury: A review of research approaches and findings. *Archives of Physical Medicine and Rehabilitation*, 85, S21–S35
- Dijkers, M.P. (1998). Community integration: Conceptual issues and measurement approaches in rehabilitation research. *Top Spinal Cord Injury Rehabilitation*, 4, 1–15.
- Douglas, J. M. (2017). “So that's the way it is for me—always being left out.” Acquired Pragmatic Language Impairment and Social Functioning following Traumatic Brain Injury. *Brain Impairment*, 18(3), 321-331.
- Douglas, H., Swanson, C., Gee, T., & Bellamy, N. (2005). Outcome measurement in Australian rehabilitation environments. *Journal of Rehabilitation Medicine*, 37, 325-329.
- Doyle, S., Bennett, S., Fasoli, S.E., & McKenna, K.T. (2010). Interventions for sensory impairment in the upper limb after stroke. *The Cochrane Database of Systematic Reviews*, 2005(6).
- Edwards, D., Hahn, M., Baum, C., & Dromerick, A. (2006). The impact of mild stroke on meaningful activity and life satisfaction. *Journal of Stroke and Cerebrovascular Disease*, 15, 151–157.
- Egbert, N., Koch, L., Coeling, H., & Ayers, D. (2006). The role of social support in the family and community integration of right-hemisphere stroke survivors. *Health Communication*, 20(1), 45-55.
- Ekstam, L., Uppgard, B., von Koch, L., & Tham, K. (2007). Functioning in everyday life after stroke: A longitudinal study of elderly people receiving rehabilitation at home. *Scandinavian Journal of Caring Science*, 21, 434–446.
- Ellmo, W., Graser, J., Krchnavek, B., Hauck, K. & Calabrese, D. (1995). *Measure of cognitive-linguistic abilities*. Florida: Speech Bin Inc.
- Ferré P. (2009). Identification de profils communicationnels parmi les cérébrolésés droits: Profils transculturels. *Revista Neuropsicologia Latinoamericana*, 1, 32-40.
- Ferré, P., & Joannette, Y. (2016). Communication abilities following right hemisphere damage: prevalence, evaluation, and profiles. *Perspectives ASHA Special Interest Group*, 1, 106 - 115.
- Fink, J.N., Selim, M.H., Kumar, S., Silver, B., Linfante, I., Caplan, L. R., & Schlaug, G. (2002). Is the association of national institutes of health stroke scale scores and acute magnetic

- resonance imaging stroke volume equal for patients with right- and left-hemisphere ischemic stroke? *Stroke*, 33(4), 954–958.
- Fleming, J., Kuipers, P., Foster, M., Smith, S., & Doig, E. (2009). Evaluation of an outpatient, peer group intervention for people with acquired brain injury based on the ICF 'Environment' dimension. *Disability and Rehabilitation*, 31(20), 1666–1675.
- Foerch, C., Misselwitz, B., Sitzler, M., Berger, K., Steinmetz, H., Neumann-Haefelin, T., et al. (2005). Difference in recognition of right and left hemispheric stroke. *Journal of Medicine*, 366, 392–393.
- Folstein, M. F., Robins, L. N., & Helzer, J. E. (1983). The mini-mental state examination. *Archives of general psychiatry*, 40(7), 812–812.
- Fougeyrollas, P., Noreau, L., Bergeron, H., Cloutier, R., Dion, S.A., & St Michel, G. (1998). Social consequences of long-term impairments and disabilities: Conceptual approaches and assessment of handicap. *International Journal of Rehabilitation Research*, 21, 127–141.
- Frymark, T. (2004). FIM or foe? Functional independence measures fall short, data show. *ASHA Leader*.
- Geyh, S., Peter, G., Muller, R., Bickenbach, J.E., Kostanjsek, N., Ustun, B.T., et al. (2011). The personal factors of the International Classification of Functioning, Disability and Health in the literature — a systematic review and content analysis. *Disability and Rehabilitation*, 33(13–14), 1089–1102.
- Gialanella, B., Bertolinelli, M., Lissi, M., & Prometti, P. (2011). Predicting outcome after stroke: The role of aphasia. *Disability and Rehabilitation*, 33, 122–29.
- Gillespie, D. C., Bowen, A., & Foster, J. K. (2006). Memory impairment following right hemisphere stroke: a comparative meta-analytic and narrative review. *The Clinical Neuropsychologist*, 20(1), 59–75.
- Godwin, E., Chappell, B., & Kreutzer, J. (2014). Relationships after TBI: A grounded research study. *Brain injury*, 28(4), 398–413.
- Gottesman, R. F., Kleinman, J. T., Davis, C., Heidler-Gary, J., Newhart, M., & Hillis, A. E. (2010). The NIHSS-plus: Improving cognitive assessment with the NIHSS. *Behavioural Neurology*, 22(1-2), 11–15.
- Grohn, B., Worrall, L., Simmons-Mackie, N., & Hudson, K. (2014). Living successfully with aphasia during the first year post-stroke: A longitudinal qualitative study. *Aphasiology*, 28(12), 1405–1425.

