Experiences of people with severe aphasia and spouses attending an Interdisciplinary Community Aphasia Group

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ABSTRACT

Background: Community aphasia groups are recognized as an area of need and value for people with chronic aphasia and their significant others. However, our understanding of attendees’ experiences is limited by the small amount of qualitative research available. The present study aimed to describe participant experiences of an Interdisciplinary Community Aphasia Group, as part of a better understanding of its underlying processes and value.

Methods: Four people with chronic, severe aphasia and their spouses attended an Interdisciplinary Community Aphasia Group held at a university speech clinic for 2 h once weekly over 12 weeks. The group was co-facilitated by a speech-language pathologist and a social worker, with the support of two aides (one a person with aphasia, and the other a member of the general community). The group addressed the following areas: communication therapy, conversation, participation in meaningful and accessible activities, psychological and social support, and aphasia information and education. Following the program, the people with aphasia (via multimodal communication) and spouses participated in separate semi-structured interviews with an independent interviewer. The interviews addressed members’ perceptions of the program (both in relation to themselves and their spouse) along with recommendations for improvement. The interviews were analyzed using Framework Analysis.

Results: Members shared preferences for program activities and group format, with some experiences leading to suggestions for improvement. The group dynamics and environment were considered positive overall, and members highlighted a range of positive impacts for both themselves and their spouse. Together, these elements informed members’ evaluation that the model contained something for everyone, but may not be a “one-stop shop” given ongoing needs for therapy. An overarching theme for spouses addresses therapy and recovery in relation to the impact of peers, views and beliefs, and adjustment.

Conclusions: The Interdisciplinary Community Aphasia Group model has overall acceptability for people with chronic, severe aphasia and their spouses, and can be adapted to ensure feasibility in clinical practice. Ongoing research is required to best tailor community groups for people with aphasia and significant others, and to reinforce the need for their proliferation.

IMPLICATIONS FOR REHABILITATION

- People with aphasia and their spouses can benefit from a wide range of programming, including participation in meaningful and accessible non-verbal activities. An interdisciplinary staff team can contribute positively to member experience and impacts, with peer staff offering valuable mentoring roles. Various aspects of member identity and life narrative impact on community aphasia group participation; understanding members’ needs in the context of previous experiences can improve tailoring of program content.

Introduction

People with chronic post-stroke aphasia and their family members report that meaningful relationships including support, engagement in meaningful activities, successful communication, and striving for a positive way of life, are essential factors for “living successfully” with the condition [1]. Access to speech pathology services including community therapy groups has been raised as a need by both people with aphasia and family members [1,2]. In addition, specific requirements indicated by family members include addressing their own needs, putting life into perspective, and focusing on and celebrating the person with aphasia’s strengths and improvements [2]. Community aphasia groups are defined as involving: (1) two or more people with aphasia who are living in the community meeting regularly, with or without formal group facilitators and/or significant others; and (2) at least two of the following aims: communication therapy, conversation activity, social and/or psychological support, stroke/aphasia education, and participation in accessible activities [3].
community aphasia group characteristics have been presented in the literature [4–6] and broadly focus on group size, composition, location, staffing, programing, and outcome measurement. The 80 community aphasia groups documented to be available in Australia [7] are wholly insufficient to service the 100,000 people with aphasia living in the community [8]. Furthermore, despite the substantial “third-party impacts of aphasia on family members [9,10], their inclusion in aphasia rehabilitation, and more specifically community aphasia group service provision is limited [2,6,11].

