

THE BENEFITS OF GROUPS FOR PEOPLE WITH APHASIA-

“We just thought this was Christmas”

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for the Degree of  
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By

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## Abstract

Background: Previous studies of aphasia groups have demonstrated some communication and psychosocial benefits for people with aphasia. To date, however the perceived benefits of various types of groups for people with aphasia and their family members have not been fully explored in the literature.

Aim: There were two aims of this study 1) to explore the range of perceived benefits for adults with aphasia post-stroke from participating in groups and 2) to explore the range of perceived benefits for family members of having a relative with aphasia post-stroke participate in groups.

Methods and procedures: A qualitative descriptive method was used. Semi structured in-depth interviews were conducted with ten participants with aphasia and six of their family members. The data was analysed using qualitative content analysis.

Results and conclusions: Analysis revealed 27 categories of benefits for individuals with aphasia and 12 categories of benefits for family members including communication, psychosocial and social participation benefits. The benefits of groups identified in this study suggest that different types of groups may be useful in addressing a variety of goals for individuals with aphasia and their relatives, helping them to live more successfully with aphasia.

## Chapter 1: Introduction

The research literature has documented that people with aphasia participate in a variety of groups post-stroke (Elman, 2007a; Kearns & Elman, 2008). These groups have included general groups (Howe, Worrall, & Hickson, 2008b), groups for individuals who have had a stroke (Hartke, King, & Denby, 2007), participant-led aphasia groups (Pound, 2012), volunteer-led aphasia groups (Hoen, Thelander, & Worsley, 1997), and speech-language therapy (SLT) aphasia groups (Wertz et al., 1981). Furthermore, the types of SLT groups have been varied including groups that have focused on reducing the communication impairment (Pulvermuller et al., 2001), improving everyday communication abilities (Bollinger, Musson & Holland; 1993), and decreasing the negative psychosocial impact of living with aphasia (Marshall, 1993). Groups may be valuable for people with aphasia because they can provide a setting for promoting natural conversation (Ross, Winslow, Marchant, & Brumfitt, 2006), obtaining support from others with a similar experience of aphasia (Elman & Bernstein-Ellis, 1999b), and increasing confidence (Elman & Bernstein-Ellis, 1999b). However, it is important to investigate if group participation is achieving the suggested communication and psychosocial benefits for people with aphasia and their family members. There are concerning statistics showing that having few social contacts outside the home was one of the most important predictors of depression in stroke survivors (Alstrom, Adolfrion, & Asplind, 1993). More recently, the World Health Organisation (WHO, 2011) reported that people with disability experience discrimination, lower income, isolation and poorer health outcomes. Some recommended areas of research called for by WHO are regarding the quality of life and well being for people with disabilities and the effectiveness of programmes for persons with disabilities. To date, research into the benefits for people with aphasia



participating in different types of groups such as SLT aphasia groups, volunteer-led groups, participant-led groups, groups for people with stroke and general groups is lacking. This thesis will investigate the perceived benefits of different types of groups from the perspective of individuals with aphasia and their family members.

## **1.1 Aphasia and social participation**

Aphasia is an acquired neurogenic language disorder that results from damage to the brain, usually a stroke. It is characterized by an impairment of all language modalities: speaking, listening, reading, and writing (Hallowell & Chapey, 2008). In New Zealand, it is estimated that 6000 people have a stroke each year, and that there are 32,000 stroke survivors (Stroke Foundation New Zealand, 2010). Aphasia affects approximately 35% of people who have had a stroke annually (Dickey et al., 2010). For the majority of stroke survivors with aphasia, the communication disability is present for the rest of their lives. Aphasia can also be defined in a social context as “An impairment due to brain damage in the formulation and reception of language, often associated with diminished participation in life events and reduced fulfilment of desired social roles” (Simmons-Mackie, 2008, p292). Social participation has been described as the performance of people in social life domains through interaction with others in the context in which they live. Two key components of participation are the need to interact and to communicate (Dalemans, Witte, Wade, & van den Heuvel, 2010).

The ability to communicate is core to all relationships, including friendships. The presence of aphasia can make it difficult for people to maintain friendships post-stroke (Davidson, Howe, Worrall, Hickson, & Togher, 2008a; Northcott & Hilari, 2011). Hilari and Northcott (2006) reported that 63.9% of people with aphasia had

less contact with friends and 30% reported no friends 12 months post-onset of aphasia. Davidson, Howe, Worrall, Hickson, and Togher (2008b) found that participation in leisure and educational activities was closely tied to everyday communication with friends. Interactions with friends and family, social activities, and community involvement may become increasingly difficult for people with aphasia (Sarno, 1993) and they may experience a profound negative change in their ability to participate in everyday life. The impact of aphasia on communication may also lead to negative changes in the person's quality of life (Cruice, Worrall, Hickson, & Murison, 2003). With the risk of such negative consequences, a social model of therapy has been advocated that considers a person's needs over time and incorporates the effects of aphasia on the person's whole life including their family members (Holland 2006; Simmons-Mackie, 2008). The use of therapy groups is one way to address the social and emotional needs of individuals with aphasia (Ferguson, 2007).

## **1.2 Benefits of groups**

A number of benefits of group participation have been reported in the literature. For the purposes of this study, a group is considered to be a multi-party interaction involving at least three people that has a shared focus and in which there is some affiliation between the participants (Ferguson, 2007). The benefits of groups will be highlighted in the next sections in relation to the benefits for the general population and the benefits for people with chronic disabilities. Finally, the research on the benefits of groups for individuals with aphasia, including the benefits of general groups, groups for individuals with stroke, participant-led aphasia groups, volunteer-led aphasia groups, and SLT groups will be discussed.

### **1.2.1 Benefits of participating in groups for the general population**

Some researchers have investigated the benefits of belonging to groups in relation to the general population. Research has found that involvement in groups can provide a sense of community and enable individuals to feel that they are part of something and that they can be of influence or be useful to others (McMillan & Chavis, 1986). At a basic level, in groups people learn tolerance of others, how to interact and work together (Bowler, Donovan, & Hannerman, 2003). Perren, Arber, and Davidson (2003) reported that older men's involvement in civic groups, sports clubs, social clubs, and religious groups facilitated social interaction. They reported on research that group participation offered older men opportunities to pursue a personal goal or to make a recognised social contribution through community activity, which can improve the well-being for older men post retirement. In a qualitative study of women involved in informal groups, Kees (1999) found that the groups provided support, strength, and connection that the participants did not necessarily obtain from their family and work roles.

### **1.2.2 Benefits of participating in groups for individuals with chronic disabilities**

The benefits of group involvement have also been studied in relation to people with chronic disabilities. Support groups for people with disability or illness have been advocated, particularly as they can provide information about illness and disability, increase client participation with their own treatment programmes, provide psychosocial support, and assist with improving quality of life (Davis, Cohen, & Apolinsky, 2005; Lewis, 2001). For example, a qualitative study, investigating the experience of being in a wheelchair rugby group for individuals with mobility impairments (Goodwin, et al., 2009), found that the participants identified with a

shared sense of community and membership. Participation in the wheelchair rugby group enabled the players to pursue shared goals and to improve their self esteem. The group was also found to aid the participants' acceptance of their new identity of having paraplegia, helping them to remove the stigma associated with the impairment.

### **1.2.3 Benefits of participating in groups for individuals with aphasia**

There have been a number of descriptive reports about different types of groups for people with aphasia (Aten, 1991; Avent, 1997; Elman, 2007a; Kearns & Elman, 2008; Pachalska, 1991). However, relatively few studies have investigated the benefits of groups for people with aphasia. The following sections describe research that has been conducted in this area in relation to different types of groups.

#### *1.2.3.1 Benefits for individuals with aphasia of participating in general groups*

There is a lack of research on the benefits for people with aphasia of participating in general community groups. In a study by Howe et al. (2008b), people with aphasia were interviewed to identify barriers and facilitators to community access. There was evidence that people with aphasia felt excluded from interactions in groups in the community such as committees and a weight loss group.

#### *1.2.3.2 Benefits for individuals with aphasia of participating in groups for people with stroke*

There are also few studies that have examined the benefits for people with aphasia of participating in groups specifically for individuals who have had a stroke. In one study, Hartke et al. (2007) investigated the use of small writing groups to improve long-term adaptation after a stroke. The research included 12 participants who had had a stroke with a mild aphasia and 14 individuals who had had a stroke

without aphasia. The investigators found a trend in improvement in positive identity for all participants, but no significant change and no significant change in depression or well-being. In another study, Legg, Stott, Ellis, and Sellars (2007) used focus groups to investigate the functions that Volunteer Stroke Service groups fulfilled for their members with aphasia or dysarthria post-stroke. The investigation revealed that the groups met a range of functions for the individuals with eight themes of benefits identified: 1) includes members in an interpersonal network, 2) provides members with the opportunity to develop interpersonal relations, 3) provides members with support, 4) provides opportunities for personal growth and development, 5) supplies members with a purpose, structure, and routine, 6) helps members establish and confirm their identity, beliefs, and values, 7) helps members accomplish individual and shared goals, and 8) provides members with the opportunity to influence others and be influenced. The study report provided little information about what the group activities entailed. In addition, it was unclear how many individuals with aphasia were included in the investigation and the benefits for the individuals of aphasia of participating in the groups were not reported separately from the overall findings. The authors, did, however, highlight the usefulness of qualitative methods for investigating this area of research.

### *1.2.3.3 Benefits for individuals with aphasia of participating in participant-led aphasia groups*

Although there is at least one descriptive report about participant-led aphasia groups in the literature (Pound, 2011), there is a lack of research investigating the benefits of these types of groups.

#### *1.2.3.4 Benefits for individuals with aphasia of participating in volunteer-led aphasia groups*

Hoen et al.(1997) investigated a community programme run by volunteers who had been trained by speech-language therapists. The programme provided long-term support for people with aphasia. On two occasions, six months apart, the participants with aphasia, who had enrolled for varying times in the programme, completed a short form of the Ryff's Psychological Well-being (Thelander, Hoen, & Worsley, 1994). The participants demonstrated significant positive changes in five out of six of the areas on the well-being scale: autonomy, environmental mastery, personal growth, purpose in life, and self-acceptance. The authors noted a testing effect in the results for the participants and so the study is flawed. Also, the aim of this study did not reflect improving quality of life (QoL) as a goal, and the actual functional communication aim was not measured

#### *1.2.3.5 Benefits for individuals with aphasia of participating in SLT aphasia groups*

The SLT group studies that have reported benefits for people with aphasia include treatments with a wide range of goals and approaches. As Davis (2007, p. 190) reported, in the aphasia literature, there is “no single entity for which the label 'group therapy' applies” and that it can only be assumed to involve two or more clients and a speech-language therapist. Some studies have identified benefits in relation to communication impairments as demonstrated by statistically significant changes on impairment focused outcome measures (Pulvermuller et al., 2001), while other studies have demonstrated changes in outcome measures related to activities and participation (Bollinger et al., 1993). Studies that have used a combination of group and individual approaches have not been included in this discussion, as it is not possible to attribute

any changes specifically to the group component of the intervention (Clausen & Beeson, 2010; Makenzie, 1991; Marshall & Wallace, 2009; van der Gaag, 2005). In addition, investigations in which there were no statistically significant changes in the post-treatment outcome measures and/or no positive perceived positive effects reported as part of a qualitative research study have not been included (Antonucci, 2009; Brumfitt & Sheeran, 1997; Drummond & Simmons, 1995; Radonjic & Rakuscek, 1991).

As expected, some group SLT treatment studies have demonstrated benefits in relation to improvements in communication. Many of these investigations have only measured outcomes involving the Body functions domain of the World Health Organization's International Classification of Functioning, Disability, and Health (i.e., "the physiological functions of body systems" (WHO, 2001, p. 10) such as the expression of spoken language). For example, studies investigating group constraint-induced aphasia therapy (CIAT, also referred to as constraint-induced language therapy), have demonstrated benefits in relation to communication Body functions (Pulvermuller et al., 2001; Pulvermuller, Hauk, Zohsel, Neininger, & Mohr, 2005). CIAT focuses on improving participants' spoken language by using intensive practice, constraining responses to verbal expression, shaping responses, and including relevant stimuli. Participants in the Pulvermuller et al. (2001) study demonstrated significant improvements post-treatment on sections of the Aachen Aphasia Battery (Huber, Poeck, Weniger, & Willness, 1983 as cited in Pulvermuller et al. 2001) including the naming and comprehension subtests.