- Guide for the Uniform Data Set for Medical Rehabilitation (1997). FIM(TM) instrument. Buffalo State University: New York.
- Haley, W., Roth, D., Kissela, B., Perkins, M., & Howard, G. (2011). Quality of life after stroke: a prospective longitudinal study. *Quality of Life Research*, 20(6), 799-806.
- Hammond, F.M., Hart, T., Bushnik, T., Corrigan, J.D., & Sasser, H. (2004). Change and predictors of change in communication, cognition, and social function between 1 and 5 years after traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 19, 314–328.
- Hanks, R., Rapport, L.J., Millis, S.R., & Deshpande, S.A. (1999). Measures of executive functioning as predictors of functional ability and social integration in a rehabilitation sample. *Archives of physical medicine and rehabilitation*, 80(9), 1030-1037.
- Henry J. D., Crawford J. R. (2004). Verbal fluency deficits in Parkinson's disease: a meta-analysis. *Journal of the International Neuropsychological Society*, 10, 608–622
- Hewetson, R., Cornwell, P., & Shum, D. (2018). Social participation following right hemisphere stroke: Influence of a cognitive-communication disorder. *Aphasiology*, 32(2), 164-182.
- Hewetson, R., Cornwell, P., & Shum, D. (2017). Cognitive-communication disorder following right hemisphere stroke: Exploring rehabilitation access and outcomes. *Topics in Stroke Rehabilitation*, 24(5), 330-336.
- Hilari, K. (2011). The impact of stroke: are people with aphasia different to those without? *Disability and Rehabilitation*, 33(3), 211 - 218.
- Hilari, K. & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, 20(1), 17–36.
- Hilari, K., Northcott, S., Roy, P., Marshall, J., Wiggins, R.D., Chataway J., & Ames, D. (2010). Psychological distress after stroke and aphasia: the first six months *Clinical Rehabilitation*, 24(2), 181-90.
- Hilari, K., Wiggins, R., Roy, P., Byng, S., & Smith, S. (2003). Predictors of health-related quality of life (HRQOL) in people with chronic aphasia. *Aphasiology*, 17(4), 365-381.
- Hilari, K., Woen, S., & Farrelly, S.J. (2007). Proxy and self-report agreement on the Stroke and Aphasia Quality of Life Scale-39. *Journal of Neurology, Neurosurgery, and Psychiatry*, 78(10), 1072-1075.
- Hinckley, J.J. (2014). A case for the implementation of cognitive-communication screenings in acute stroke. *American Journal of Speech-Language Pathology*, 23(1), 4–14.
- Hinckley, J. J. (2006). Finding messages in bottles: Living successfully with stroke and