In order for more successful and sustainable community aphasia groups to proliferate in Australia and other countries around the world, we need to develop a greater understanding of the positive and negative experiences of those who have sought these services. Taking together the evidence from a review of consumer experiences of community aphasia groups [6] and subsequent studies involving people with aphasia and/or family members [11–15] supports the view that these services have the capacity to facilitate living well with aphasia. Viewed in the context of the World Health Organisation’s International Classification of Functioning, Disability, and Health (ICF) [16], community aphasia groups appear to effectively address all domains as well as contribute to psychological well-being. However, the existing research is preliminary in nature, with a number of limitations present. Currently, there are a broad mix of different group models reported, some of which are combined with 1:1 sessions/interventions, last for a short period of time (e.g., a weekend), or involve stroke survivors without aphasia, without delineating the experiences of particular participant groups. These variables make it difficult to understand the specific mechanisms impacting within an already complex phenomenon. A major concern is the under-representation of certain consumer subgroups, including those living with aphasia at a younger age (under 50), and from culturally and linguistically diverse backgrounds. Next, many community aphasia groups do not include family members in direct session time. The notions that (1) aphasia is experienced not only by people with aphasia but also those close to them [17–19] and (2) people with aphasia and family members have contrasting views regarding living successfully with aphasia [20] and the possible benefits [13] and outcomes [21] of community aphasia groups [15] reinforces the need to explore the perspectives of both groups. However, many studies have combined data regarding outcomes from both people with aphasia and significant others [15,21–24], making it difficult to delineate experiences by member type. In addition, the overwhelming majority of experiences reported to date are positive. Recently, explorations of the barriers, as well as the facilitators to accessing community aphasia groups, include some mediocre to negative experiences [11,25], while research seeking the insights of those from disbanded groups and who have left groups reveal the potential to experience disablement and marginalization [26,27]. Finally, people with severe aphasia are minimally present within community aphasia group research, often being excluded from community aphasia groups or subsequent research interviews [21,28]. Given the potential for people with severe aphasia to experience social exclusion generally [27,29], and the likelihood that it is this very subgroup of people with severe aphasia for whom community aphasia groups might be so vital in providing social and communication opportunities, the experiences of this subgroup require additional exploration.

**Aim**

This study sought to focus on the experiences of four individuals with chronic, severe aphasia and their spouses who were interviewed as part of a larger research study examining the efficacy of a 12-week community aphasia group program involving speech-language pathologist and social worker co-facilitation. Readers are directed to our companion publication for full details regarding the main study and quantitative results [30].

**Method**

**Participants**

The study was advertised through the Communication Research Registry, and researchers placed written advertisements online through Aphasia Community, Aphasia New South Wales, the Stroke Foundation, and the Stroke Recovery Association of New South Wales. Primary investigators at two health networks in Sydney distributed advertisements by mail to suitable candidates on current and past caseloads following an inclusion criteria screen. Details of the study were also placed in the Speech Pathology Email Chats online forum (open to speech-language pathologists).

Inclusion criteria for the people with aphasia (*=also relevant to significant others) comprised of (1) history of left-hemisphere stroke, (2) stroke onset of at least 12 months prior, (3) ability to communicate “yes/no” regardless of modality, (4) available to undertake assessments and attend program sessions*; (5) pre-morbid fluent English speaker*; (6) living in the community, (7) not currently undergoing aphasia-specific intervention or attending a stroke or aphasia group*, (8) able to manage toileting, and (9) no significant/uncorrected cognitive, psychiatric, vision, and/or hearing impairment that could interfere with group participation*.

A total of four people with chronic, severe aphasia and their spouses were recruited to the main study, after providing informed consent to participate. All eight participants agreed to participate in the interview component of data collection. See Table 1 for the demographic details of the people with aphasia and Table 2 for spouse details (in corresponding columns).

**Interdisciplinary Community Aphasia Group**

**Study design**

We conducted a Phase I clinical trial investigating the efficacy of an Interdisciplinary Community Aphasia Group. The main study involved a mixed methods design (see [[30]] [citation removed to ensure blinded review] for the full study details and quantitative results; staff-specific qualitative results will be published in the near future). The study was approved by the La Trobe University Human Research Ethics Committee (application 15–008) as is registered on the Australian New Zealand Clinical Trials Registry (ACTRN12615000664549).