Another study that demonstrated benefits in relation to improvements in the Body functions domain of the ICF was conducted by Falconer and Antonucci (2012).

The investigators used Semantic Feature Analysis (SFA) as a treatment for four participants with aphasia in a group setting. All participants demonstrated improvements in communicative efficiency in connected speech tasks; however the improvements varied for each participant. Interestingly, the authors noted that aspects of the treatment, unrelated to the specific SFA intervention, such as the supportive group environment may have played a role in the improvements that were observed. The outcomes of this study need to be interpreted with caution as the study had a small sample size and lacked a control group.

Some studies that have focused on groups with participation and psychosocial goals have only demonstrated benefits in relation to outcome measures that target the Body functions domain of the ICF. For example, Marshall (1993) investigated a problem-focused group for individuals with mild aphasia. The aims of the group treatment included reducing the psychosocial effects of aphasia and improving the social, vocational, and recreational integration of aphasic clients within their society. The group focused on helping members solve everyday problems related to communication e.g., communicating in an emergency and preparing for a doctor's appointment and helped teach them strategies to compensate for the problems. Although the participants demonstrated improvements post-treatment on the Porch Index of Communicative Ability (PICA, Porch, 1981), the investigator did not include any participation or psychosocial outcome measures in the study.

Some SLT group treatment studies have demonstrated benefits in relation to the Activities and Participation component of the ICF (i.e., Activities referring to "execution of a task or action by an individual" such as conversing with another person and Participation referring to "involvement in a life situation" (WHO, 2001, p.



10)). For example, Aten, Caligiuri, and Holland (1982) conducted a study in which selected communication situations were focused on during the 12 week SLT group treatment. All participants demonstrated improved scores post-treatment on the Communicative Abilities in Daily Living test (CADL, Holland, 1980), an Activity-focused outcome measure.

Ross et al. (2006) examined the effects of a SLT group treatment on communication, life participation, and psychological well-being in individuals with chronic aphasia. The aims of the group were to improve total communication and conversational skills, develop an understanding of disability and rights, and engage in social participation. The participants demonstrated changes in conversational skills as measured by the Conversational Analysis Profile for People with Aphasia (CAPPA, Whitworth, Perkins, & Lesser, 1997), but there were no significant changes observed in the psychosocial measures administered. The authors noted, however, that the participants reported anecdotally a positive change in their 'communicative experiences' including the range of people spoken to and topics shared with others as a result of the group intervention. The authors suggested that it would have been useful to have included a qualitative research component to the study in order to examine the outcomes of the group more comprehensively. This study also used multiple treatment approaches so it is difficult to ascertain which approach led to any of the perceived benefits.

Key research in the area of aphasia group treatment which has demonstrated communication benefits within the Body functions domain and the Activities and Participation component of the ICF, as well as psychosocial benefits is an investigation presented in two parts by Elman and Bernstein-Ellis (1999a; 1999b). In

the first part of the study, the researchers compared the effects of an aphasia treatment group to social groups. The participants were randomly assigned to either a four-month treatment group or a deferred treatment group. The results on the SPICA (shortened PICA, Disimoni, Keith, & Darley, 1980 as cited in Elman & Bernstein-Ellis, 1999a) and the Western Aphasia Battery (WAB, Kertesz, 1982) showed participants receiving group communication treatment had significantly higher scores on communicative and linguistic measures than participants not receiving treatment. There were also significant changes post-treatment on the CADL (Holland, 1980). The use of the control group in the Elman and Bernstein-Ellis (1999a) study is important as it demonstrated that the communication abilities of the people with aphasia improved more in the SLT communication treatment group than in the social group. The researchers followed up the quantitative investigation with a qualitative study to investigate any psychosocial benefits of participating in the SLT group (Elman & Bernstein-Ellis, 1999a). Semi-structured interviews were used to investigate the participants with aphasia and their family members' perceptions of the positive and negative aspects of participating in the treatment group. The participants reported the following benefits of participating in the groups: liked being with others, liked the support of others with aphasia, liked making friends, liked being able to help others, liked seeing others improve, felt more confident, enjoyed conversations, improved talking, and improved reading and writing. The family members perceived similar benefits for the participants with aphasia. Interestingly, the authors reported that the data about the psychosocial benefits of the group would not have been available if only quantitative methods had been employed and emphasized the value of gathering qualitative data about treatment groups.

Vickers (2010) has investigated the social benefits of group participation for

people with aphasia. The study found that the participants who were attending weekly SLT aphasia groups reported significantly higher scores than the participants who were not involved in the groups in these social participation domains: 1) attending movies, plays with friends, 2) attending religious services with friends/family, 3) making new friends, and 4) socialising with friends. The individuals with aphasia who attended the aphasia groups also reported significantly higher frequency of contact within social networks post-aphasia and less perceived social isolation on the Friendship Scale (Hawthorne, 2006, cited in Vickers, 2010) than the non-attendees. This study is important in that it demonstrates the value of aphasia groups in reducing social isolation for people with aphasia. Unfortunately, the study report provided few details regarding the content and structure of the groups and there is a lack of information about the psychometric properties of the communication and social participation assessment used in the investigation.

### **1.3 Benefits for family members of having a relative with aphasia participate in groups**

Although a number of studies have examined the outcomes of groups that involve both people with aphasia and family members (Borenstein, Linell, & Wahrburg, 1997) and the outcomes of groups that are specifically for family members (Fox, Poulsen, Bawden & Packard, 2004; Johannsen-Horbach, Crone, & Wallesch, 1999; Rice, Paull, & Muller, 1987), there is a lack of research on the benefits for family members of having a relative with aphasia participate in groups. As reported previously, Elman and Bernstein-Ellis (1999b) asked family members to identify the perceived benefits for their relative with aphasia of participating in a SLT group;

however the investigators did not ask the family members if they perceived any benefits for themselves of having the relative with aphasia participate in the group. One study that has identified a benefit for family members was conducted by Brown, Worrall, Davidson, and Howe (2011). In this qualitative study, family members were interviewed about how to live successfully with aphasia. Within the category of experiences with services, family members reported benefits of group aphasia therapy in that the groups enabled family members to meet other people with aphasia and gain support.

#### **1.4 Summary and aims**

Although a number of studies have not included control groups and used small sample sizes, the research literature has provided some evidence that there are varied benefits of participating in groups for individuals with aphasia. It has also highlighted that in some investigations, there is not always congruence between the treatment goals and the outcome measures used to determine the effectiveness of the groups (Marshall, 1993). This issue is made more difficult due to the lack of appropriate measures to assess the effects of aphasia group treatments in relation to many of the goals (Kearns & Elman, 2008). In order to measure the outcomes of the varied goals of aphasia groups, it is recommended that clinicians use a range of appropriate outcome measures that are congruent with the aims of the intervention (Cieza et al., 2005; Howe, Rotherham, Tillard, & Wyles, 2011). The findings also suggest that groups can provide indirect benefits for participants with aphasia and for family members that are not explicitly identified within the goals of the treatment (Elman & Bernstein-Ellis, 1999b; Falconer & Antonucci, 2012; Legg et al., 2007; Ross et al.,

2006). Qualitative methods have been recommended as one way to identify some of these benefits (Elman & Bernstein-Ellis, 1999b; Falconer & Antonucci, 2012; Ross et al., 2006). Speech-language therapists need to be aware of these possible indirect benefits of groups in order to better understand why and how group treatment works and also to assess these areas to see if changes have occurred as the result of treatment.

In general, there have been relatively few studies that have examined the benefits of participating in groups for individuals with aphasia. The studies that have been conducted have tended to focus on participation in a specific group. Elman (2007b) has called for more research in the area of groups for people with aphasia in order to compare and assess the benefits of various types of groups. Furthermore, few investigations have focused on the perspective of the participants with aphasia regarding their perceptions of the benefits of participating in groups. Finally, the perspective of family members has also not been fully explored, especially in relation to any benefits that may result for family members from having a relative with aphasia participate in groups. The current study will therefore address this gap in the literature by focusing on the following aims:

- 1) To explore the range of perceived benefits for adults with aphasia post-stroke of participating in groups.
- 2) To explore the range of perceived benefits for family members of having their relative with aphasia post-stroke participate in groups.

## Chapter 2: Methods

A qualitative descriptive research approach was used in the current study to investigate the group experiences of people with aphasia (Sandelowski, 2000). This approach was appropriate for this study as it provided a framework to investigate issues from the perspective of the individuals directly involved (Hansen, 2006). In addition, it fit with the aims of the study because it provided a broad summary of the data in everyday terms, remaining close to the data and the face value of words and events, and avoiding abstract conceptualizing of the data in terms of a specific philosophical framework (Sandelowski, 2000).

### **2.1 Participants**

#### **2.1.1 Eligibility criteria**

The eligibility criteria for the participants with aphasia (PWAs) were that the individual:

- had aphasia caused by a stroke (as determined by an Aphasia Quotient (AQ) of less than 93.8 the Western Aphasia Battery-Revised (WAB-R) (Kertesz, 2007)).

Participants who had an AQ of 93.8 or above on the WAB-R were included if they had a previously confirmed diagnosis of aphasia and if they continued to identify as having aphasia;

- was 18 years of age or older;

- reported that they had participated in groups at some stage since the onset of their aphasia;

- was able to participate in an in-depth interview in English using speech, gesture, writing, pictures, and/or drawings as determined by the investigator, who was a qualified speech-language therapist.

The eligibility criteria for the family member participants (FMs) was that the individual:

- lived with one of the PWAs;
- was aged 18 years or older;
- was able and willing to participate in an in-depth interview in English.

### **2.1.2 Recruitment**

Participants were recruited from community stroke and aphasia groups in Christchurch and Auckland. Eleven individuals with aphasia and seven family members expressed interest in participating in the study; however one individual with aphasia and their family member withdrew from the study for personal reasons. Written informed consent was obtained prior to commencing data collection (see Appendices D and E). All research information forms (see Appendices B and C) and consent forms for PWAs were provided in an “aphasia friendly format” (Rose, Worrall, Hickson, & Hoffman, 2010). The researcher was a qualified speech-language therapist who was familiar with using supported conversation strategies with people with aphasia (Kagan, 1998). The researcher used these supportive strategies (e.g., clarifying the person’s response and using resources such as pictograms and written key words) in order to help the PWAs understand the consent process.

### **2.1.3 Sampling**

Maximum variation sampling (Patton 2002) was used to focus on selecting information-rich cases to obtain the greatest diversity in a small group of participants. Choosing participants with various experiences increases the possibility of gathering information on the research question from a variety of perspectives. The use of maximum variation sampling enabled the researcher to identify shared patterns that were found across heterogeneous cases, as well as the range of unique variations experienced by the participants (Patton, 2002). In the current study, sampling was sought for the PWAs in relation to gender, age, aphasia severity, and time post onset of aphasia. A total of 16 participants participated in the study. Ten PWAs, two females and eight males, and six FMs, all females, participated in the investigation.

Eight male and two female PWAs participated in the study (see Table 2.1 for demographic details for the PWAs). The PWAs ranged from 51 to 83 years with a mean age 69 years ( $\pm 9.5$  SD). The length of time post-onset of aphasia ranged from seven months to eight years with a mean of 6.7 years ( $\pm 3.7$ SD). The WAB AQ range for the PWAS was 14.1– 98.2, with a mean of 70.37 and a standard deviation of  $\pm 30.4$ .



**Table 2.1 Demographic details of PWAs**

<b>Participant Number</b>	<b>WAB-R AQ</b>	<b>Time post onset of aphasia</b>	<b>Age</b>	<b>Types of groups PWA participated in since onset of aphasia</b>	<b>Living situation</b>	<b>Gender</b>	<b>Physical ability</b>
<b>PWA1</b>	91.7	16 months	65	others with stroke, participant-led	Lives with son	F	Uses wheelchair
<b>PWA2</b>	34.4	7 months	83	SLT, others with stroke, general groups	Lives with spouse	M	Independent
<b>PWA3</b>	51.6	3 years	71	others with stroke	Lives with spouse	M	Uses wheelchair
<b>PWA4</b>	92.7	3 years	77	SLT, others with stroke, general groups	Lives alone	M	Independent
<b>PWA5</b>	14.1	6years 6months	62	SLT	Lives with spouse	M	Uses wheelchair
<b>PWA6</b>	95.6	8 years	81	Participant-led, volunteer led, general	Lives with spouse	M	Independent
<b>PWA7</b>	50.2	5years 9 months	68	SLT, participant-led, volunteer led	Lives with partner	M	Independent
<b>PWA8</b>	79.8	5years 9 months	65	participant-led, SLT	Lives with spouse	M	Independent
<b>PWA9</b>	98.2	8 years	67	SLT, volunteer-led, participant-led, others with stroke, general	Lives alone	M	Independent
<b>PWA10</b>	95.4	4 years	51	participant-led, SLT	Lives with spouse	F	Independent

Five FMs, four wives and one female defacto partner, participated in the study (see Table 2.2 for demographics details of the FMs). The mean age of the FMs was 63 years (+/- 12.1 SD), with a range from 51 years to 78 years. Three participants were working at the time of the study, two part-time and one full-time, while the other three FMs were retired.