- aphasia. *Topics in stroke rehabilitation*, 13(1), 25-36.
- Hirshorn, E.A., Thompson-Schill, S.L. (2006). Role of the left inferior frontal gyrus in covert word retrieval: neural correlates of switching during verbal fluency. *Neuropsychologia*, 44, 2547–2557.
- Holland, A. (2006). Living successfully with aphasia: Three variations on the theme. *Topics in Stroke Rehabilitation*, 13(1), 44–51.
- Hommel, M., Trabucco-Miguel, S., Joray, S., Naegele, B., Gonnet, N., & Jaillard, A. (2008). Social dysfunctioning after mild to moderate first-ever stroke at vocational age. *Journal of Neurology, Neurosurgery & Psychiatry*.
- Inouye, M., Hashimoto, H., Mio, T., & Sumino, K. (2001). Influence of admission functional status on functional change after stroke rehabilitation. *American Journal of Physical Medicine and Rehabilitation*, 80, 121-25.
- Jette, A. M., Keysor, J., Coster, W., Ni, P., & Haley, S. (2005). Beyond function: Predicting participation in a rehabilitation cohort. *Archives of Physical Medicine and Rehabilitation*, 86(11), 2087–2094.
- Kagan, A., Simmons-Mackie, N., Victor, J.C., Carling-Rowland, A., Hoch, J., Huijbregts, M., Streiner, D., & Mok, A. (2011). *Assessment for Living with Aphasia (ALA)*. Toronto: Aphasia Institute.
- Katz, N., Harman-Maeir, A., Ring, H., & Soroker, N. (2000). Relationships of cognitive performance and daily function of clients following right hemisphere stroke: Predictive and ecological validity of the LOTCA Battery. *Occupational Therapy Journal Research*, 20, 3-17.
- Kersten, P., Low, J.T., Ashburn, A., George, S.L., & McLellan, D.L. (2002). The unmet needs of young people who have had a stroke: Results of a national UK survey. *Disability Rehabilitation*, 24(16), 860-866.
- Kertesz, A. (2007). *The Western Aphasia Battery-Revised*. New York: Grune & Stratton.
- King, R., Shade-Zeldow, Y., Carlson, C., Feldman, J., & Philip, M. (2002). Adaption to stroke: A longitudinal study of depressive symptoms, physical health, and coping process. *Topics in Stroke Rehabilitation*, 9, 46-66.
- Klonoff, R., Sheperd, P., O'Brien, J., Chiapello, K., & Dennis, A. (1990). Rehabilitation and outcome of right-hemisphere stroke patients: Challenges to traditional diagnostic and treatment methods. *Neuropsychology*, 4, 147-163.
- Knox, L., Douglas, J., & Bigby, C. (2015). 'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners

- with TBI. *Brain Injury*, 29(6), 745-757.
- Knox, L., & Douglas, J. (2009). Long-term ability to interpret facial expression after traumatic brain injury and its relation to social integration. *Brain and Cognition*, 69(2), 442-449.
- Kuipers, P., Kendall, M., Fleming, J., & Tate, R. (2004). Comparison of the Sydney Psychosocial Reintegration Scale (SPRS) with the Community Integration Questionnaire (CIQ): psychometric properties. *Brain Injury*, 18(2), 161-177.
- Laliberté, M-P, Alary Gauvreau, C.A., & Le Dorze, G. (2016). A pilot study on how speech-language pathologists include social participation in aphasia rehabilitation. *Aphasiology*, 30(10), 1117 – 1133.
- Landis, R.L., & Koch, G.G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33(1), 159-174.
- Le Dorze, G. L., & Brassard, C. (1995). A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases. *Aphasiology*, 9(3), 239-255.
- Le Dorze, G., Salois-Bellerose, É., Alepins, M., Croteau, C., & Hallé, M.C. (2014). A description of the personal and environmental determinants of participation several years post-stroke according to the views of people who have aphasia. *Aphasiology*, 28(4), 421-439.
- Lefebvre, H., Pelchat, D., Swaine, B., Gélinas, I. & Levert, M.J. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury*, 19, 585-597.
- Levasseur, M., Richard, L., Gauvin, L., & Raymond, É. (2010). Inventory and analysis of definitions of social participation found in the aging literature: Proposed taxonomy of social activities. *Social Science & Medicine*, 71(12), 2141-2149.
- Lezak, M.D. (1978). Living with the characterologically altered brain-injured patient. *Journal of Clinical Psychology*, 39, 592-598.
- Loonstra, A.S., Tarlow, A.R. & Sellers, A.H. (2010). COWAT metanorms across age, education, and gender. *Applied Neuropsychology*, 8(3), 161-166.
- Lynn Snow, A., Cook, K. F., Lin, P.-S., Morgan, R. O. & Magaziner, J. (2005). Proxies and other external raters: Methodological considerations. *Health Services Research*, 40, 1676–1693.