**Program**

The program, based on a manualized protocol, ran weekly for 2 h across 12 consecutive weeks at a metropolitan university communication disorders clinic. None of the research team, including group staff, had engaged with the participants in prior contexts. The group was designed to address living well with aphasia for people with aphasia and family members, and included a focus on all program elements within Rose and Attard’s definition [3] (see Supplementary Tables S1 and S2 for program schedule). All sessions included both the members with aphasia and spouses. The sessions were audio-visual recorded and involved a combination of members with aphasia-only, spouse-only, and mixed-group time (including breaks). The mixed and member with
aphasia-only sessions were generally facilitated by the first author (a speech-language pathologist experienced in communicating with people with aphasia—as part of her Ph.D. research). She was supported by a social worker experienced in working with stroke survivors, and two aides (a peer with aphasia who facilitates a peer-led community aphasia group, and a member of the community with experience in linguistic profiles of aphasia). In addition, three sessions involved facilitation by a yoga therapist, a music therapist, and an art therapist and peer with aphasia. The second author (an experienced social worker) predominantly facilitated the spouse-only sessions. Additional staff included a peer aide—a stroke survivor with aphasia who has facilitated other community aphasia groups, and an aide—a member of the general community. The first author facilitated a full day of training for the social worker and aides prior to the program and both briefing and debriefings were held for each program session (see [30] for further information). Program attendance was high (over 80% of sessions) for all dyads. The first author collected pre, post, and 1-month follow-up data for a range of outcome measures across all domains of the ICF; additional information about the Interdisciplinary Community Aphasia Group and the report of quantitative findings can be sourced from the main study paper [30].

Data collection

The eight interviews were conducted by two independent speech-language pathologists (primary interviewer: 7; secondary interviewer: 1) with experience in communicating with people with aphasia and collecting qualitative data. All of the interviews with people with aphasia and three spouse interviews were conducted face to face in participants’ homes, with one spouse interview conducted over Skype. The interviews were audio- and video-recorded. Within each dyad, individuals chose to be present for at least some of one another’s interviews. All interviews addressed members’ perceptions of the program (both in relation to themselves and their spouse) along with recommendations for improvement. A semi-structured interview schedule used with all participants (see Supplementary Material [questionnaire]) was developed by the first author and refined in collaboration with two speech-language pathology researchers experienced in interviewing people with aphasia. Each interview was conducted in one sitting at the request of the participants. The interviews with the participants with aphasia ranged in duration from 21 (Daisy) to 73 (Simon) min, and 30 (Fiona) to 40 (Heidi) min for spouses. The interviewers used “Supported Conversation of People with Aphasia” strategies during interviews with the people with aphasia. Supported Conversation of People with Aphasia includes the following key strategies: acknowledging that communication breakdown is likely during the interview process; making overt acknowledgment of the participants’ competence; introducing new topics both verbally and with key written words or pictorial representation if required; and writing key content down in large print on blank paper, with any pictorial representations as basic line drawings. Expression was promoted with the provision of keywords as options, picture scales to convey mood/level of agreement etc. (see Figure 1), and program content including photos of staff and members, and an aphasia-friendly program schedule. In addition, as each concept was explored, the interviewers checked their own understanding of the people with aphasia’s responses as well as the people with aphasia’s understanding. This included summarizing points one at a time and asking for verification with written and visual support throughout. Following the interviews, the primary interviewer completed brief audio-recorded reflections. The interviews were digitally transcribed by a professional transcription company and reviewed for accuracy by the first author. The first author digitally transcribed the interviewer’s reflections.

