

Perceived Benefits for Family Members of Group Participation by Their Relatives with Aphasia

Annette Rotherham¹, Tami Howe², Gina Tillard³

¹Canterbury District Health Board, Christchurch, New Zealand; ²School of Audiology and Speech Sciences, University of British Columbia, Vancouver, British Columbia, Canada, Van Couver, Canada; ³Department of Communication Disorders, University of Canterbury, Christchurch, New Zealand, Christchurch, New Zealand

Purpose: Aphasia impacts family members. Therefore family members may also derive indirect benefits when their relative with aphasia chooses to participate in a group. The current study explored the benefits for family members of their relative with aphasia participating in a variety of types groups post-stroke as perceived by family members and their relatives with aphasia.

Methods: The study used a qualitative descriptive research approach. Semi-structured interviews were conducted with sixteen participants: six family members and ten adults with aphasia post-stroke. Qualitative content analysis was used to analyze the interview transcripts. Member checking, peer debriefing, and triangulation of data sources was used to enhance the rigour of the study.

Results: The participants identified 10 benefits that family members may experience as a result of their relative with aphasia participating in various types of groups post-stroke: improves communication between the family member and the individual with aphasia at home, provides support for family members, provides an opportunity for social contact for family members, enables access to aphasia-related information, reduces individual with aphasia's reliance on the family member for socialization, provides an opportunity for the family member to have time on their own, enables the family member to experience positive feelings, allows family members to focus on their role in the family, provides a meaningful role for the family member, and increases participation for the family member.

Conclusions: These indirect benefits may help to address some of the psychosocial, information, communication, and participation needs of family members of individuals with aphasia.

Keywords: Aphasia, Groups, Family, Qualitative research, Benefits



Received: October 4, 2016

Revision: December 12, 2016

Accepted: December 13, 2016

Correspondence:

Annette Rotherham

227 Major Hornbrook Raod, Christchurch
8081, New Zealand

Tel: +006433765531

Fax: +006433378939

E-mail: annettelrotherham@gmail.com

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INTRODUCTION

Adults with aphasia may benefit from participation in a variety of types of groups (e.g., peer-facilitated, volunteer-facilitated, speech-language pathologist (SLP)-facilitated, general) [1-3]. Aphasia often has a significant impact on families [4,5], therefore family members may also derive benefits when their relative with aphasia becomes involved in a group [12]. Previous research in the area has tended to focus on the benefits of groups that have a direct focus on family members [6-8] or on both family members and people with aphasia [9]. There have not been any studies that investigate the benefits for family members of having a relative with aphasia participate in groups. Family

members in a qualitative study by Bernstein and Ellis were asked to identify the perceived benefits of an SLP-facilitated group for their relative with aphasia [10], these participants were not asked to identify any benefits that they may have derived themselves from their relative's participation in the group. One qualitative investigation that has reported findings in this area involved families' perceptions of living successfully with aphasia [11]. Semi-structured in-depth interviews with 24 family members of adults with aphasia revealed seven themes relating to the meaning of living successfully with aphasia: getting involved in life, support for the person with aphasia, communication, family members' own needs, putting life in perspective, focusing on and celebrating strengths and improvements, and experiences with services. Within the theme of experiences with services, the family members reported that therapy groups were facilitative in that they enabled the relatives to meet other people who were living with aphasia. Furthermore, a more recent qualitative study investigating the core components of a successful peer-led aphasia support group added to these findings [3]. The focused ethnography, involving seven family members and 19 people with aphasia, found that peer-facilitated aphasia groups provided friendship and mutual support for family members, as well as for the individuals with aphasia. Finally, a recent modified Delphi study that focused on the accessibility of a speech-language pathology clinic revealed similar results. The investigation included nine family member/friend participants, nine participants with aphasia post-stroke, and two student speech-language therapy participants. The researcher found that many family members perceived that it was beneficial to be able to meet informally with each other during their relatives' speech-language pathology group meeting time.

"Ensuring that family/carers/ significant others experience less third-party disability" was identified as an important category of aphasia treatment outcomes in a recent international consensus study that included clinicians and managers [13]. Identifying potential benefits that family members may experience when their relative with aphasia participates in a group can help to inform our clinical practice in this area. It can improve our understanding of the effects of group participation and help clinicians to target more strategically the frequently limited resources in speech-language pathology services. To date, however, the research in this area has been limited. The current study therefore uses a qualitative approach to address this gap in the literature by focusing on the following aim: to

explore the benefits for family members of their relative with aphasia participating in a variety of types of groups post-stroke as perceived by family members and their relatives with aphasia.