- Mackenzie, C. & Brady, M. (2008). Communication difficulties following right-hemisphere stroke: Applying evidence to clinical management. *Evidence-based communication assessment and intervention*, 2(4), 235-247.
- Mackenzie, C., Brady, M., Begg, T., & Lees, K.R. (2001). Communication ability following right brain damage: The family perspective. *Advances in Speech-Language Pathology*, 3(2), 81-95.
- Macrae, C.N., & Bodenhausen, G.V. (2000). Social cognition: Thinking categorically about others. *Annual Review of Psychology*, 51, 93-120.
- Malle, B.F., Moses, L.J., & Baldwin, D.A. (2001). *Intentions and intentionality: Foundations of social cognition*. Cambridge, MA: MIT Press.
- Martin, I., & McDonald, S. (2003). Weak coherence, no theory of mind, or executive dysfunction? Solving the puzzle of pragmatic language disorders. *Brain and Language*, 85, 451-466.
- Mayo, N. E., Wood-Dauphinee, S., Côté, R., Gayton, D., Carlton, J., Buttery, J., & Tamblyn, R. (2000). There's no place like home: An evaluation of early supported discharge for stroke. *Stroke*, 31(5), 1016-1023.
- McColl, M., Davies, D., Carlson, P., Johnston, J., & Minnes, P. (2001). The community integration measure: Development and preliminary validation. *Archives of Physical Medicine and Rehabilitation*, 82, 429-434.
- MacDonald, S. (2017). Introducing the model of cognitive-communication competence: A model to guide evidence-based communication interventions after brain injury. *Brain Injury*, DOI: 10.1080/02699052.2017.1379613
- McDonald, S., Bornhofen, C., Shum, D., Long, E. Saunders, C., Neulinger, K. (2006). Reliability and validity of 'The Awareness of Social Inference Test' (TASIT): A clinical test of social perception. *Disability and Rehabilitation*, 28, 1529-1542.
- McDonald, S., & Flanagan, S. (2004). Social perception deficits after traumatic brain injury: Interaction between emotion recognition, mentalizing ability, and social communication. *Neuropsychology*, 18(3), 572-579.
- McDonald, S., Flanagan, S., Rollins, J., & Kinch, J. (2003). TASIT: A new clinical tool for assessing social perception after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 18(3), 219-238.
- McDonald, S., Honan, C., Kelly, M., Byom, L., & Rushby, J. (2014). *Social and communication disorders following traumatic brain injury*. In S. McDonald, L. Togher & C. Code (Eds.). New York: Psychology Press.

- McDonald, S., Johnson, C.J. (2005). Assessment of subtle cognitive-communication deficits following acquired brain injury: A normative study of the Functional Assessment of Verbal Reasoning and Executive Strategies (FAVRES). *Brain Injury*, 19(11), 895-902.
- Mitchell, R.L., & Phillips, L.H. (2015). The overlapping relationship between emotion perception and theory of mind. *Neuropsychologia*, 70, 1-10.
- Mildner, V. (2008). *The Cognitive Neuroscience of Human Communication*. Sussex: Taylor & Francis.
- Monetta, L., & Joannette, Y. (2003). Specificity of the Right Hemisphere's Contribution to Verbal Communication: The Cognitive Resources Hypothesis. *Journal of Medical Speech-Language Pathology*, 11(4), 203-211.
- Morris, M., Perry, A., Unsworth, & et al. (2005). Reliability of the Australian therapy outcome measures for quantifying disability and health. *International journal of therapy and rehabilitation*, 12(8): 340
- Muus, I., Petzold, M., & Ringsberg, K.C. (2009). Health-related quality of life after stroke: reliability of proxy responses. *Clinical Nursing Research*, 18(2), 103-118.
- Myers, P.S. (1999). *Right hemisphere damage: Disorders of communication and cognition*. London: Singular.
- Myers, P.S. (1978). Analysis of Right Hemisphere communication deficits: Implications for speech pathology. *Aphasiology*, 1-7. Retrieved from <http://aphasiology.pitt.edu/archive/00000414/01/0807.pdf>
- Nasreddine, Z.S., et al. (1996). The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of American Geriatric Society*, 53(4), 695-699.
- National Stroke Audit (2014). *Rehabilitation Services Report*. National Stroke Foundation. Melbourne, Australia.
- National Stroke Foundation. (2013). *Rehabilitation Stroke Services Framework*. National Stroke Foundation: Melbourne.
- National Stroke Foundation. (2013). *The economic impact of stroke in Australia*. National Stroke Foundation: Melbourne.
- Nichol, A.D., Higgins, A.M., Gabbe, B.J., Murray, L.J., Cooper, D.J., & Cameron, P.A. (2011). Measuring functional and quality of life outcomes following major head injury: common scales and checklists. *Injury*, 42, 281-287.
- Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke?