Table 1. Participant demographics for participants with aphasia (Simon, Daisy, Max, Ron).

| Demographic                | Simon A       | Daisy B      | Max C       | Ron D       |
|----------------------------|---------------|--------------|-------------|-------------|
| Age (years)                | 60            | 69           | 53          | 73          |
| Gender                     | Male          | Female       | Male        | Male        |
| Ethnicity                  | Anglo-Australian | Anglo-Australian | Eastern European | Anglo-Australian |
| Bilingualism               | No            | No           | Yes         | No          |
| Time post onset (months)   | 34            | 81           | 31          | 41          |
| Aphasia type               | Broca’s       | Wernicke’s   | Broca’s     | Broca’s     |
| Aphasia severity*          | 26.5          | 45.9         | 47.4        | 36.2        |
| Hemiparesis                | Yes           | Yes          | Yes         | Yes         |
| Mobility                   | Independent   | Wheelchair use | Independent | Use of cane |
| Current work               | Unemployed    | Retired      | Retired     | Retired     |
| Immediately pre-stroke employment | Full time | Full time | Full time | Full time |
| Past/current community aphasia group attendance | 3-month University-based community aphasia group; current informal aphasia lunch group | Limited (stroke group) | 3-month University-based community aphasia group; current informal aphasia lunch group | Limited (within first year post-stroke) |

*As measured pre-group using the Western Aphasia Battery-Revised Aphasia Quotient (Kertesz, 2007). All names are pseudonyms.

Table 2. Participant demographics for spouses (Melissa, Felix, Fiona, Heidi).

| Demographic                | Melissa A | Felix B | Fiona C | Heidi D |
|----------------------------|-----------|---------|---------|---------|
| Age (years)                | 57        | 72      | 41      | 71      |
| Gender                     | Female    | Male    | Female  | Female  |
| Ethnicity                  | Anglo-Australian | Anglo-Australian | Eastern European | Anglo-Australian |
| Bilingualism               | No        | No      | Yes     | No      |
| Current work               | Homemaker (unemployed), carer | Retired, carer | Homemaker, carer | Semi-retired (Employed part time) |
| Immediately pre-stroke work |          |         |         |         |
| Past/current community aphasia group attendance | Employed part-time | None | Limited carer-specific contact | None |

All names are pseudonyms.
Analysis

We selected the Framework Analysis approach [33], which involves five distinct phases (see Table 3). Microsoft Excel was used to compile the frameworks for the participants with aphasia and spouse data sets.

In the initial stage of identifying a thematic framework (Phase 2), the first author addressed a priori issues by collecting the themes, subthemes, and related key description words from empirical research papers exploring the community aphasia group experiences and perceptions of people with aphasia and family members (see Supplementary Tables S3 and S4). These papers had been identified through the systematic search strategy described by Attard, Loupis, Togher, and Rose (2018) [30]. The semi-structured interview schedule questions were added, and related items grouped together. Additional emergent themes from the transcripts and analytical themes were included throughout the Indexing phase, and in turn, the framework was iteratively reshaped and refined. In relation to rigor, we established the quality of our research through meeting the criteria of credibility, transferability, dependability, and confirmability described by Lincoln & Guba [34]. Credibility (that the results are consistent with participant’s views and researcher’s interpretations) included a member checking process throughout the interviews. Here, the interviewers (who are experienced in non-leading interviewing styles, particularly in the context of working among people with aphasia) used paraphrasing, asked yes/no and follow-up questions, and summarized ideas in an iterative fashion. Transferability (that the results are meaningful and transferable outside of the sample) is promoted by a thick description of the sample participants and Interdisciplinary Community Aphasia Group, along with triangulation with data arising from our social work and aide staff interviews (manuscript under review). Dependability (that the analysis process and the final research product is traceable and able to be scrutinized) and confirmability (that the results are closely linked to the original data) involved member checking of written summaries of the themes and subthemes. This involved the first author emailing the dyads a summary of the themes and subthemes (in aphasia-friendly form for the participants with aphasia) with the invitation

Table 3. Processes undertaken across the five key phases of Framework Analysis.