<b>Table 2.2. Demographic details of FMs</b>				
<b>Participants</b>	<b>Age</b>	<b>Gender</b>	<b>Relationship to PWA</b>	<b>Occupation</b>
<b>FM1</b>	74	Female	Spouse	Retired
<b>FM2</b>	69	Female	Spouse	Retired
<b>FM3</b>	52	Female	Spouse	Part-time working
<b>FM4</b>	78	Female	Spouse	Retired
<b>FM5</b>	54	Female	De facto partner	Part-time working
<b>FM6</b>	51	Female	Spouse	Full time working

## **2.2 Ethical considerations**

Ethical approval was obtained from the University of Canterbury (UC) Human Ethics Committee prior to commencing the study. Informed consent was gained and data was stored to ensure privacy and confidentiality was maintained. As required by the UC ethics committee, participants were given the option to receive a copy of the transcript from their own interview.

### **2.3 Data collection**

Prior to commencing the interviews, demographic information was obtained from the PWAs and FMs (see Appendix G and H). The researcher also administered the Western Aphasia Battery- Revised (WAB-R) to the PWAs. Semi -structured in-depth interviews were used to collect the data (Taylor & Bogden, 1984). The researcher, a qualified speech-language therapist, used supported conversation strategies (Kagan, 1995) (e.g., clarifying the person’s response, using resources such as pictograms, a white board, and providing written yes- no options) to help the PWAs to participate in the interviews. In addition, the investigator modified the interviewing approach with the PWAs (e.g., altering the question style) as recommended by Luck and Rose (2007).

Interviews lasted approximately 60 minutes and took place at a convenient time and location chosen by each participant (e.g. in their home or at a community venue). The interviews with the PWAs followed a topic guide (See Appendix F) that included the following topics:

1. Description of current groups involved in (e.g., “Tell me about the groups you are currently involved in”);
2. Experiences and any positive aspects/benefits, if any, of being in current groups that do not involve other people with aphasia (e.g. “Tell me about what you get out of being in that group”);
3. Experiences and any positive aspects/benefits, if any, of being in current groups that involve other people with aphasia (e.g. “Tell me about what you get out of being in that group”);

4. Experiences and any positive aspects/benefits, if any, of being in current groups that involve a speech-language therapist (e.g. “Tell me about what you get out of being in that group”).

The interviews with the FMs followed a similar topic guide and included the following topics:

- Can you tell me about any groups that (name) goes to?
- What is good about that group/s for PWA? For you?
- Are there positive things for you that (name) goes to groups?
- Are there any negative aspects about the group/s?

All interviews with the PWAs and FMs were audio-recorded. The interviews with the PWAs were also video recorded to capture any nonverbal communication. The audio and/or video recordings were transcribed verbatim based on the conventions of Poland (2001). The transcriptions of the PWAs included details regarding gestures and nonverbal information such as pointing to pictures or communication books.

## **2.4 Data analysis**

The interview transcripts were analysed based on qualitative content analysis (Graneheim & Lundman, 2004). This analysis involved a multi-step process:

Step 1: The researcher became immersed in the data by reading and rereading the transcripts.

Step 2: The data was divided into content areas. In this study, there were three content areas based on the two aims of the study:

1. Benefits for the individuals with aphasia
2. Benefits for family members
3. Other content.

Step 3: The first two content areas provided the data for the unit of analysis. The “other content” area was not analysed as it focused on topics other than the perceived benefits of groups.

Step 4: The unit of analysis was divided into meaning units which are defined as words, sentences, or paragraphs containing aspects related to each other through their content and context such as:

“Well, um they actually feel part of the community again.”

Step 5: The meaning units were then analysed to create codes, which are condensed pieces of text that focus on a specific issue. These codes were then grouped for each participant, keeping close to the participant's own words, such as:

“Feel part of the community.”

Step 6: From these codes, categories were developed that incorporated all the codes from all the participants, for both PWAs and FMs. A category was defined as a group of codes that shared a commonality (Graneheim & Lundman, 2004) such as:

‘Provides an opportunity to feel part of the community.’

Because the PWAs reported different types of benefits for themselves in relation to the different of groups that they participated in, these categories were grouped together in relation to six types of groups:

1. Benefits of SLT aphasia therapy groups
2. Benefits of volunteer-led aphasia groups
3. Benefits of participant-led aphasia groups
4. Benefits of groups that involve individuals who have an understanding of aphasia
5. Benefits of groups for people who have stroke
6. Benefits of general groups (e.g., community groups).

## **2.5 Rigour and reflexivity**

The analysis of the data was carefully reviewed and agreement reached through consensus between the researcher and the two supervisors regarding the codes and categories of benefits in order to enhance the credibility of the research findings. Member checks were also used to augment the rigour of the study (Hansen, 2006). The member check process enabled a deeper explanation of the results and some negotiation of meaning to occur between the researcher and the participants (Doyle, 2007). All PWAs and FMs were invited to participate in the member check meetings. In total, six PWAs and four FMs, attended the member check meetings. At each meeting, the participants were split into two groups: PWAs and FMs. The aim of the member check meetings was to present the preliminary findings to the participants. This allowed the participants an opportunity to review the results to ensure that the data reflected what they had said in their interviews and to provide an opportunity for them to provide additional comments regarding what they perceived to be the benefits of groups. The findings were presented to the PWAs in an aphasia-

friendly format. The member check sessions were audio-taped and facilitated by qualified speech-language therapists, with a second person present to transcribe any relevant non-verbal data. The additional comments about the results were transcribed and analysed, following the steps of qualitative content analysis described above.

In qualitative research, it is acknowledged that the researcher is an active instrument in the data collection and analysis process; therefore, it is important to consider the researcher's background (Patton, 2002). The researcher is a qualified speech language therapist with 15 years clinical experience, including facilitating communication groups for people with aphasia and other acquired communication disorders. The researcher kept a reflexive journal and documented relevant reflexive and contextual information immediately after each interview.

## ***Chapter 3: Results***

The analysis of the data revealed that the PWAs and the FMs perceived numerous categories of benefits. The results will be presented in two parts reflecting the two aims of the study:

- 1) To explore the range of perceived benefits for adults with aphasia post-stroke of participating in groups
- 2) To explore the range of perceived benefits for family members of having their relative with aphasia post-stroke participate in groups.

Participant quotes have been included throughout this chapter to illustrate some of the categories. Codes have been included at the beginning of each quotation to identify the specific participant being quoted (e.g., PWA6 = Participant with aphasia number 6; FM3= Family member participant number 3).

### **3.1 Benefits of groups for individuals with aphasia**

Twenty-seven categories of benefits for individuals with aphasia of participating in groups were reported by PWAs and FMs. These results are presented in Table 3.1.



<b>Table 3.1 Benefits of groups for individuals with aphasia as perceived by PWAs and FMs</b>	
1. Improves communication	15. Provides a sense of empowerment
2. Provides a positive communication environment	16. Provides an opportunity to help each other
3. Improves confidence	17. Provides a sense of worth
4. Provides an opportunity for social contact	18. Provides an opportunity to feel part of the community
5. Provides information about aphasia	19. Meets unmet need as healthcare system is inadequate
6. Helps to identify with others with aphasia	20. Provides a comparison
7. Helps to identify with others with stroke	21. Experiences positive feelings
8. Provides support	22. Provides an opportunity to make physical improvements
9. Provides stimulation	23. Provides a sense of normalisation
10. Provides a feeling of hope and encouragement	24. Builds networks
11. Provides an opportunity for humour	25. Experiences positive feelings in family groups
12. Provides an opportunity to utilise skills	26. Provides a sense of identity
13. Focuses on goals	27. Facilitates return to previous activities
14. Provides an opportunity to share news and interests	

### **3.1.1 Benefits of groups for individuals with aphasia as perceived by PWAs**

PWAs reported 25 of the 27 benefits of groups for individuals with aphasia. They identified different benefits in relation to each of the six types of groups they reported participating in post-stroke: 1) SLT aphasia groups, 2) volunteer-led aphasia groups, 3) participant-led aphasia groups, 4) groups that involve individuals who have an understanding of aphasia, 5) groups for individuals with stroke, and 6) general groups (see Table 3.2). The benefits of the different types of groups as perceived by the PWAs are reported in the following sections

**Table 3.2 Benefits of different types of groups for individuals with aphasia as perceived by PWAs**

Type of group	SLT aphasia groups	Volunteer-led aphasia groups	Participant-led aphasia groups	Groups that involve individuals who have an understanding of aphasia	Groups for people with stroke	General groups
<b>Benefit</b>						
1. Improves communication	×		×			
2. Provides a positive communication environment	×	×	×	×		
3. Improves confidence	×		×			
4. Provides an opportunity for social contact	×	×	×		×	×
5. Provides information about aphasia	×	×	×			
6. Helps to identify with others with aphasia		×	×			
7. Helps to identify with others with stroke					×	
8. Provides support			×		×	
9. Provides stimulation			×		×	
10. Provides a feeling of hope and encouragement			×		×	

11. Provides an opportunity for humour	×				×	
12. Provides an opportunity to utilise skills			×			
13. Focuses on goals	×					
14. Provides an opportunity to share news and interests	×					
15. Provides a sense of empowerment	×					
16. Provides an opportunity to help each other			×			
17. Provides a sense of worth			×			
18. Provides an opportunity to feel part of the community			×			
19. Meets unmet need as healthcare system is inadequate			×			
20. Provides a comparison			×		×	
21. Experiences positive feelings					×	
22. Provides an opportunity to make physical improvements					×	
23. Provides a sense of normalisation						×
24. Builds networks						×
25. Experiences positive feelings from being with the family group						×

### 3.1.1.1 SLT aphasia groups

Seven PWAs reported participating in SLT aphasia groups post-stroke. These groups included an intensive SLT group, as well as SLT groups that focused on improving conversation. There were nine categories of benefits associated with this type of group, each of which is presented in Table 3.3 and described below.

1. Improves communication	6. Provides an opportunity for humour
2. Provides a positive communication environment	7. Focuses on goals
3. Improves confidence	8. Provides an opportunity to share news and interests
4. Provides an opportunity for social contact: friendship	9. Provides a sense of empowerment
5. Provides information about aphasia	

#### *1. Improves communication*

PWAs reported that the SLT aphasia groups helped them to improve their communication:

PWA4: *“Oh well, it was time to try to get something back in to me, to try.”*

Interviewer: *“And how did you feel, you were going to do that?”*

PWA4: *“Oh well, basically with talk, talking to people.”*

Participants reported that these groups provided an opportunity to practise specific communication skills such as giving a presentation:

PWA8: *“Well I by the way I make the presentation, and so I guess that’s the reason it helps me.”*

In addition, some PWAs reported that these groups helped their communication skills because the speech-language therapist providing worksheets for the group members. One participant reported enjoying having some work to go on with at home to stimulate language.

PWA7: *“So I got them in there and they’ve given me much more than I done many years beforehand.”* (Picks up more sheets of paper and shows to interviewer)

## *2. Provides a positive communication environment*

Providing a positive communication environment was another benefit of SLT groups that was identified by PWAs. For example, one participant reported that he felt less nervous in a SLT aphasia group and made more of an effort to communicate:

PWA10: *“Cause ah, because you don’t feel as nervous [in a group with a speech-language therapist], to, you get to know them, you don’t feel so nervous and you can try and try again.”*

One individual with aphasia described the therapist as being “gifted” in being able to help group members communicate. Another participant, who had a severe aphasia and used communication aids and gesture to express his messages, indicated that he generally preferred to be involved in groups where there was a speech-language

therapist or someone who had been trained by a therapist to facilitate groups.