- International Journal of communication disorders*, 46(5), 524-534.
- Novack, T.A., Bush, B.A., Meythaler, J.M., & Canupp, K. (2001). Outcome after traumatic brain injury: Pathway analysis of contributions from premorbid, injury severity, and recovery variables. *Archives of Physical Medicine Rehabilitation*, 82, 300-305.
- Oakley, F., Kielhofner, G., Barris, G. & Reichler, R. K. (1986). The role checklist: Development and empirical assessment of reliability. *Occupational Therapy Journal of Research*, 6, 157-169.
- Obembe, A.O., Eng, J.J. (2016). Rehabilitation interventions for improving social participation after stroke: A systematic review and meta-analysis. *Neurorehabilitation and Neural Repair*, 30(3), 384-92.
- Oczkowski, W., & Barreca, S. (1993). The functional independence measure: its use to identify rehabilitation needs in stroke survivors. *Archives of Physical Medicine and Rehabilitation*, 74, 1291-94.
- Oczkowski, C. & O'Donnell, M. (2010). Reliability of proxy respondents for patients with stroke: A systematic review. *Journal of stroke and cerebrovascular diseases*, 19(5), 410-416.
- Odell, K., Wollack, J., & Flynn, M. (2010). Functional outcomes in patients with right hemisphere brain damage. *Aphasiology*, 19(9), 807 – 830.
- Ottenbacher, K.J., Hsu, Y., Granger, C.V., & Fiedler, R.C. (1996). The reliability of the functional independence measure: a quantitative review. *Archives of Physical Medicine and Rehabilitation*, 77, 1226-32.
- Owensworth, T., Fleming, J., Strong, J., Radel, M., Chan, W. & Clare, L. (2007). Awareness typologies, long-term emotional adjustment and psychosocial outcomes following acquired brain injury. *Neuropsychological Rehabilitation*, 17(2), 129-150.
- Owensworth, T., Little, T., Turner, B., Hawkes, A., & Shum, D. (2008). Assessing emotional status following acquired brain injury: The clinical potential of the Depression, Anxiety and Stress Scales. *Brain Injury*, 22, 858-869.
- Owensworth, T. & Shum, D. (2008). Relationship between executive functions and productivity outcomes following stroke. *Disability and rehabilitation*, 30 (7), 531-540.
- Papathanasiou, I., Coppens, P., Potagas, C. (2013). *Aphasia and related neurogenic communication disorders*. Burlington: Jones & Bartlett Learning.
- Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about aphasia: Living with loss*

- of language after stroke*. Buckingham: Open University Press.
- Patton, M.Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbery Park, CA: Sage.
- Perry, A., Morris, M., Unsworth, C., Duckett, S., Skeat, J., Dodd, K., Taylor, N., & Reilly, K. (2004). Therapy outcome measures for allied health practitioners in Australia: the AusTOMs. *International Journal for quality in Health Care*, 16 (4), 285-291.
- Ponsford, J.L., Downing, M.G., Olver, J., Ponsford, M., Acher, R., Carty, M. & Spitz, G. (2014). Longitudinal follow-up of patients with traumatic brain injury: Outcome at two, five and ten years post-injury. *Journal of Neurotrauma*, 31, 64-77.
- Rath, J.F., Hennessy, J., & Leonard, D. (2003). Social problem solving and community integration in postacute rehabilitation outpatients with traumatic brain injury. *Rehabilitation Psychology*, 48(3), 137-144.
- Reis, H. T., & Downey, G. (1999). Social cognition in relationships: Building essential bridges between two literatures. *Social Cognition*, 17(2), 97-117.
- Reistetter, T.A. & Abreu, B.C. (2005). Appraising evidence on community integration following brain injury: A systematic review. *Occupational Therapy International*, 12, 196–217.
- Robertson, I., Ridgeway, V., Greenfield, E., & Parr, A. (1997). Motor recovery after stroke depends on intact sustained attention: A 2-year follow-up study. *Neuropsychology*, 11, 290-95.
- Salter, K., Foley, N., Jutai, J., Bayley, M., & Teasell, R. (2008). Assessment of community integration following traumatic brain injury. *Brain Injury*, 22(11), 820-835.
- Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: A qualitative meta-synthesis. *Journal of Rehabilitation Medicine*, 40(8), 595-602.
- Salzer, M., Baron, R.C. (2006). *Community integration and measuring participation*. Philadelphia: University of Pennsylvania Collaborative on Community Integration.
- Sander, A., Clark, A., & Pappadis, M. (2010). What is community integration anyway?: Defining meaning following traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 25, 121-127.
- Sarno, M.T. (1997). Quality of life in aphasia in the first post-stroke year. *Aphasiology*, 11, 665-679.
- Schuling, K., de Haan, R., Limburg, M. & Gronier, K.H. (1993). The Frenchay Activities