| Phase                                | Process undertaken                                                                 |
|--------------------------------------|------------------------------------------------------------------------------------|
| 1. Familiarisation                   | - Data immersion. Gaining an overview of the body of material by reading and re-reading transcripts  
                                         - Beginning the process of abstraction and conceptualization—listing key ideas and recurrent themes  
                                         - Recording analytic thoughts, impressions  |
| 2. Identifying a thematic framework   | - Drawing upon:  
                                         - a priori issues (those informed by the original research aims including topic guide and research notes [and themes from previous research])  
                                         - emergent issues raised by the respondents themselves, and  
                                         - analytical themes arising from the recurrence or patterning of particular views or experiences  |
| 3. Indexing                          | - labeling data in manageable “bites” for later retrieval and exploration (to be refined further)  
                                         - systematically applying the thematic framework to the data in its textual form—reading and annotating all data according to the framework  |
| 4. Charting                          | - "lifting" the data from their original context and rearranging them according to the appropriate thematic reference  
                                         - devising a matrix of “subject charts” with headings and subheadings, selecting illustrative passages  
                                         - abstraction and synthesis. Studying each passage of text and entering a distilled summary of the respondent’s views on the chart  |
| 5. Mapping and interpretation       | - reviewing the charts and research notes  
                                         - comparing and contrasting the perceptions, accounts, and experiences;  
                                         - searching for patterns and connections and seeking explanations for these within the data.  |

Adapted from Ritchie & Spencer (1994).
to respond with comments. Two dyads responded with the endorsement and two dyads did not respond.

Results

The members’ experience of the group comprises four major, overlapping themes: logistics, group dynamics and environment, impact, and evaluation. In addition, two overarching themes span across these for the spouses. The relationship is illustrated in Figure 2. The major themes are outlined below for members with aphasia, followed by the outline for spouses, and finally the overarching themes.

**Members with aphasia**

The major themes for the members with aphasia are shown in Figure 3 (note that logistics is labeled programming for these members). Themes representing the members with aphasia are marked with an A in the text. Illustrative quotes for each theme and selected subthemes are found throughout the text and in Table 4.

**Theme A1. Programming**

The male participants discussed the activities they enjoyed as well as those they were less interested in. Art was the most highly preferred activity, and the Life Book session was also perceived positively. Some enjoyed music, yoga, and iPads while others favored these less. Other areas addressed by fewer members include stroke and aphasia information content (viewed as "helpful" by Max), a preference for structured activities by Simon, and enjoyment of morning tea by Max. Daisy, in contrast, responded with ambivalence, describing "going through the motions":

"Interviewer: ... So when you think of these things [indicating written words], so we’ve got music, yoga, art, just general talking or communicating, and sharing. Were any of these things good [gesture: thumb up] or bad [gesture: thumb down]?

... Daisy: um, that’s just any mine [gesture: waves hand—‘whatever’], I just move in and then I think, all right [gesture: mimes sitting and looking ahead with expressionless face] like that."

**Theme A2. Group dynamics and environment**

Simon reported the group felt comfortable and friendly. All members with aphasia referred positively to the main staff and guest staff (also see Theme 3). Ron’s comments suggested he connected especially well with Christine, the art session facilitator, and associated with Greg, the aide, with a sense of humor. The experience of communication access varied: while Simon found content to be clear, the first three weeks of predominantly whole-group session time were characterized by confusion and difficulty understanding for Ron, making for a “bad” start to the program. In line with this, Ron’s experience of the program improved from week 4 onwards as it became easier to understand in the context of the smaller split group size. Regarding group format and dynamics/environment, while warming to the whole-group sessions over time, Ron preferred the split-group format because not only was it more fun and interesting, it allowed for more opportunities to communicate without the spouses’ input. In contrast, Simon and Max preferred the whole-group sessions as there were more opportunities to listen and the requirement for communicating was lower. While Max indicated the morning tea was a positive time where people socialized, Daisy’s experience of the group appeared to be characterized by disengagement overall:

"Interviewer: So did you feel that you were able to [writes] ... um ... interact or communicate with the other people?

Daisy: No [shakes head, frowns] no communication.

Interviewer: Okay. So you felt at week four that this was not really happening for you.