SLT aphasia groups also created a positive communication environment by setting up an expectation that members should communicate:

PWA4: “*Um, you in a ... [gestures pointing in a row] and you’ve gotta talk.*”

Another way in which speech-language therapists created a positive communication environment was by leading and providing a direction for the group:

PWA10: “*Um because she, you know that they all, she was a leader of them all.*”

SLT groups also provided a positive communication environment by enabling the PWAs to get to know other people who had aphasia. In some cases, PWAs indicated that it was difficult to communicate with others with aphasia without the assistance of the therapist:

PWA4: “[Name of speech-language therapist], *yeah, ah, they’re quite good they give you the experience of getting to know the other people, getting to know them, by their stroke [aphasia] as well.*”

### *3. Improves confidence*

Participants reported that another benefit of participating in SLT groups was that the groups helped to improve their confidence. This was often in relation to having the experience of talking to others and realising they could get their message across and be understood. Sometimes these experiences gave them the confidence to communicate outside of the group. For example, one participant reported that she had been avoiding talking to the assistants in a delicatessen since her stroke and as a result had not bought olives for a long time. She stated that her participation in a SLT group

helped her to feel more confident about ordering olives at the delicatessen once again:

PWA10: *“Its help my confidence... because I wouldn't order anysing [anything] at the deli cause I had to speak.”*

#### *4. Provides an opportunity for social contact*

PWAs perceived that SLT groups were beneficial because they provided an opportunity for social contact. For example, one participant described a friendship that had arisen out of an SLT group. She stated that in the SLT group they had exchanged contact details and arranged to meet for coffee outside of the group.

#### *5. Provides information about aphasia*

PWAs also indicated that SLT groups were beneficial because the speech-language therapist provided information about aphasia:

PWA10: *“Yes....When she says things they make sense. She give me some good....good.... (Looks around the room) (Pause).”*

Interviewer: *“Strategies?”*

PWA10: *“YES! Yes.”*

#### *6. Focuses on goals*

Another reported benefit of SLT groups was that the groups focused on communication goals:

PWA7: *“Well I get this one first, (points to a communication goal written on a page) I think about on the next one after it.”*



Interviewer: “So you’ve got some goals?”

PWA7: “Yes.”

*7. Provides an opportunity for humour*

One perceived benefit of participating in SLT groups was having the opportunity to enjoy humour:

PWA5: “*Yeah wee bear* (points to pictographic folder picture of “laughter”).”

*8. Provides an opportunity to share news and interests*

Having an opportunity to share news and interests was another reported benefit of the SLT groups. For example, one participant who had a severe aphasia indicated that he enjoyed being able to share news and interests at the group by bringing in digital photos that were projected onto a screen:

PWA5: “*Um* (wife brings over camera) *yeah, e-ba*, (holds up camera, then points in a half circle and over, draws large rectangle in air) *um um um.*”

I: “*Right so you’re, you’re. Oh you can put them* [photos of his holiday] *on a big screen?*”

PWA5: “*Yeah* (points at interviewer).”

*9. Provides a sense of empowerment*

Two participants indicated that another benefit of an SLT group was that it empowered them to start their own participant-led aphasia group. The group started out as a group involving a speech-language therapist. The therapist, however, reportedly encouraged the individuals to believe that they had the skills themselves to

meet their goals in a group, without requiring her input:

PWA6: “*But she said that no you’re you’re handling it ok by yourselves.*”

This participant reported that this group had gone on to have several members with aphasia and to be a successful aphasia self help group.

### *3.1.1.2 Volunteer-led aphasia groups*

Six participants reported participating in volunteer-led aphasia groups at some time post-stroke. The participants reported that these groups focused mainly on having conversations. There were four categories for this type of group presented in Table 3.4 and described below.

<p><b>Table 3.4 Benefits for individuals with aphasia of volunteer-led aphasia groups as perceived by PWAs</b></p>
--------------------------------------------------------------------------------------------------------------------

- |                                                                                                                                                                                                                                                            |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ol style="list-style-type: none"><li>1. Provides a positive communication environment</li><li>2. Provides an opportunity for social contact</li><li>3. Provides information about aphasia</li><li>4. Helps to identify with others with aphasia</li></ol> |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

#### *1. Provides a positive communication environment*

PWAs indicated that the volunteer-led groups were beneficial because they

provided a supportive communication environment.

## *2. Provides an opportunity for social contact*

The volunteer-led groups also provided an opportunity for the individuals with aphasia to have some social contact. For example, the following PWA reported that the group was the only place he could talk to other people as he lived alone:

*PWA9: "The, probably the position of being able to talk to somebody...and I was on my own before but at that time and ah I had ah I just felt I could communicate with somebody."*

## *3. Provides information about aphasia*

Participants reported that the volunteer-led groups provided them with information about aphasia. For example, one participant indicated that he had learned about the use of an aphasia identity card in a volunteer-led group.

## *4. Helps to identify with others with aphasia*

PWAs reported that meeting others with aphasia and being able to identify with them was another benefit of volunteer-led aphasia groups. They indicated that they were often unaware that other people also have aphasia, so that it was a benefit to meet others and realise they were not alone:

*PWA9: "The most important factor I think was that stroke victims were not alone... that there is a group and um you, you get up on Wednesday morning and ah it's a big deal for you...and ah we just thought that, this was Christmas."*

### 3.1.1.3 Participant-led aphasia groups

Five PWAs were involved in a participant-led aphasia self-help group that had been established by people with aphasia for people with aphasia and their families.

There were 15 categories of benefits identified for this type of group that are described below.

<b>Table 3.5 Benefits for individuals with aphasia of participant-led aphasia groups as perceived by PWA</b>	
1. Improves communication	9. Provides a feeling of hope and encouragement
2. Provides a positive communication environment	10. Provides an opportunity to utilise skills
3. Improves confidence	11. Provides an opportunity to help each other
4. Provides an opportunity for social contact: companionship	12. Provides a sense of worth
5. Provides information about aphasia	13. Provides an opportunity to feel part of the community
7. Provides support	14. Provides an opportunity to utilise skills
8. Provides stimulation	15. Provides a comparison

### *1. Improves communication*

Participants felt that going to groups where there were others with aphasia provided opportunities to improve communication. PWAs reported that being able to talk to others, listen in a group setting, and be with others who understood aphasia helped their communication.

### *2. Provides a positive communication environment*

PWAs reported that aspects of the participant-led group environment contributed to making it more positive for communicating. They indicated that the other individuals with aphasia had a better understanding than other people of what they were trying to communicate. One participant felt that he could communicate in this group better than in other situations:

Interviewer: *“Yep, so find it um easier with the [name of group] aphasia group?”*

PWA7: *“Yes they know what to do it.”*

Another PWA reported that the environment created at the group enabled him to feel less concerned about embarrassing himself:

PWA6: *“I guess, its ah (short pause) it’s feeling that you’ve you’ve overcome... the concern of ah of making of a fool of yourself I’m talking that ah..ah I think the feeling of hey it doesn’t matter ah.. the the colleagues all have the same problem.”*

Some PWAs reported that the format and structure of the group was also beneficial for communicating. These included having only one person speak at a time and having minutes taken and distributed to the other members via email. The assignment of roles to some people with aphasia to be facilitators for other individuals

with aphasia was also identified as being beneficial.

### *3. Improves confidence*

Increasing confidence was another benefit of participant-led aphasia groups that was reported by PWAs:

PWA10: *“You have to get out to ah improve your speech. I think it is good for confidence and cause...I...because...life is all about people.”*

### *4. Provides social contact*

PWAs expressed that the participant-led aphasia groups provided social contact for the members with aphasia:

PWA6: *“I think companionship is quite significant.”*

### *5. Provides information about aphasia*

Participants found that the information they gained from others with aphasia in the participant-led group was very beneficial:

PWA9: *“Um I’ve gained a knowledge of aphasia.”*

The information that was provided included shared experiences, written information, and information about useful websites.

### *6. Helps to identify with others who have aphasia*

Being able to identify with other people who have aphasia was highlighted as being important to a number of participants in the participant-led aphasia group. They indicated that it was helpful to know others experienced the same communication

difficulties that they had:

PWA6: *“And ah having other people with aphasia...with the same problem....we found it ...was ah quite quite helpful.”*

Some participants reported that prior to participating in the participant-led aphasia group that their aphasia had isolated them socially and that their social contact had involved only interacting with their family. When they became a part of the aphasia group, they reported that they realised others had aphasia and they did not feel as isolated by the aphasia:

PWA10: *“But now, I haven’t because my...this is isolating...my aphasia, so you just, you just shrank down to your family, come to see you.”*

Another benefit reported by one PWA was that by having a number of people with aphasia in the same group it helped to improve the public’s awareness of aphasia. The members had reportedly become motivated to raise awareness of aphasia in the community and to inform other people with aphasia that the group was available for them.

Some PWAs expressed the importance of having a separate identity from stroke groups. They reported that their needs were not met in the stroke clubs where the focus was not about aphasia. One participant saw a need for a group that focused specifically on aphasia and communication so he felt it was necessary to establish the participant-led aphasia group in his community:

PWA6: *“We felt very quickly, ‘no’ the the stroke people were were not remotely interested in trying to help the speech side.”*

### *7. Provides support*

The participant-led aphasia group also reportedly provided the opportunity for members to share experiences and gain support from others about living with and “handling aphasia.”

### *8. Provides stimulation*

Having a regular group to attend for the PWAs provided some stimulation and a regular outing. One participant felt it was a form of therapy to go out:

PWA8: *“If I didn’t go outdoors.... Ah but if I, I don’t generally watch TV.....Um... but if I get out..... If I get out, then um, I think that’s a form of therapy, to do something.”*

### *9. Provides a feeling of hope and encouragement*

Another reported benefit of these groups was being provided with a feeling of hope through meeting others with aphasia:

PWA9: *“They just said, thank you, thank you, thank you, this is the, the, you’ve given us hope now and before they didn’t have hope.”*

Participants also talked about feeling encouraged by others and being inspired by others in their group”:

PWA7: *“And she was amazing, but she got better and better all the time.”*

### *10. Provides a sense of worth*

Another perceived benefit of participant-led aphasia group was that it provided members with a sense of worth. For example, one participant reported that having the opportunity to work with others in the group on a committee to organize an aphasia



conference gave him a “sense of worth”:

PWA9: *“Ah, it gives a sense of worth....which is quite amazing that you don't, you don't feel as though you need to have worth but you do actually need worth.”*

#### *11. Provides an opportunity to help each other*

Participants also felt that by being part of the participant-led aphasia group, they could not only get support for themselves, but that it also provided them with an opportunity to help others:

PWA10: *“Yeah I, cause I want to help people, I really want to help people...because when I had a sroke [stroke] no one came to see me who knew what it was like.”*

#### *12. Provides an opportunity to feel part of the community*

PWAs also reported that being part of the aphasia group helped them to feel that they belonged to the community again. They indicated that they had not been participating in community activities as frequently after their stroke and that the aphasia group reconnected them with their community:

PWA9: *“Well, um they actually feel part of the community again....they, they thought that having the stroke um separated them but it doesn't really.”*

#### *13. Meets unmet need as healthcare system inadequate*

One participant reported that one of the benefits of the aphasia group was that it met an unmet need for people with aphasia in his community. He indicated that the members felt the stroke groups that were available in the community did not focus enough on communication. He also indicated that individuals were often only offered

a short period of one-to-one speech language therapy during the first months post-stroke and that there was not enough speech-language therapy available for people with aphasia:

PWA6: *“There’s no doubt that speech therapy helps but its nowhere near enough intensive...so virtually ah most of us have found we had to try to improve ourselves... the formal speech therapy system... is just nowhere near enough adequate.”*

He reported that as a result of these issues, the members decided to develop their own aphasia self-help group.

Another participant indicated that the participant-led aphasia group also met an unmet need in the community. He reported that a volunteer-led aphasia group that he had participated in was not meeting his needs:

PWA9: *“I did, didn’t feel that I was making any headway, I was you know....I was just tapping my feet and so I left.”*

#### *14. Provides an opportunity to utilise skills*

Providing an opportunity to utilise skills that they had had prior to the onset of aphasia was another benefit that PWAs reported. One participant indicated that he was able to have the opportunity to use his pre-stroke skills by giving presentations to the group. Two other participants felt that they could no longer fulfil the community group roles that they had had pre-stroke. By attending the participant-led aphasia group, the two individuals reported that they had gained some confidence to utilise their pre-stroke skills again and to return to the community groups in different roles.