METHODS

The investigation used a qualitative descriptive research approach [14], underpinned by the constructivist paradigm [15]. The study was part of a larger investigation that also explored the perceived benefits of group participation for adults with aphasia [2]. Prior to the commencement of the study, ethical approval was obtained from the relevant ethics committees. Written informed consent was obtained from all participants, with supported conversation strategies [16] used to obtain consent from the individuals with aphasia..

Sampling and recruitment

The specific form of purposeful sampling used in this investigation for the participants with aphasia (PWAs) was maximum variation sampling [17] with variation sought in relation to age, gender, aphasia severity, and time post-onset of aphasia. Inclusion criteria for the family member participants (FMs) were that the individuals were 18 years or older, lived with one of the PWA, and were able to participate in an interview conducted in English. Participants were recruited from stroke, SLP-facilitated, and peer-facilitated aphasia groups in two New Zealand cities.

Participants

Eleven individuals with aphasia and seven of their family members initially expressed interest in participating in the study; however, one individual with aphasia and their family member withdrew for personal reasons. Table 1 and Table 2

Table 1. Demographic Information of Family Members

Participant number	Relationship to PWA	Gender	Age	Working status
FM1	Spouse of PWA2	Female	74	Retired
FM2	Spouse of PWA3	Female	69	Retired
FM3	Spouse of PWA5	Female	52	Part-time working
FM4	Spouse of PWA6	Female	78	Retired
FM5	De facto partner of PWA7	Female	54	Part-time working
FM6	Spouse of PWA8	Female	51	Full time working

Table 2. Demographic information of PWAs

Participant number	Gender	Age	Time post- onset of aphasia	WAB-R AQ	Living situation	Physical ability	Types of groups participated post-onset of aphasia
PWA1	Female	65	16 months	91.7	Lives with son	Uses wheelchair	Stroke
PWA2	Male	83	7 months	34.4	Lives with spouse	Independent	SLP, stroke, general
PWA3	Male	71	3 years	51.6	Lives with spouse	Uses wheelchair	Stroke, general
PWA4	Male	77	3 years	92.7	Lives alone	Independent	SLP, stroke, general
PWA5	Male	62	6 years 6 months	14.1	Lives with spouse	Uses wheelchair	SLP
PWA6	Male	81	8 years	95.6	Lives with spouse	Independent	Peer-facilitated, volunteer-facilitated, general
PWA7	Male	68	5 years 9 months	50.2	Lives with partner	Independent	SLP, peer-facilitated, volunteer-facilitated
PWA8	Male	65	5 years 9 months	79.8	Lives with spouse	Independent	SLP, peer-facilitated, general
PWA9	Male	67	8 years	98.2	Lives alone	Independent	SLP, peer-facilitated, volunteer-facilitated, stroke, general
PWA10	Female	51	4 years	95.4	Lives with spouse	Independent	SLP, peer-facilitated, general

provide the demographic information for the participants. Sixteen participants completed the study: six female FMs and eight male and two female PWAs. The FMs consisted of five spouses and one defacto partner who were aged from 51 to 78 years. The PWAs were aged from 51 to 83 years and were seven months to eight years post-stroke with Western Aphasia Battery-Revised [18] Aphasia Quotients (AQ) that ranged from 14.1 to 98.2. Individuals with aphasia who had an AQ that was 93.8 or higher were included in the investigation, if they had been diagnosed with aphasia previously, continued to identify as having aphasia, and were observed to make aphasic errors in conversation with the first author, who was a qualified SLP. The PWAs reported that they had participated in the following types of groups post-stroke: seven PWAs had participated in SLP-facilitated groups including an intensive outpatient treatment group and outpatient groups that focused on improving conversation, five PWAs had participated in peer-facilitated groups, three PWAs had participated in volunteer-facilitated aphasia conversation groups, five PWAs had participated in stroke groups (including community stroke clubs, a community stroke activity group, a physiotherapy stroke treatment group, and a community stroke gym group), and seven PWAs had participated in general groups (including service organizations, a choir, a golf group, a yacht club, an exercise group, and informal groups of friends and family). Further demographic details about the participants have been reported previously [2].

Semi-structured interviews

Semi-structured interviews [19] were conducted with the FMs and PWAs based on the following topic guide:

1. Groups (e.g. Can you tell me about any groups that PWA goes/you go to?)
2. Benefits of groups (e.g. What is good about [each specific group]?/Are there any positive things the PWA/you get(s) from the [specific group]?)
3. Any potential negative aspects. (Are there any negative things about the group?).

During the interviews with the PWAs, the first author, a qualified speech-language pathologist, used strategies based on supported conversation for adults with aphasia [16] to support the participation of these participants. The interviews with the FMs were audio-recorded, while the interviews with the PWAs were video-recorded to capture their nonverbal communication.