- Index. Assessment of functional status in stroke patients. *Stroke*, 24, 1173-1177.
- Schwartz, S., & Baldo, J. (2001). Distinct patterns of word retrieval in right and left frontal lobe patients: a multidimensional perspective. *Neuropsychologia* 39, 1209–1217
- Shadden, B. B., & Agan, J. P. (2004). Renegotiation of identity: The social context of aphasia support groups. *Topics in language disorders*, 24(3), 174-186.
- Shao, Z., Janse, E., Visser, K., & Meyer, A. S. (2014). What do verbal fluency tasks measure? Predictors of verbal fluency performance in older adults. *Frontiers in Psychology*, 5, 772.
- Shorland, J., & Douglas, J. M. (2010). Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. *Brain Injury*, 24(4), 569-580.
- Simmons-Mackie, N.N., Damico, J.S. (2007). Access and social inclusion in aphasia: interactional principles and applications. *Aphasiology*, 21(1), 81-97.
- Simmons-Mackie, N., & Damico, J.S. (2001). Intervention outcomes: A clinical application of qualitative methods. *Topics in language disability*, 22, 21-36.
- Stein, M.S., Kilbride, C., Reynolds, F.A. (2016). What are the functional outcomes of right hemisphere stroke patients with or without hemi-inattention complications? A critical narrative review and suggestions for further research. *Disability and Rehabilitation*, 38, 315-328.
- Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American journal of health promotion*, 10(4), 282-298.
- Stolwyk, R. J. (2016). Cognitive Screening Following Stroke: Are we following best evidence-based practice in Australian Clinical Settings? *Australian Psychologist*, 51(5), 360-365.
- Stroke Foundation (2017). Clinical guidelines for stroke management 2017. Melbourne Australia.
- Struchen, M. A., Pappadis, M. R., Sander, A. M., Burrows, C. S., & Myszka, K. A. (2011). Examining the contribution of social communication abilities and affective/behavioral functioning to social integration outcomes for adults with traumatic brain injury. *The Journal of head trauma rehabilitation*, 26(1), 30-42.
- Swinburn, K., Porter, G., & Howard, D. (2004). *Comprehensive Aphasia Test*. Psychology Press.
- Taule, T., & Raheim, M. (2014). Life changed existentially: a qualitative study of