### *15. Provides a comparison*

Another benefit of the participant-led aphasia group was being able to compare themselves with others who had aphasia and who had had a stroke. Participants reported that they found it helpful to see that others' communication and physical abilities were affected in similar and different ways to themselves:

PWA1: *“And I can compare with um a stroke, you know? And my walking and my speech is ah better... it's encouraging.”*

Another participant found it encouraging to realize his communication skills were better than those of others in the group with aphasia:

PWA9: *“You sort of scale yourself alongside them....ah and you find that you're um a darn sight better off than you had originally thought anyway.”*

#### *3.1.1.4 Groups that involve people who have an understanding of aphasia*

One participant reported a benefit of participating in groups in which people who had an understanding of aphasia were present.

##### *1. Positive communication environment*

One PWA indicated that groups in which individuals who had an understanding of aphasia were present were beneficial because these individuals created a positive communication environment. She stated that she found it easier to communicate in groups with the family members of people with aphasia or with a specific group of friends who had an awareness of aphasia. Because the people in

these groups knew she had aphasia and understood aphasia, she felt she could talk freely and not have people ask her questions about her speech. She also stated that it was more difficult to interact with the individuals with aphasia in the participant-led group:

PWA10: *“Go to the carers’ group because they can, they can speak, talk and they go to coffee every month..... Oh because yeah...they can understand me....when I speak to them, the others [others with aphasia] they can’t understand me.”*

#### *3.1.1.5 Groups for people with stroke*

Five PWAs reported participating in groups that were specifically for individuals who had had a stroke. These groups included community stroke clubs, a community stroke activity group, a physiotherapy stroke treatment group, and a community gym group for people who have had a stroke. There was no speech-language therapy involvement in any of these groups. Nine categories of benefits were identified for this type of group.

<b>Table 3.6 Benefits for individuals with aphasia of groups for people with stroke as perceived by PWA</b>	
1. Provides an opportunity for social contact	6. Provides an opportunity for humour
2. Helps to identify with others with stroke	7. Experiences positive feelings
3. Provides support	8. Provides an opportunity to make physical improvements
4. Provides stimulation	9. Provides a comparison
5. Provides a feeling of hope and encouragement	

*1. Provides an opportunity for social contact*

PWAs reported that the groups involving others with stroke were beneficial because they provided them with an opportunity to socialise. Some of the participants named people they had made a connection with and who they sat with at these groups:

PWA3: *"Yes thank you.....Ah friends, good (Smiles, laughs)."*

One participant with significant expressive difficulties reported:

PWA2: *"Good to say "hello" yeah... and a cup of morning tea."*

Another participant indicated that the stroke group provided him with the opportunity to meet people from a variety of backgrounds:

PWA4: *"Generally the group is by far the better one, you sort out other*

*people...there's just so many different people of very different places and if you want to talk to X group or Y group, you get different people."*

## *2. Helps to identify with others with stroke*

Participants reported that one benefit of participating in stroke groups was that it enabled them to identify with other people who had had a stroke:

PWA1: *"They are like me."*

PWAs indicated that they shared experiences and knew that others understood the daily problems they faced due to changes in their physical and communication abilities.

## *3. Provides support*

PWAs reported that they received support and help from the stroke groups. One participant stated that other people in the stroke club knew what it was like to have a stroke and this support could not be gained in general groups:

PWA4: *"And the stroke club too...I get... help and guidance (gestures weighing up with both hands),,whereas the [name] club, it's more in line with...the garden's rosy. There's no stroke club in it."*

## *4. Provides stimulation*

Another perceived benefit of the stroke groups was that they provided some stimulation:

PWA1: *"Well it's um it's stimulating... and I can't get because I'm I can't drive....and there was the [name of group] have encouraged me to get out... and um I'm*

*interested.”*

Another way in which the stroke groups provided stimulation was by encouraging participants to attempt activities that they might not try on their own. For example, one participant reported that she tried mini-golf at the stroke group and that it provided her with a sense of achievement. The participant indicated that she would not have tried this activity outside the stroke club with her family because of her physical difficulties:

PWA1: *“My family are fit and ah and ah I’m, I’m ah slow and that’s um that’s um ah ah groups are like me.”*

PWAs who were involved in service organisations, sports clubs, and committees prior to their stroke reported that the stroke group provided a substitute for these activities post-stroke:

PWA4: *“Oh, well...in the past...I’ve been involved in committees and all those sort of things, I, well, I can’t get onto that anymore...both [the stroke group and conversation group] give me something, to ah get by on.”*

##### *5. Provides a feeling of hope and encouragement*

PWAs also felt it was encouraging to meet others with stroke and to see their improvements and how they managed in life after their stroke.

##### *6. Provides an opportunity for humour*

One participant reported humour as one of the benefits of participating in her stroke group:

PWA1: *“Their sense of humour... “They’re um they’re social members and they’re they’re funny.”*

#### *7. Experiences positive feelings*

One individual reported that a benefit of the stroke group was that it enabled him to feel happy:

Interviewer: *“Why do you go to the stroke club?”*

PWA3: *“Amen...happy (points at happy picture in pictographic resource folder).”*

#### *8. Provides an opportunity to make physical improvements*

One participant identified the opportunity to make physical improvements as a benefit from participating in a stroke group that involved exercise.

#### *9. Provides a comparison*

An individual who participated in a group physiotherapy stroke treatment programme reported that the group enabled him to compare his physical abilities with others:

PWA?X: *“But there, nobody could do it [physical task]....do it as well [as me].”*

#### *3.1.1.6 General groups*

Four participants reported benefits in relation to general groups that they participated in. The groups included a choir, a golf group, service organisations, and being with informal groups of friends or family members. These groups did not



necessarily involve people who had aphasia or who had had a stroke. Participants identified four benefits of these types of groups.

<b>Table 3.7 Benefits of general groups for individuals with aphasia as perceived by PWAs</b>	
1. Provides an opportunity for social contact	3. Builds networks
2. Provides a sense of normalisation	4. Experiences positive feelings in family groups

*1. Provides social contact*

PWAs reported that one benefit of these types of groups was that they provided an opportunity for social contact:

PWA4: *“Oh, well it’s [attending the service club] beneficial to me I suppose...Ah, well just meeting people.”*

*2. Provides a sense of normalisation*

One participant indicated that a benefit of being in groups with other people who had not had a stroke was that it helped him to feel normal again:

PWA9: *“Oh, ah overall the benefits of that sort of thing [choir and golf club] you know are normalisation...we just play [golf] together and the word stroke would never arise.”*

### *3. Builds networks*

Building networks involving people with varied backgrounds and professions was another benefit of general community groups that was reported:

PWA4: *“It’s...but say if I wanted to talk to somebody about business or drain laying or whatever... Ah I’d know people to sort out.”*

### *4. Experiences positive feelings in family groups*

Two PWAs indicated that participating in family groups was important to them because of the positive feelings they experienced in them:

PWA9: *“Oh well, let’s face it, there’s the family group is the family group, one and only.”*

### 3.1.1.7 Benefits of groups for individuals with aphasia as perceived by FMs

FMs reported 12 benefits of participating in groups for individuals with aphasia, ten of which overlapped with the benefits reported by the PWAs. These results are listed in Table 3.8 and presented in the following sections.

<b>Table 3.8 Benefits of groups for individuals with aphasia as perceived by FMs</b>	
1. Improves communication	7. Provides an opportunity for humour
2. Provides a positive communication environment	8. Provides support
3. Improves confidence	9. Provides stimulation
4. Provides an opportunity for social contact	10. Provides a sense of identity
5. Provides information about aphasia	11. Provides an opportunity to utilise skills
6. Helps to identify with others with aphasia	12. Facilitates return to previous activities

#### *1. Improves communication:*

FMs reported that the PWAs' communication skills improved as the result of being involved in groups:

FM3: *“I guess there’s the communication, itself...the use of the language ... gaining skills in ... expressing what he’s thinking or ... gaining skills in listening to other people and what they’ve experiencing and sharing too.”*

## *2. Provides a positive communication environment*

Another benefit of groups for individuals with aphasia involved the provision of a positive communication environment. Some FMs reported that they felt their relative with aphasia was more engaged when participating in a group with a speech-language therapist or a trained volunteer. For example, one FM whose husband had significant communication difficulties reported that her husband appeared to listen more and be more attentive when in a group led by a speech-language therapist:

FM1: *“In the speech groups...-you can see – just by looking at him and watching him you can see that he’s taking it all in..., and then when we come home he’ll try to um say the person’s name that said.”*

Another FM highlighted the importance of having a person who had the skills to facilitate positive communication for groups involving her relative with aphasia:

FM5: *“Groups have been very difficult for [name of family member with aphasia]... initially. If they weren’t well facilitated then it all disintegrated into a very destructive situation very quickly.”*

## *3. Improves confidence*

FMs reported that individuals with aphasia gained confidence from participating in groups:

FM4: *“It’s given him his confidence back.”*

## *4. Provides opportunity for social contact*

FMs also indicated that groups were positive because they provided the

individuals with aphasia with opportunities for social contact:

FM5: *“Some contact, some form of contact.”*

Another FM highlighted the importance of groups for providing some social contact outside of the family for her relative with aphasia:

FM3: *“That he’s involved with people other than just the family so he is broadening his social network.”*

Some FMs also reported that PWAs had formed new friendships as the result of participating in groups.

#### *5. Provides information*

FMs reported that some of the groups their relatives with aphasia participated in were beneficial because the individuals with aphasia were able to obtain more information about aphasia.

#### *6. Helps to identify with others with aphasia*

Participants also perceived that groups were beneficial for individuals with aphasia because it allowed them to identify with others with aphasia:

FM5: *“He quite enjoys that because um he’s with people that have got the same thing.”*

#### *7. Provides an opportunity for humour*

FMs also indicated that some groups were beneficial for the individuals with aphasia because they provided an opportunity for the relatives to engage in humour:

FM1: *"Yea, and he also jokes with some of the ladies... and another chap he's got cerebral palsy ... they've got quite a thing going between them they, you know, the other chap can't talk properly...They've got hand signs they do to one another."*

#### *8. Provides support*

FMs also reported that groups were beneficial for their relatives with aphasia because of the support they provided for them:

FM5: *"I think... it's the support..It's knowing that you're not alone...and [name of family member with aphasia] benefits from that very much."*

#### *9. Provides stimulation*

Relatives perceived that the groups were stimulating for the PWAs by providing an outing for them. Some FMs stated that if their relative did not participate in regularly scheduled groups, then they would be at home most of the time:

FM2: *"I just think the change of scenery... if he wasn't going to the stroke club he wouldn't do anything apart from me taking him out for lunch."*

#### *10. Provides a sense of identity*

One FM stated that the groups provided her relative with aphasia with a sense of identity:

FM5: *"I would imagine you do lose any sense of identity you know and I think you can re-establish it in a group."*

#### *11. Opportunity to utilise skills*

One spouse reported that the aphasia group had been beneficial for her

husband and other members with aphasia because it provided them with an opportunity to use skills they had developed prior to their stroke.

#### *12. Facilitates return to previous activities*

Another FM reported that the group had been beneficial for her spouse because he had returned to gardening as a result of a discussion that had occurred in the group:

FM1: *“Because they asked him what he was interested in before um he had a stroke... And now he’s back doing gardening again he’s starting to look after his beans.”*

### **3.2 Benefits for family members of having a relative with aphasia participate in groups**

The study revealed ten benefits for family members of having their relative with aphasia participate in groups as perceived by the FMs and the PWAs. These benefits are highlighted in the following sections.

### 3.2.1 Benefits for family members of having a relative with aphasia participate in groups as perceived by FMs

FMs reported ten benefits of having a relative with aphasia participate in groups. These categories are presented in Table 3.9 and described below.