... Daisy: [shakes head] no, up communication at everybody ... [gesture: lifts hand—‘I don’t know’] ... that’s everything, is nothing, it’s no one and not everything, it’s not difficult, it’s [gesture: hand out to the side—‘whatever’/fine?/pushes air out with mouth]."
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Table 4. Members with aphasia themes: example extracts.

### Theme A1: Programming

_“Interviewer: Here we have Christine and John, you did art with them._

_Ron: Yeah, no—yes, [Points at images] /kn/ [Christine] and John._

_Interviewer: John? Yeah? You pointed at—_

_Ron: Okay [tapping the table to reinforce] [smiles]._

_Interviewer: So did you enjoy working with—?_

_Ron: Yeah, yeah._

_Interviewer: …with John?_

_Ron: Yeah. God. Christine was, oh, Jesus._

_Interviewer: So you found that [gesture thumb up] good, are you telling me?_

_Ron: Yeah, yeah.”_

_“Interviewer: … you also did things like music [writes] …_

_Max: Yeah [nods]_

_Interviewer: … and art [writes] … and Yoga [writes]_

_Max: Not … good [shakes head]”_

### Theme A2: Dynamics and environment

_“Interviewer 2: … You like the whole big group?_

_Simon: Yeah [nods]_

_Interviewer 2: Yeah. Why?_

_Simon: Uh … [points repeatedly to the group picture] [gesture: flips hand over—‘I don’t know’]_

_Interviewer 2: When you were a small group, was it a lot more you having to talk?_

_Simon: [laughs]_

_Interviewer 2: [laughs] So, am I right in thinking that the bigger group, you could listen more?_

_Simon: Yeah [nods]_

_“Interviewer: So I’ll put that word down, [writes] so if I put ‘confused’ down, do you think, um …?_

_Ron: Huge. Huge [points to word]_

_Interviewer: Yes?_

_Ron: Huge [points to word]_

_Interviewer: Okay. So this is a big one, confused?_

_Ron: Yes [nods]_

_“Interviewer: Okay. Yeah and not … so not have to talk?_

_Simon: Yeah “_

_“Interviewer: So I’ll put that word down, [writes] so if I put ‘confused’ down, do you think, um …?_

_Ron: Huge. Huge [points to word]_

_Interviewer: Yes?_

_Ron: Huge [points to word]_

_Interviewer: Okay. So this is a big one, confused?_

_Ron: Yes [nods]_

_“Interviewer: Okay. Yeah, yeah._

_Ron: Yes, ok, [points to weeks] okey dokey. Okay but ooooh Jesus, oh, God. [shakes head]_

_“Interviewer: So a lot, a lot … … going on?_

_Ron: Yes. But, [points at image 2 on picture scale] okay, okay [puts hand over his face] [bewildered facial expression] oh, God [nods]_

_Interviewer: Mm-hmm, yep. Did you feel like you understood?_

_Ron: [shakes head] no”._

### Theme A4: Evaluation

_“Interviewer: … Would you [writes] recommend the group to other people with aphasia?_

_Daisy: [nods] mm. Yeah [shrug] [indiscernible] would go and do the movies, [indiscernible] okay [shakes head], and then we’ll be very good. …_

_“Interviewer: … Yeah. So, for you, you’d had enough of the group?_

_Daisy: Yes [nods] boof._

_“Interviewer: For other people, if you meet them, with aphasia—_

_Daisy: good [indiscernible] very good, they can say it ([stay i.e., go). That’s all right if they wanna go, let them go, but [indiscernible] [shakes head] [puffs air out with mouth]”_

_“Interviewer: … so based on your experience of the group with Michelle [speech-language pathologist], do you think it’s a good model for groups in the community?_

_Max: Yeah [nods]._

_“Interviewer: Yeah, so if you met somebody with aphasia would you recommend it to them?_

_Max: Yes [nods]._

_“Interviewer: You would._

_Max: Yeah. … “Interviewer: What, for you, if you told somebody else, [gesture: thumb up] “yes, go to the group”, and they said to you, “why should I go?” [gesture: hands up ‘why’], which thing do you think you would point to as being very important?_