Data analysis

Verbatim transcription of the audio- and video-recordings was completed based on the conventions of Poland [20]. Qualitative content analysis was used to analyse the interview transcripts to inductively identify codes of perceived benefits for family members and for the individuals with aphasia [21]. Perceived benefits for the individuals with aphasia are reported elsewhere [2].

Rigour and reflexivity

Member checking [22], peer debriefing [23], and triangulation of two data sources (FMs and PWAs) [24] were used to increase the rigour of the investigation. A reflective journal was also utilized to identify personal experiences and biases that may have influenced the study [24].

RESULTS

FMs identified 10 benefits that they may experience as a result of their relative with aphasia participating in various types of groups post-stroke. PWAs reported two benefits, provides an opportunity for social contact for family members and enables access to aphasia-related information, that overlapped with the benefits identified by the FMs. The 10 benefits are reported below along with examples of participant quotations that illustrate some of the findings.

Improves communication between the family member and the individual with aphasia at home

FMs reported that groups sometimes helped the individuals with aphasia to communicate better with their family members at home. For example, one FM, whose spouse with severe aphasia relied on communication aids to express himself, found that he did not need as much prompting to use his aids and was less dependent on her to guess what he wanted to communicate after he participated in a SLP-facilitated group.

Provides support for the family member

Although the aphasia and stroke groups were focused on providing a service for the individuals with aphasia, some family members attended these groups or met informally with other family members while these groups were being held. FMs reported that this provided them with an opportunity to discuss issues and to obtain support from other relatives of people with aphasia as indicated in this quotation from one FM: “Well I think it makes you realise you’re not on your own... Yeah and both of us...We’ve got that support there.”

Provides an opportunity for social contact for family members

Participants indicated that families benefitted from the social contact they had with other family members as the result of accompanying their relatives with aphasia to some of the group sessions or meeting informally with other family members while their relatives participated in the groups. This is il-

lustrated in this quotation by one FM: “Ah friendship... I’ve got to know a lot of the ladies and we...look out for one another... they’re all concerned about one another.”

Enables access to aphasia-related information

Participants also reported that families benefitted from being able to access aphasia-related information as the result of information that their relative was provided with in some of the groups. For example, one PWA reported that a benefit of SLP-facilitated groups was that it enabled his family member to develop a better understanding of aphasia because the information about aphasia that he took home was also available for his family.

Reduces individual with aphasia’s reliance on the family member for socialization

FMs reported that when their 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: “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 indicated 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 social opportunities for their relative with aphasia.

Provides an opportunity for the family member to have time on their own

FMs highlighted that another benefit was that it provided an opportunity for significant others to have some time on their own. For one FM, leaving her spouse who had aphasia and a physical disability post-stroke in a controlled environment where people knew about stroke, provided her with a sense of security in order that she could have some time on her own. This participant indicated that if she left her husband at home alone, she felt pressured to get back to him, whereas in the stroke group she perceived he was with people who knew what to do and could contact her if a safety issue arose.

Enables the family member to experience positive feelings

FMs indicated that they experienced a range of positive feelings as a result of their relative with aphasia feeling good about participating in groups as illustrated by this quotation by one FM: “Well it’s obviously a sense of (laughing) of success.... it’s having a knock-on effect...if [name of PWA]’s hap-

pier I'll be happier."

Allows family members to focus on their role in the family

Some FMs felt the groups helped them to focus on their role in the family more. For example, one FM reported that by having her husband with aphasia participate in a SLP-facilitated group that focused on communication, she felt she could focus on her role as the individual's wife, rather than being a teacher: "Yeah I don't think you can you know be a lover.... and be a teacher if you know what I mean."

Provides a meaningful role for the family member

Some FMs reported finding a new meaningful role for themselves in the groups that the individuals with aphasia attended. For example, some FMs took on new roles that they found meaningful (e.g., forming an informal family members' group, providing secretarial support for their relative's peer-facilitated aphasia group).

Increases participation for the family member

One FM reported that she became involved in the leisure activity of gardening again because a discussion in a SLP-facilitated group reportedly stimulated her husband with aphasia to want to garden again post-stroke.

DISCUSSION

The investigation found that family members may derive a number of benefits as the result of their relative with aphasia participating in various types of groups. These indirect benefits included access to support, social contact, and aphasia-related information for the family members, as well as improved communication between the family members and the individuals with aphasia at home. The benefits also included the opportunity for significant others to have time on their own while their relative with aphasia attended the groups and to experience positive feelings themselves as a result of their relatives feeling happy about their group participation. When the individuals with aphasia participated in groups, family members also reported that they often felt positive because it reduced their relatives' reliance on them to organize and provide social opportunities for them. In addition, family members identified benefits in relation to participation including being able to take on rewarding roles such as providing secretarial support for a peer-facilitated aphasia group, participating again in a leisure activity such as gardening, and being

able to focus on their family role rather than being a communication teacher.