<b>Table 3.9 Benefits for family members of having a relative with aphasia participate in groups as perceived by FMs</b>	
1. Provides opportunity for social contact for the family member	6. Provides support for the family member
2. Individual with aphasia communicates better with the family member	7. Provides a role for the family member
3. Provides an opportunity for the family member to have time on own	8. Increases participation for the family member
4. Experiences positive feelings	9. Provides a safe environment for the individual with aphasia
5. Decreases individual with aphasia's reliance on the family member for socialization	10. Provides information about aphasia for the family member



*1. Provides opportunity for social contact for the family members*

Some FMs reported that they accompanied the individuals with aphasia to some of the group sessions. While the groups were focused on providing services for the PWAs, these FMs indicated that they also attended the groups or met casually with other family members who had relatives with aphasia in the groups, making friendships with them:

FM1: *“Ah friendship um... there’s ah I’ve got to know a lot of the ladies and we... look out for one another...they’re all concerned about one another.”*

*2. Individual with aphasia communicates better with the family member*

PWAs reported that groups sometimes helped the individuals with aphasia to communicate better at home. For example, one participant, whose spouse with severe aphasia relied on communication aids to express himself, found that as a result of the group, he did not need as much prompting to use his aids and was less dependent on her to guess what he wanted to communicate:

FM3: *“Um so that he will actually now go to his book he will go to his communicator without a lot of prompting because he’s had practice...in using it.”*

*3. Provides an opportunity for the family member to have time on own*

FMs highlighted that one benefit of groups was that they provided an opportunity for them to have some time on their own. For some FMs, a longer group like a stroke club allowed a half day to get chores done, or to relax at home on their own:

FM2: *“It gives me time without him there... I get three hours.”*

#### *4. Experiences positive feelings*

FMs indicated that they themselves experienced a range of positive feelings as a result of their relative with aphasia feeling good about participating in groups. Participants reported that if their relative with aphasia felt happy about participating in groups then that would affect how the family member felt:

FM5: *“Well it’s obviously a sense of (laughing) of success.... it’s having a knock-on effect...if [name of PWA]’s happier I’ll be happier.”*

Positive feelings were also reported by FMs as a result of the knowledge that their relative was meeting people and making friends in the groups:

FM2: *“Um, just makes me feel much better [that he meets people at the group] because he used to have a lot of friends and people are scared of people when they’ve had a stroke.”*

#### *5. Decreases individual with aphasia’s reliance on the family member for socialization*

Group membership for the individuals with aphasia resulted in socialization outside the family. FMs reported that when the relative with aphasia belonged to a group, the burden on the family, to provide all the social stimulation for the individuals with aphasia was reduced:

FM3: *I think [name of PWA] can tend to be very dependent on me ... so perhaps it’s even for my sake that he does have that wider network.”*

FMs also identified that it was beneficial to have groups for individuals with aphasia set up and established in the community, as this reduced the burden of the family

member having to initiate and organise appropriate social gatherings for their relative with aphasia.

#### *6. Provides support for the family member*

FMs gained support via the groups that the individuals with aphasia belonged to in an indirect manner. Although as stated previously, the aphasia and stroke groups were focused on providing a service for the individuals with aphasia, some family members also attended the groups or met casually with other family members during the groups. This provided the family members with an opportunity to discuss issues and get support from other family members:

FM4: *“Well I think it makes you realise you’re not on your own...Yeah and both of us....We’ve got that support there.”*

Another family member reported that she was able to share experiences with other family members during these informal meetings:

FM3: *“Being able to share our experiences....share ideas of how we were coping.”*

#### *7. Provides a role for the family member*

Some FMs felt the groups helped them return to their previous role in the family or sometimes to find a new role in the groups the individuals with aphasia attended. For example, one family member reported that she felt she could focus on her role as wife, rather than teacher or therapist:

FM6: *“And I knew and of course .. Yeah I don’t think you can you know be a lover and be a teacher if you know what I mean.”*

As a result of the individual with aphasia's involvement in a particular group, some family members also became involved and found a rewarding role within the group:

FM4: *"Then because I was doing all the typing at that stage too for it [aphasia group] and I'm still doing a lot of the typing... Which I love doing."*

#### *8. Increases participation for the family member*

As the result of a topic discussed in one group, one FM reported that both she and her husband had become involved in an activity that they had done prior to the individual with aphasia's stroke. The group had reportedly stimulated her husband with aphasia to try gardening again, influencing his wife's involvement in the activity as well.

#### *9. Provides a safe environment for the individual with aphasia*

For one FM, leaving her spouse who had aphasia and a physical disability in a controlled environment, where people knew about stroke, provided her with a sense of security. If she left him at home alone, she reported that she always felt the pressure to get back to him, whereas in the stroke group he was with people who knew what to do if a safety issue arose and they could contact her:

FM2: *"Where I don't have to worry about him being at home [when he is at the stroke club]."*

#### *10. Provides information about aphasia for the family member*

Information about aphasia was provided at some of the groups that the individuals with aphasia attended. FMs reported that this was beneficial for them as

they were able to find out about treatment programmes, research, and conferences from information provided at the groups for their relatives with aphasia:

FM6: “*So that’s I guess what it is for me ....to find out what’s happening.... What’s the newest and latest?*”

### **3.2.2 Benefits perceived by PWAs for family members**

PWAs reported two benefits for family members of having a relative with aphasia participate in groups, both of which overlapped with the ten benefits identified by the FMs (see Table 3.10).

<b>Table 3.10 Benefits for family members of having a relative with aphasia participate in groups as perceived by PWAs</b>	
1. Provides opportunity for social contact for the family member	2. Provides information about aphasia for the family member

#### *1. Provides social contact for the family member*

When identifying benefits of groups, one PWA reported that the groups provided some social contact for his wife.

#### *2. Provides information about aphasia for the family member*

Another PWA reported that a benefit of groups was that it enabled his family member to develop a better understanding of aphasia. He stated that the information about aphasia that he took home was also available for his family.

## Chapter 4: Discussion

The study explored the perceived benefits for individuals with aphasia of participating in groups and the perceived benefits for family members of having a relative with aphasia participate in groups. The PWAs and the FMs perceived numerous categories of benefits. The results will be discussed in relation to each of the two study aims.

### **4.1 Benefits of groups for participants with aphasia**

Analysis of the data revealed a total of 27 categories of benefits of participating in groups for individuals with aphasia. PWAs reported 25 of these categories. FMs reported 12 categories of benefits for individuals with aphasia, with ten of these overlapping with the benefits reported by the PWAs. The current study adds to the literature by revealing a more extensive range of perceived benefits of groups for individuals with aphasia than other investigations to date. Unlike previous research, the study also highlights benefits in relation to a variety of types of groups that involve people with aphasia. Many of the perceived benefits focused on psychosocial areas such as: providing an opportunity for social contact, providing an opportunity to feel part of the community, providing support, helping to identify with others with aphasia as well with others who had had a stroke, providing a feeling of hope and encouragement, providing a comparison with others, improving confidence, providing a sense of worth, providing an opportunity for humour, providing an opportunity to help each other, and providing a sense of empowerment. Other benefits included improving communication, providing a positive communication environment, providing information about aphasia, and providing stimulation.

Previous qualitative research in this area has revealed some similar results to the current investigation. For example, a few of the benefits identified in relation to SLT aphasia groups in the current study (e.g., provides an opportunity for social contact, improves communication, and improves confidence) overlapped with the perceived positive aspects of a specific SLT treatment group identified in a qualitative investigation by Elman and Bernstein-Ellis (1999b). Similarly, some of the perceived benefits of groups for people with stroke reported in this investigation (e.g., provides an opportunity for social contact, provides support) are similar to those identified in a qualitative study involving individuals with aphasia and dysarthria in a stroke group (Legg et al., 2007).

Interestingly, the findings of the current study also overlapped with a number of the outcomes provided in a descriptive report of individuals with aphasia who were involved in two community project groups (Pound, 2011). Some of the reported outcomes, such as a sense of meaning and purpose, community belonging and feeling included, and gaining inspiration and hope, were similar to some of the findings in the current investigation.

Firstly, Pound (2011) describes a sense of meaning and purpose as an outcome for people with aphasia from participating in a project aimed at improving services for people affected by aphasia in the United Kingdom. The individuals reported that they felt useful and valued again as the result of having something to contribute. Pound (2011) discusses the concept of active citizenship, highlighting that merely taking part in activities does not equate to social inclusion or social engagement, but rather that people need to feel valued and make a contribution to their community to develop a sense of real belonging. Similarly, in the current study PWAs identified providing a

sense of worth as a benefit of participant-led aphasia groups. The participants reported that meeting others with aphasia and being involved in projects in the participant-led aphasia groups provided them with this sense of worth.

Secondly, community belonging and feeling included, was identified as another outcome of participating in aphasia group projects in the descriptive report by Pound (2011). Similarly, providing an opportunity to feel part of the community was identified as a benefit of participant-led aphasia groups in the current investigation. Some PWAs indicated that after their stroke, they were not able to take part in their previous roles within community groups. They indicated that by being part of an aphasia group they were able to feel part of the community again.

Thirdly, Pound (2011) reported that gaining inspiration and hope was another outcome for the individuals with aphasia who were involved in the community aphasia project groups. Likewise, within the current study, providing a feeling of hope and encouragement was reported as a benefit of participant-led aphasia groups and groups for people with stroke. The PWAs reported that they appreciated meeting others with aphasia and that it encouraged them and helped them to see their own potential. The presence of hope is associated with adjustment, perseverance, and positive health outcomes for people recovering from illness and injury. Furthermore, research into the role of hope with people post stroke has shown that hope is multidimensional and linked with positive outcomes. Hope has a role in providing motivation and is linked to goal setting and optimism (Bright, Kayes, McCann, & McPherson, 2011). Providing a realistic hope for people with chronic health conditions also has psychological benefits (Bergin & Walsh 2005) by providing motivation for recovering at least some of what has been lost (Liechty & Braun,



2006).

Finally, another outcome reported for the individuals in the Pound (2011) report was being able to share experiences and worries and to give help and advice. Similarly, in the current study, some PWAs reported that they wanted to be able to help others with aphasia and to provide them with information and hope for the future. They indicated that this was one of the motivators for participating in these groups.

The current investigation also contributed to the literature by revealing a number of benefits of groups that have not been reported previously. These categories included providing a positive communication environment, providing stimulation, providing a comparison with others, providing an opportunity for humour, providing information about aphasia, and providing a sense of empowerment.

A positive communication environment was identified as a benefit of SLT, volunteer-led and participant-led aphasia groups, as well as groups that involved individuals who have an understanding of aphasia. In the SLT and the volunteer-led aphasia groups, part of the positive communication environment was reportedly created by the skills of the SLT or volunteer facilitator. PWAs reported feeling encouraged to talk and to contribute in these groups. In the SLT aphasia groups, PWAs also reported that the skills of the therapist enabled them to get to know other individuals with aphasia better and to find out more information about them that they would not have been able to obtain otherwise. One participant indicated he did not like to attend organized groups if there was no trained facilitator present. FMs also perceived that a benefit of groups such as SLT and volunteer-led aphasia groups was that the SLT or volunteer could use their facilitation skills to create a more positive

communication environment for the individual with aphasia. For example, one FM reported a difference in her relative with aphasia's ability to communicate depended upon whether or not there was a skilled facilitator present. When a facilitator such as an therapist who was aware of his range of communication aids was present, she perceived that her husband usually participated more actively. For this reason, the individual with aphasia reportedly did not want to participate in groups where a therapist was not available. Another FM reported that group experiences were very negative for her husband with a more severe aphasia if a trained facilitator was not present. Some PWAs also indicated that a positive communication environment was created in groups that involved other people with aphasia. They reported that they did not feel as nervous in these types of groups because they knew the other members understood aphasia. One PWA reporting feeling more at ease and able to contribute to conversations when those around her knew and understood about aphasia such as in a group with relatives of people who had aphasia. The results of the current study demonstrate and reinforce that careful, skilled facilitation is a key element in the creation of a positive communication environment in group situations for individuals with aphasia. These findings are congruent with research by Simmons-Mackie and Elman (2011). These investigators found that facilitation skills were a key component in a group discourse analysis and emphasised the role of speech-language therapists in negotiating a positive identity for people with aphasia.

Another benefit of groups that was unique to this study was that the participant-led aphasia groups and the groups for people with stroke were perceived to provide stimulation for the individuals with aphasia. FMs also reported that, in general, groups provided stimulation for their relatives with aphasia. Participants reported a need to do something and to have a place to go during their weekly routine.

They indicated that they found it stimulating to meet different people and to try new or different activities. Some PWAs felt that having an opportunity to go out and leave the house was therapeutic in itself. The benefit of stimulation fits with Brown et al.'s (2010) finding that a core theme of living successfully with aphasia is "doing things." Engaging in stimulating activity is important for all adults and may be particularly especially important after a stroke when so many aspects of life have changed.

Providing a comparison with others with aphasia and stroke is another benefit of groups that has not been reported in the literature before. Participants indicated that this was a benefit in relation to groups for people with stroke and the participant-led aphasia groups. This finding is closely tied in with hope and encouragement and identifying with others with stroke and aphasia. The PWAs found it beneficial and encouraging to see how others had been affected by aphasia and stroke and wanted to compare their own progress to the other individuals. This provided a realisation for some that their own communication and physical skills could be worse, while it gave other the incentive to keep trying to make improvements.