- experiences at 6 – 8 months after mild stroke. *Disability and rehabilitation*, 36(25), 2107-2119.
- Tate, R.L. (2011). *Manual for the Sydney Psychosocial Reintegration Scale Version 2*. Unpublished manuscript, Rehabilitation Studies Unit, University of Sydney.
- Tate, R., Hodgkinson, A., Veerabangsa, A., & Maggiotto, S. (1999). Measuring psychosocial recovery after traumatic brain injury: Psychometric properties of a new scale. *Journal of Head Trauma Rehabilitation*, 14, 543 – 557.
- Thrift, A.G., Cadilhac, D.A., Thayabaranathan, T., Howard, G., Howard, V.J., Rothwell, P.M., & Donnan, G.A. (2014). Global stroke statistics. *International Journal of Stroke*, 9, 6-18.
- Togher, L., McDonald, S., Coelho, C.A., & Byom, L. (2014). Cognitive communication disability following TBI: examining discourse, pragmatics, behaviour and executive function. In *Social and communication disorders following traumatic brain injury* (2nd ed). London: Psychology Press.
- Togher, L., Power, E., Tate, R., McDonald, S. & Rietdijk, R. (2010). Measuring the social interactions of people with traumatic brain injury and their communication partners: The adapted Kagan scales, *Aphasiology*, 24(6-8), 914-927.
- Tombaugh, T.N., & McIntyre, N.J. (1992). The mini-mental state examination: a comprehensive review. *Journal of the American Geriatrics Society*, 40(9), 922-935.
- Tompkins, C. (2012). Rehabilitation for cognitive-communication disorders in right hemisphere brain damage. *Archives of Physical Medicine and Rehabilitation*, 93(1), S61–S69.
- Tompkins, C.A., Baumgaertner, A., Lehman, M.T., & Fassbinder, W. (2000). Mechanisms of discourse comprehension impairment after right hemisphere brain damage: in lexical ambiguity resolution. *Journal of Speech-Language and Hearing Research*, 43, 62-78.
- Tompkins, C.A., Lehman, M.T., Wyatt, A.D., & Schultz, R. (1998). Functional outcome assessment of adults with right hemisphere brain damage. *Seminars in Speech and Language*, 19(3), 303-321.
- Tsouli, S., Kyritsis, A. P., Tsagalis, G., Virvidaki, E., Vemmos, K.N. (2009). Significance of Aphasia after first-ever acute stroke: Impact on early and late outcomes. *Neuroepidemiology*, 33, 96-102.
- Tsouna-Hadjis, E., Vemmos, K.N., Zakopoulos, N., & Stamatelopoulos, S. (2000). First-stroke recovery process: The role of family social support. *Archives of Physical Medicine and Rehabilitation*, 81(7), 881-887.
- Turner, B., Fleming, J., Cornwell, P., Haines, T., & Ownsworth, T. (2009). Profiling early

- outcomes during the transition from hospital to home after brain injury. *Brain Injury*, 23, 51-60.
- Uchino, B. (2006). Social Support and Health: A review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine*, 29(4), 377-387.
- Van Heugten, C. M., Walton, L., & Hentschel, U. (2015). Can we forget the Mini-Mental State Examination? A systematic review of the validity of cognitive screening instruments within one month after stroke. *Clinical Rehabilitation*, 29(7), 694–704.
- Vertesi, A., Lever, J.A., Molloy, D.W., Sanderson, B., Tuttle, I., Pokoradi, L. & Principi, E. (2001). Standardized Mini-Mental State Examination: use and interpretation. *Canadian Family Physician*, 47, 2018-2023.
- Vigneau, M., Beaucousin, V., Herve, P-Y., Jobard, G., Petit, L., Crivello, F., Mellet, E., Zago, L., Mazoyer, B., & Tzourio-Mazoyer, N. (2011). What is right-hemisphere contribution to phonological, lexico-semantic, and sentence processing? Insights from a meta-analysis. *NeuroImage*, 54, 577-593.
- Viscogliosi, C., Desrosiers, J., Belleville, S., Caron, C.D., Ska, B., & BRAD Group. (2011). Differences in participation according to specific cognitive deficits following a stroke. *Applied Neuropsychology*, 18(2), 117-126.
- Vossel, S., Weiss, P. H., Eschenbeck, P., & Fink, G. R. (2013). Anosognosia, neglect, extinction and lesion site predict impairment of daily living after right-hemispheric stroke. *Cortex*, 49(7), 1782-1789.
- Williams, L.S., Weinberger, M., Harris, L.E., Clark, D.O., & Biller, J. (1999). Development of a stroke-specific quality of life scale. *Stroke*, 30(7), 1362-1369.
- Wolf, T.J., Baum, C., & Connor, L.T. (2009). *Changing face of stroke: Implications for occupational therapy practice*. *American Journal of Occupational Therapy*, 63, 621–625.
- World Health Organization (2011). World report on disability. World Health Organization.
- World Health Organization. (2001). *International Classification of Functioning, Disability and Health*. Switzerland.
- Wozniak, M.A., Kitner, S.J., Price, T.R., Hebel, J.R., Sloan, M.A., & Gardner, J.F. (1999). Stroke location is not associated with return to work after first ischemic stroke. *Stroke*, 30, 2568-73.
- Wray, F. & Clarke, D. (2017). Longer-term needs of stroke survivors with communication

- difficulties living in the community: A systematic review and thematic synthesis of qualitative studies. *British Medical Journal Open*, 7(10), e017944.
- Yin, R.K. (2014). *Case study research: Design and methods*, 5th ed. Thousand Oaks: Sage Publications.
- Ylvisaker, M., & Feeney, T.J. (1998). *Collaborative brain injury intervention: Positive everyday routines*. San Diego: Singular Pub. Group.