Some of these benefits mirror aphasia rehabilitation goals and needs in relation to support, information, and respite that family members have identified as being important for themselves in previous investigations [5,25]. This reinforces the study by Brown and colleagues [11] that found that recognizing the family members' own needs was important in relation to living successfully with aphasia. For example, long-term access to support has been identified as being important for family members of people with aphasia [5,25-27]. In the current study, FMs reported that informal contact with other family members provided them with support by enabling them to share experiences and strategies with others who understood aphasia. Shadden and Agan [28] highlight that it is critical to recognize that like their relatives with aphasia, family members may also experience identity theft as the result of living with aphasia. Although some family members may require more formal support services, others may benefit from the informal support provided by being in contact with other family members who are dealing with similar difficulties [29]. The findings from the current investigation concur with previous research that found that family members perceived that they gained support from therapy and peer-facilitated aphasia groups that their relative with aphasia participated in [3,12]. In the study by Chow [12] participants highlighted that it would be useful if family members had access to a private room to meet informally on their own while their relatives with aphasia attended their SLP group sessions. SLPs may need to consider simple options such as this in order to facilitate the potential development of informal support networks for the family members of their clients with aphasia.

Another benefit reported by the participants was increased opportunities for social contact for the family members. Previous studies have found that some family members of adults with aphasia experience reduced social participation themselves [4,25]. In the current study, the informal meetings with other family members were perceived to address this concern for some of the individuals by providing them with increased opportunities for socialization.

The need for aphasia-related information has been identified as being important for families at various stages of aphasia recovery with the recognition that informational needs change over time [5,25,31]. The groups that focused on aphasia in this study were perceived to be valuable because the information that was provided for the people with aphasia in

the groups could also be shared with their family members.

Participants also perceived that the groups that focused on communication were beneficial because they resulted in improved communication between the individual with aphasia and their family within the home environment. One family member indicated that her husband required less prompting to use his communication aids to express himself at home after participating in a SLP-facilitated group that had focused on encouraging him to use these aids. Documenting changes in communication in everyday contexts that occur as the result of speech-language therapy can be difficult [32]. Clinicians could consider involving family members more often in helping to document some of the specific changes that occur in everyday communication as the result of SLP treatment.

Relatives found that having the option for time on their own when the individuals with aphasia were at the groups was also beneficial for them. The FMs reported that they often enjoyed having the house to themselves or being able to go shopping or for a walk on their own. Having a time away from one another may be beneficial for the well-being of both the individual with aphasia and their family [25]. It can be difficult, however, for some family members to balance supporting their relative with aphasia to achieve independence and autonomy with their concerns about their relative's safety [11]. One FM reported that the stroke group that her relative with aphasia attended was beneficial because it helped her to allay her safety concerns of leaving him on his own at home while she went out.

Family members also perceived that it was beneficial for them when their relative with aphasia participated in groups because it reduced the individual with aphasia's reliance on them to organize and set up social activities for them. Some FMs in the current study reported that the individuals with aphasia had reduced friendships and opportunities to socialize post-stroke. Similarly, Hilari and Northcott found that many individuals with aphasia experience a loss of and reduced contact with friends post stroke [33]. Language difficulties post-stroke can make it harder for many adults with aphasia to organize their own social activities. For example, language impairments can make it more difficult for adults with aphasia to contact friends to set up meetings and to obtain information about leisure and social groups in their communities [34,35]. As a result, people with aphasia can become more dependent on family members post-stroke to organize social activities for them [27]. In the current study, having suitable groups available for people with aphasia to choose to partici-

pate in, reportedly reduced the burden on the family members to have to arrange social activities for their relative.

Limitations and future research

One limitation of the study is that it involved a small number of participants who had been recruited from groups in two New Zealand cities. Furthermore, all the family member participants were females and from a European background. As it is a qualitative investigation, the results are not generalizable. Rather it is intended that readers judge the transferability of the findings to their own settings based on the details provided in the participant and results sections of the research report [24].

CONCLUSION

The study has identified a wide-range of indirect benefits that family members may experience as the result of their relative with aphasia choosing to participate in various types of groups. Speech-language pathologists and managers should not underestimate the value of these benefits in helping to address some of the psychosocial, information, communication, and participation needs of the family members of their clients with aphasia. Clinicians should consider how they can enhance these potential benefits when developing group interventions for adults with aphasia in order to help both them and their families live more successfully with aphasia.

CONFLICT OF INTEREST

The author has no conflict of interests.

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