Providing an opportunity for humour was another category of benefits in the SLT aphasia groups and the groups for people with stroke that has not been reported previously. FMs also reported that this was a benefit of groups for individuals with aphasia. Laughter and humour have been found to have medical benefits and therapeutic effects on the body and mind (Perry, 2005). People with communication disorders can often miss out on the opportunity to express humour or may find it hard to follow humour in group situations. Finding ways to be humorous despite the communication disorder is one way of expressing one's personality and making a connection with others and can be used to put others at ease (Davidson et al., 2008a).

In group interactions, laughter can indicate the level of engagement of the members and can foster rapport and social closeness (Kovarsky, Curran, & Nichols, 2009). It is also a tool used in group facilitation to reinforce the connections of the group and to help in the development of a positive identity in relation to aphasia (Simmons-Mackie & Elman, 2011). In the study by Howe, Worrall, and Hickson (2008a), humour was highlighted as facilitative of positive interaction. This may be because engaging in humour suggests that the individual with aphasia is a competent partner in the conversation. The role of laughter in conversation for people with aphasia has been also studied (Madden, Oelschlaeger, & Damico, 2002) and was found to have four main functions in conversations: as a turn-taking cue, to display understanding, as an orientating cue, and as an instruction to hear, which indicates conversational repair. Laughter was found to be an important means for re-establishing social interaction despite a person's linguistic difficulties. Humour and laughter have also been found to have a role in establishing positive identity for people with aphasia (Simmons-Mackie & Elman, 2011) and providing meaning to nonverbal communication, serving multiple communicative and social functions (Hengst, 2006). Groups can provide the setting and environment for people with aphasia to enhance their pragmatic communication skills and to express aspects of their personality through humour that may be more difficult in other situations.

Another benefit that has not been highlighted previously was that groups were beneficial in providing information about aphasia. This benefit was associated with SLT, volunteer-led aphasia, and participant-led aphasia groups. FMs also highlighted this benefit. The ability to gain information about aphasia was reported to be provided in a variety of formats in groups including written information provided by the therapist, resources obtained from a resource library affiliated with the group, or

sharing information with others with aphasia in the group. This finding reinforces other research findings as a study by Worrall et al. (2011) identified that people with aphasia wanted information about stroke, aphasia and therapy and informational support was highlighted as a key indicator of positive health related quality of life outcomes for people with aphasia (Hilari & Northcott 2006); however access to information is difficult for individuals with aphasia due to the effect of aphasia on reading written information and it is possible that information provided to individuals with aphasia is not fully understood. It has been highlighted in the literature that written health information needs to be provided for people post aphasia in an 'aphasia friendly' format and at several stages post stroke. Six months post stroke has been identified as a helpful time to receive written information (Rose, Worrall, Hickson, & Hoffmann, 2010). Aphasia groups were a tool to provide informational support for individuals and family at a time that was appropriate.

Finally, another benefit revealed by this investigation involved providing a sense of empowerment. This benefit was reported in relation to SLT aphasia groups. One therapist in a SLT group reportedly helped the individuals with aphasia to feel empowered to start their own self help aphasia group. Shadden (2005) highlights the loss of identity associated with having aphasia. The author suggests that health practices from the beginning of the individual's time in hospital may encourage people with aphasia to feel incompetent. Individuals with aphasia and family members may then start to consider changes in communication as being defined only in relation to feedback from the therapist. Shadden (2005) suggests that this can have a detrimental effect over time as the chronic nature of aphasia becomes a reality for an individual. Providing therapy that promotes a positive communication identity (Simmons-Mackie & Elman, 2011) and maximises interpersonal strengths (Holland,

2007), may empower those affected by aphasia to live more successfully with aphasia in the long-term (Brown et al., 2010).

The current study also adds to the literature by identifying benefits that the participants perceived about participating in general groups, an area that, to the author's knowledge, has not been previously investigated. In the present investigation, one key benefit of general groups was that they provided a sense of normalization. Belonging to a service club, committee, choir, or sports club helped the PWAs to feel normal again because their disability was not the focus of the interactions. It is important to note that the PWAs in the study who reported that they still participated in general groups post-stroke all had mild aphasia.

#### **4.2 Benefits for family members**

The second aim of the study was to investigate the perceived benefits for family members of having a relative with aphasia participate in groups. Family members identified ten categories of benefits for themselves, while participants with aphasia identified two benefits for family members. These two categories overlapped with the categories identified by the FMs. Some benefits such as providing support for the family members and providing information for the family members were similar to the benefits of groups identified for the individuals with aphasia.

This study contributes to the literature in this area because, to the author's knowledge, there has not been any research that has specifically investigated the benefits for family members of having a relative with aphasia participate in groups. The effect of aphasia on family members has been examined in a number of studies

(Brown et al., 2011, Long, Hesketh, & Bowen, 2009; McGurk, Kneebone, & Pit ten Cate, 2011; Natterlund, 2010; Worrall et al., 2010). Post-stroke, people with aphasia can become more dependent on family members for support and socialisation (Natterlund, 2010). This can provide extra stress and burden on the family and can change the roles they have in relation to the individual with aphasia. The benefits of groups identified for family members in the current study may alleviate the stress on families and facilitate more positive family dynamics.

FMs reported that having the time on their own when the individuals with aphasia went to group was beneficial. Some FMs indicated that the time during which the individuals with aphasia attended the groups was the only period during the week when they themselves could relax and participate in an activity of their choice. The spouses reported that they often enjoyed having the house to themselves or being able to go shopping or for a walk. This reinforces the findings of Brown et al. (2011) where a theme of recognising the family members' own needs in relation to living successfully with aphasia was identified.

Another reported benefit of groups for family members involved groups providing a safe environment for the individuals with aphasia. It can be difficult for family members to balance supporting their relative with aphasia to achieve independence and autonomy with their concerns about safety (Brown et al., 2011). In the current study, one FM reported that when her relative with aphasia was at a group, such as the stroke club, she knew that the volunteers at the club would be able to look after him if anything happened to him and therefore she did not have to worry about him.

Groups were also reported to reduce the individual with aphasia's reliance on

the family members for socialization. Groups that were organized in the community for individuals with aphasia and/or stroke reduced the burden of the family members having to provide and organize all the social stimulation and interaction for their relative with aphasia. Some FMs reported that the individuals had reduced friendships and opportunities to socialise post-stroke. They reported that they therefore felt better when the individuals with aphasia had opportunities in groups to meet new people outside of the family.

The groups were also perceived to be beneficial because they provided an opportunity for social contact family members themselves. The groups enabled the family members, either through accompanying the person with the aphasia to the group, or through informal meetings with other relatives of people with aphasia in the group, to have opportunities for social contact with people who understood their situation. FMs reported that this informal contact with other family members provided them with support, enabling them to share experiences and strategies with others who understood aphasia. The needs of spouses of people with aphasia regarding support have been investigated and long term access to support is often identified as being important (Le Dorze & Signori, 2010; Natterlund, 2010). McGurk et al. (2011) also investigated the coping strategies of caregivers of people with aphasia and how they are associated with depressive symptoms. These researchers found that an anticipated level of social support for family members was associated with reduced symptoms of depression.



### **4.3 Clinical implications**

The current study highlights that there are wide-ranging benefits of participating in a variety of groups for individuals with aphasia. The benefits of these groups may also extend to positive outcomes for the family of these individuals. Clinicians can use the benefits identified in this study as a framework during collaborative goal-setting with group members. The findings may also be useful in the development of outcome measures to identify whether group members make improvements in relation to these goals in SLT, volunteer-led, and/or stroke groups.

Another key finding of this study was that the creation of a positive communication environment can be a benefit of certain types of groups such as SLT aphasia groups, groups with facilitators who have been trained about aphasia, and groups in which the individuals have an awareness of aphasia. It was noted that the skills of a facilitator are very important in the participation of group members and in building a positive communication environment in these groups. One family member in the current study reported that poor communication facilitation by a group leader can result in very negative group experiences for some individuals with aphasia. Facilitators, including speech-language therapists, volunteers, and other group leaders such as stroke club group coordinators, need to ensure that they develop skills that enhance communication and self-esteem for individuals with aphasia within groups (Simmons-Mackie & Elman, 2011).

Another key clinical implication of the study is that speech-language therapists, in conjunction with individuals with aphasia and their families need to consider a broad range of types of groups that may meet the needs of people with aphasia. In the current study, individuals with aphasia were involved in a wide range

of groups. Participants identified important benefits of participating in a variety of groups, not just SLT aphasia groups. Benefits included gaining support from others, meeting other people, sharing humour, and feeling stimulated. Hilari and Northcott (2006) and Simmons Mackie (2008) have questioned whether the provision of supported conversation groups, communication partners, and other “protected” social opportunities are more effective than other interventions that focus on fostering interaction and inclusion in the wider community. They have suggested there is a need for more efficacy studies looking at interventions that address wider social participation and social companionship for people with chronic aphasia.

One benefit of the participant-led aphasia group that was reported on in this study was that it “met an unmet need” that the health system was not providing. This relates directly to speech-language therapy services and how they are organised for supporting people with aphasia and families throughout their lives. The group in the current study formed out of a need to meet others with aphasia, to continue to grow and develop, and to educate the public about aphasia. Therapists can network with other support organisations associated with stroke and aphasia to help with the establishment of aphasia self-help groups. These groups may actually reduce the need for ongoing support from therapists in the long-term.

#### **4.4 Limitations and future research**

The results need to be considered in light of some limitations. Firstly, the topic guide required participants to identify benefits of groups that they were participating in at the time of the interview, as well as groups that they had participated in since the onset of their aphasia. The participants, therefore, had to rely on their memories to

identify the benefits of groups that they had participated in the past.

Another limitation of the study was that all the benefits of participant-led aphasia groups that were reported on in the study were in relation to one specific aphasia self-help group. A study including individuals' perspectives of benefits of a variety of participant-led aphasia groups would be useful. In addition, only individuals who reported that they had been participating in groups post-stroke were included in the study. It would be interesting in a future study to conduct qualitative interviews with individuals who have not participated in groups post-stroke regarding their perspectives on group participation. Future research could also explore some of the findings more fully around the benefits of different types of groups in relation to people with varied severities of aphasia. Finally, a future investigation could use participant observation in conjunction with qualitative interviews to triangulate the findings of the study.

#### **4.5 Conclusion**

The study has identified a wide-range of perceived benefits of a variety of types of groups for both the individuals with aphasia and their family members. The benefits identified in this study may be useful in addressing both communication and psychosocial goals for individuals with aphasia and their relatives, helping them to develop a positive identity (Simmons-Mackie & Elman 2011; Holland 2007) and to live more successfully with aphasia (Brown et al., 2010, 2011).

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## Appendices

Appendix A: Human ethics committee approval

Ref: HEC 2010/143

22 October 2010

Annette Rotheram  
Department of Communication Disorders  
UNIVERSITY OF CANTERBURY

Dear Annette

The Human Ethics Committee advises that your research proposal “The benefits of grounds for people with aphasia” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 21 October 2010.

In appendix H, please make it clear to participants that not only can they change their mind as stated but they also have the right to withdraw any data provided.

Best wishes for your project.

Yours sincerely

Dr Michael Grimshaw  
*Chair, Human Ethics Committee*



Appendix B: Information sheet for participants who are family members.



## **Information Sheet for participants who are family members:**

**Title of Project:** The Benefits of groups for people with Aphasia.

**Investigators:**

Annette Rotherham  
Department of Communication Disorders  
University of Canterbury

Dr. Tami Howe  
Department of Communication Disorders  
University of Canterbury

Gina Tillard  
Department of Communication Disorders  
University of Canterbury

You are invited to take part in a research study.  
We would like to interview family members of people with aphasia.  
We would like to investigate on how you perceive their group membership affects you

### **What is this project about?**

- I want to learn about the experience of groups and aphasia
- What do you get from your family member with aphasia belonging to a group?
- There are no right or wrong answers. You are the expert at living with aphasia.

### **What would I need to do?**

- You will need to sign a consent form.
- You will be interviewed in your home or somewhere else that is quiet where you feel comfortable. The interview will take between 30- 60 minutes.
- We will talk about the groups your family member goes go to and their aphasia and how this affects you.

- At the end of the study, you will be invited to a group session to hear about the results of the research.