APPENDICES

Appendix A: Social Network Interview Script

HREC No:	HREC/15/QPCH/274
Project Title:	Right Hemisphere Cognitive-Communication Disorder: Impact on Social Participation, Social Networks and Quality of Life
Name of Researchers:	Ronelle Hewetson, Petrea Cornwell, David Shum

**Queensland
Government**

“Now I am going to ask you some questions about your relationship with other people. We will begin by identifying some of the people you interact with on a regular basis. You may refer to these people in any way you want; for example, you may use just their first names or nicknames. I am not interested in the identities of these persons, I just need to have some way to refer to them so that when I ask you some follow-up questions we both know whom we are talking about.”

Question 1:

“From time to time, most people discuss things that are important to them with others. For example, these may include good or bad things that happen to you, problems you are having, or important concerns you may have. Looking back over the last 12 months, who are the people with whom you most often discussed things that were important to you?”

List names up to 10 in the order named). Prompt once if participant is finished and has named fewer than 5 people. *“Are there any more?”* If the answer is ‘no’, do not prompt further.

Question 2:

“Which of the following best describes (name)’s relationship to you?”

(Provide choice card 1 containing the following: spouse, ex-spouse, romantic partner, parent, parent-in-law, child, step-child, brother or sister, other relative of yours, other in-law, friend, neighbour, co-worker or boss, minister/priest/other clergy, therapist, home health care provider, other)

Prompt: *“Besides the people we wrote down on your list, is there anyone else who is very important to you, perhaps someone with whom you feel especially close?”* If yes, add the name. If no, move on.

Question 3:

“Next I am going to ask you some questions about the people you have just listed. We’ll start with (name).

Is (name) male or female?

Does (name) live in the same household as you?

What is (name)’s age. It is okay if you do not know the exact age, just give me your best guess.

How often do you talk with this person?

(Provide choice card 2 containing the following: every day, several times a week, once a week, once every two weeks, once a month, a couple of times a year, once a year, less than once a year).

How close do you feel is your relationship with (name)? Would you say, somewhat close, very close or extremely close.

Question 4:

“In the next set of questions, I’m going to give you two of the names you listed earlier and ask you to indicate how frequently these two people talk to each other by using the categories on this card. Let’s start with (name1) and (name2). How frequently do (name1) and (name2) talk to each other?” (Provide choice card 2)

Thank you, that concludes our questions about the people you interact with on a regular basis.

Appendix B: Overview of AusTOM items for Cognitive-Communication impairment

- Score of 0: Profound impairment when not responsive
- Score of 1: Severe impairment if responses are infrequent or severely delayed; if the person is disorientated; if impaired short-term memory is present.
- Score of 2: Moderate/severe impairment if responses are not consistent or delayed with distractibility present. Oriented to self and may be able to recall personal information. The person will require assistance to plan basic tasks.
- Score of 3: Moderate impairment is present if the person is consistently responding to stimuli and able to attend to a task for a short period of time. Concrete thinking is evident. The person is able to plan basic tasks, however requires help with complex tasks.
- Score of 4: Mild impairment is present when the person responds consistently, with relatively intact insight, full orientation and ability to recall events and plan within familiar contexts. Difficulties persist in challenging environments and with complex processing.
- Score of 5: No impairment is present when the person demonstrates no difficulty with responses, memory, insight, attention, orientation or planning.

Appendix C: Sydney Psychosocial Reintegration Scale-2 Item Description

Changes in Occupational Activities (Work and Leisure) because of the injury across:

- i) hours of work or study, or type of work or study
- ii) work or study skills
- iii) the number or type of leisure activities or interests
- iv) organising of work and leisure activities

Changes in Interpersonal Relationships because of the injury related to:

- i) a partner or spouse
- ii) relationships with other family members
- iii) relationships with other people outside family such as close friends
- iv) communication skills

Changes in Living Skill evident in

- i) social skills and behaviour in public
- ii) personal habits (care in cleanliness, tidiness and dressing)
- iii) use of transport and travel around community
- iv) living situation