### **What will happen to the information I give?**

- I will tape your interview.
- I will keep the information you give me in the recordings of your interview in the research centre of the Department of Communication Disorders, University of Canterbury.
- All information will be kept securely in the Department of Communication Disorders, University of Canterbury.
- All information will be confidential.
- The results will be part of a MSLT thesis which will be a public document with the University of Canterbury Library database

### **Are there any risks?**

- There is no danger in doing this research.

### **What if I decide I do not want to be involved?**

- You do not have to participate, it is your choice.
- You can start doing an interview and change your mind.
- You can ask questions at anytime.
- You can stop anytime
- Any information and data you have provided will be withdrawn.
- This study has been reviewed and approved by the University of Canterbury Human Ethics Committee.

### **What if I have a complaint?**

- Please feel free to discuss your participation in the project with one of the project staff.

### **What if I have more questions?**

- I am happy to give you more information.

- Please contact Annette Rotherham

Telephone: 027 5252170      Email: [annette.rotherham@pg.canterbury.ac.nz](mailto:annette.rotherham@pg.canterbury.ac.nz)  
Address: Annette Rotherham  
Department of Communication Disorders  
University of Canterbury, Christchurch

Dr. Tami Howe                      Telephone: 3642987 ext. 3619

### **The Benefits of Groups for people with Aphasia**

Name: \_\_\_\_\_

Name of my relative with aphasia: \_\_\_\_\_

Address: \_\_\_\_\_

Contact number: \_\_\_\_\_

Best time to reach me: \_\_\_\_\_

Please check one:

Please contact me to provide me with more information about the study.

I would like to participate in the study. Please contact me to set up an appointment.

Thank you for your interest. I will be in touch with you soon.

Annette Rotherham or  
0275252170

Tami Howe  
3642987 ext. 3619

## Information Sheet for Participants with Aphasia

**Title of Project:** The Benefits of groups for people with Aphasia.

**Investigators:**

Annette Rotherham  
Department of Communication Disorders  
University of Canterbury



Dr. Tami Howe  
Department of Communication Disorders  
University of Canterbury



Gina Tillard  
Department of Communication Disorders  
University of Canterbury



**We want to hear your experience of being in a group.**

**You are invited to take part in aphasia research.**

**Aphasia is a language disorder.** It can be **hard** for people with aphasia to:

- Talk



- Listen



- Read



- Write



People with aphasia are **intelligent** and **competent**.

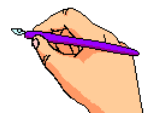
## What is this project about?

- I want to learn about the **experience of groups** and aphasia
- What do you **get** from going/ belonging to a group?
- **There are no right or wrong answers.** You are the expert at living with aphasia.
- **This is not therapy.**



## What would I need to do?

- You will need to **sign a consent form.** I will explain this.
- There will be **2 sessions**
- Each session will take about **1 hour.**



- The sessions can be at your **home** or at the **University** of Canterbury or other place.
- Session 1: I will **assess your language.**



I will also ask you some questions such as your **birth date.**

- Session 2: I will **interview you.**

We will talk about the **groups** you go to and your aphasia.



- You can have a **support person** with you during the research, if you **need to.**



- When the research is done, you will be invited to attend a **group** to hear about the **research results.**

### What will happen to the information I give?

- I will **audio tape and video record** your interview.
- I will keep the information you give me in the recordings of your interview in the **research centre** of the Department of Communication Disorders, University of Canterbury.
- All information will be **kept safely**.
- All information will be **confidential**.
- The study will be written as a **MSLT thesis** and will be a public document with the University of Canterbury Library database.



### Are there any risks?

- There is **no danger** in doing this research.



### What if I decide I do not want to be involved?

- You **do not have to participate**, it is your **choice**.
- You can start doing an interview and **change your mind**.
- You can ask **questions at anytime**.
- You can **stop** anytime
- All information you have given will be **withdrawn**



**Who has approved this research?**

- This study has been cleared by the University of Canterbury human **ethics committee**.

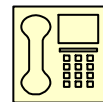
**What if I have more questions?**



- For more information
- Please contact Annette Rotherham or Tami Howe

Department of Communication Disorders  
University of Canterbury, Christchurch

Telephone: 027 5252170 or 3642987 ext. 3619



Address: Annette Rotherham

Email: [annette.rotherham@pg.canterbury.ac.nz](mailto:annette.rotherham@pg.canterbury.ac.nz)

**The Benefits of Groups for people with Aphasia**

Name: \_\_\_\_\_

Name of my relative with aphasia: \_\_\_\_\_

Address: \_\_\_\_\_

Contact number: \_\_\_\_\_

Best time to reach me: \_\_\_\_\_

Please check one:

Please contact me to provide me with more information about the study.

I would like to participate in the study. Please contact me to set up an appointment.

Thank you for your interest. I will be in touch with you soon.

Annette Rotherham or  
0275252170

Tami Howe  
3642987 ext. 3619

Appendix D: Consent form for participants who are Family members.

**Consent form for Participant / Family members:**

**Title of Project:** The Benefits of groups for people with Aphasia.

**Investigators:**

Annette Rotherham  
Dep. of Communication Disorders  
University of Canterbury

Dr. Tami Howe  
Dep. of Communication Disorders  
University of Canterbury

Gina Tillard  
Dep. of Communication Disorders  
University of Canterbury

**I understand:**

- I do not have to participate. It is **my choice**.
- I can **change my mind**.
- I can ask questions at anytime.
- I can stop the research at anytime
- There is **no danger** in doing this research

**I understand what I need to do:**

- I will be **interviewed in my home** or somewhere I feel comfortable.
- I will be asked questions about the groups my family member with aphasia I has been to.

**I understand the benefits of this research:**

- This will **help researchers** learn more about aphasia.
- This may help people who have aphasia
- There may be **no direct benefit to me**
- This is **not therapy**.



**I understand what will happen to the information I give:**

- My interviews will be **tape/video recorded**.
- I will need to give some personal details.

For example:

- My age
- My address
- Information about my family member's aphasia and groups

This information and tape recordings will be **stored safely** at the University of Canterbury.

All information I give will be **confidential**

- I would like a copy of the transcript from the interview to check.
- I would be interested in being contacted in the future about another research project.
- I understand what this research is about.

I \_\_\_\_\_ (please write full name) agree to participate in this research.

Participant's signature:

Date:

## Consent form for Participant with Aphasia

**Title of Project:** The Benefits of groups for people with Aphasia.

### **Investigators:**

Annette Rotherham  
Dep. of Communication Disorders  
University of Canterbury






Dr. Tami Howe  
Dep. of Communication Disorders  
University of Canterbury



Gina Tillard  
Dep. of Communication Disorders  
University of Canterbury



### I understand:

- I do not have to participate. It is **my choice**.
- I can **change my mind**.
- I can ask questions at anytime. 
- I can stop the research at anytime 
- There is **no danger** in doing this research. 

### I understand what I need to do:

- I will be **interviewed in my home** or somewhere I feel comfortable.
- I will participate in a **language assessment** with a speech-language therapist
- I will be asked questions about the groups I have been to.



### I understand the benefits of this research:

- This will **help researchers** learn more about aphasia.
- This may help people who have aphasia
- There may be **no direct benefit to me**
- This is **not therapy**.

### I understand what will happen to the information I give:

- My interviews will be **tape/video recorded**.
- I will need to give some personal details.

For example:

- My age
- My address
- Information about my aphasia and groups

This information and tape recordings will be **stored safely** at the University of Canterbury.

All information I give will be **confidential**



- I would like a **copy** of the typed interview to check.
- I would be interested in being contacted about possible future research projects.
- I \_\_\_\_\_ (print name) **agree** to take part in this research.

Participant's signature:

Date:

**Post form to: (envelope provided)**

Annette Rotherham  
Department of Communication Disorders  
University of Canterbury  
Private Bag 4800,  
Christchurch 8140

### **Topic Guide for Interviews with PWA**

#### **1. -Tell me about the groups you currently go to?**

- Are you involved in any group activities?
- Are you a member of any clubs, sports groups, or committees?

#### **2. Groups that do not involve other people with aphasia.**

- Tell me about what you get out of being in that group?
- Tell me about why you go to the group?
- What is good about the group?
- Tell me about the positive things about the group.
- Is there anything negative about the group?

#### **3. Groups involving other people with aphasia:**

- Tell me about what you get out of that group?
- -Tell me about why you go to the group?
- -What is good about the group?
- -Tell me about the positive things about the group.
- -Is there anything negative about the group?
- (How long have you been going to that group?)
- (Who else goes to that group?)

#### **4. Groups that involve a Speech-language Therapist:**

- Tell me about what you get out of that group?
- Tell me about why you go to the group?
- What is good about the group?
- Tell me about the positive things about the group.
- Is there anything negative about the group?
- (How long have you been going to that group?)
- (Who else goes to that group?)

Feedback “Tell me more about...”, “Can you give me an example”,  
“That’s interesting”, “ great to share that,”  
Use their words...”Power, tell me more about that”

- Tell me about any differences you find between these different groups
- Tell me about any ways your experiences in groups have changed since having aphasia.
- Tell me about any positive/good things about being in groups in general.
- Tell me about any positive/good things that you ONLY get from being in groups
- Tell me about any ways the groups differ with your aphasia.
- How are groups better than just being with one person?

Topic guide for Interviews with FM:

- Can you tell me about any groups that (name) goes to?
- What is good about that group/s for PWA? For you?
- Are there positive things for you that (name) goes to groups?
- Are there any negative aspects about the group/

**Participant I.D.:**

**Date completed:** \_\_/\_\_/\_\_

Appendix G: Demographic information: family members

Family Member Demographics form:

Please complete the following:

1. **Date of birth:** \_\_\_\_\_

2. **Gender:**

Male     Female

3. **Marital Status:**

Single

Never married

Married

Separated

Divorced

Widowed

Other, please specify: \_\_\_\_\_

4. **Highest Level of Education:**

Primary School

High School

Polytechnic

University

Other, please specify: \_\_\_\_\_

5. **Current occupation:** \_\_\_\_\_

6. **Past occupation:** \_\_\_\_\_

7. **Occupational Status:**

Full-time

Part-time

Casual

Not working

Retired

Other, please specify: \_\_\_\_\_

8. **What is your ethnicity?**

Māori

New Zealander

- Pacific Peoples
- European
- Asian
- Middle Eastern, Latin American, or African
- Other, please specify: \_\_\_\_\_

9. How would you rate your overall health?

- Poor
- Okay
- Good
- Very good

10. What is your relationship to the person with aphasia?

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11. How many years have you known him/her? \_\_\_\_\_

12. Do you live with the person with aphasia? Yes No

a. If NO, approximately how many kilometres from the person with aphasia do you live? \_\_\_\_\_

13. How often do you have contact with the person with aphasia?

- Daily
- 2-3 times per week
- Weekly
- Fortnightly
- Monthly



Participant I.D.:

Date completed: \_\_\_ / \_\_\_ / \_\_\_

Appendix H: Demographics form for participants with aphasia

### Person with aphasia demographic form

Please complete the following:

1. Date of birth: \_\_\_\_\_

2. Gender:

Male     Female

3. Marital Status:

- Single
- Never married
- Married
- Separated
- Divorced
- Widowed
- Other, please specify: \_\_\_\_\_

4. Highest Level of Education:

- Primary School
- High School
- Polytechnic
- University
- Other, please specify: \_\_\_\_\_

5. Current occupation: \_\_\_\_\_

6. Past occupation: \_\_\_\_\_

7. Occupational Status:

- Full-time
- Part-time
- Casual
- Not working
- Retired
- Other, please specify: \_\_\_\_\_

8. What is your ethnicity?

- Māori
- New Zealander

- Pacific Peoples
- European
- Asian
- Middle Eastern, Latin American, or African
- Other, please specify: \_\_\_\_\_

9. Date of stroke: \_\_\_\_\_

10. Date of discharge from acute hospital: \_\_\_\_\_

11. Date of discharge from rehabilitation unit: \_\_\_\_\_

12. How many strokes have you had? \_\_\_\_\_

13. Where do you live?

- Own home
- Care facility
- Other, please specify: \_\_\_\_\_

14. Do you use any assistive devices?

- Glasses
- Hearing aids
- Walker
- Wheelchair
- Other, please specify: \_\_\_\_\_

15. Personal Health - Please list any personal health concerns, medical diagnoses, or recent hospitalizations:

16. How much speech therapy did you have in the past?

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17. How much speech therapy do you have now?

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