_Max: People._

_“Interviewer: So actually meeting other people with aphasia._

_Max: Yes”_

### Theme A3: Impacts

The members with aphasia referred to a range of impacts for themselves associated with attending the Interdisciplinary Community Aphasia Group. Max associated his overall group experience with feeling “positive”. He benefited from connecting with others through meeting people and having conversations. Despite Daisy’s suggested experience of disengagement, she highlighted making friends as an outcome. Feeling supported was common across the other three participants; with references to sharing and learning, and Simon and Ron feeling connected to and inspired and motivated by the peer aide, Don:

_“Ron: … Yes, but okay [points at image of Don, peer aide] no, but [points] yes. Right, okay, yes [points] okay. Ah. _

_Interviewer: So when you were in—are you telling me—just by the way you’re saying that, are you telling me that you felt a bit inspired?_

_Ron: Yes, yes [smiles] [gesture: puts hand out to Interviewer—‘you’ve got it’]._

_“Interviewer: Inspired, is that the word we’re looking for?_

_Ron: Yes. Yes, yes._

_“Interviewer: Right. Because you had the opportunity to meet Don…_

_Ron: Yes [gesture: thumb up] okay_

_“Interviewer: You felt inspired, or motivated perhaps?_

_Ron: Yes, yes._

_“Interviewer: Like, “Wow, look at him.”_

_Ron: Right-o [gesture: thumb up]”._

As noted in Theme 2, Simon had positive communication experiences, with the staff contributing to his engagement with effective supported communication; while Ron’s communication experience began negatively and became more positive. In relation to communication changes, Simon perceived an increase in his spoken words while Max felt this remained stable.

Next, the members with aphasia shared a large range of comments reflecting positive participation experiences. These reflected enjoying and feeling stimulated by activities and interactions, as illustrated by Max:

_“Interviewer: so what do you think about the group?_

_Max: Feeling … uh … better [nods]_

_“Interviewer: So, you’re feeling, so positive feelings?_

_Max: Yes [nods]_

_“Interviewer: So, if you look at this picture here [shows picture scale] … … when you think about the group …?_

_Max: [points to image 5] Positive._

_“Interviewer: You feel positive about the group?_

_Max: Yeah [nods]_

_“Interviewer: So for you, all of these things [shows all words on paper: activity, doing something, meeting people, sharing, learning]_
For Ron, the art session was his first experience of painting and using pastels, and something he would likely not have tried outside of the group; while Simon, who painted avidly before his stroke, was pleased at reconnecting with this activity. In addition, Max indicated an increase in independence through participating, while Simon referred to feeling encouraged to try more things including art, meeting people, and talking outside of the group. Initially, Ron did not wish to attend, doing so at the encouragement of his wife and existing speech-language pathologist, though he gradually became more comfortable and enjoyed participating. Daisy, too, suggested that her husband instigated their participation; though unlike Ron, she would rather not have attended (nor be attending their existing weekly community-based social group for retired professionals).

Finally, members discussed impacts within the area of identity, such as increased confidence (including for Daisy), as well as mood, including feeling happier and more motivated. In contrast, Daisy felt a mix of responses, associating both image 4 on the picture scale as well as the word “angry” with her experience. A small number of comments pertained to the members with aphasia’s perceptions of their spouses’ gains from the Interdisciplinary Community Aphasia Group; the most common was receiving as well as giving support and understanding. Perceived benefits specific to one or two spouses were: improved communication skills and patience, participating in new activities, feeling happy, and learning.

Theme A4. Evaluation

All the members with aphasia perceived the Interdisciplinary Community Aphasia Group to have value and would recommend others attend such a group. Ron agreed with the Interviewer’s proposition that members new to groups could benefit from reassurance:

*Interviewer: …… and, you know, maybe that’s important for us to let other people know as well…*

*Ron: Yes, yes [nods]*

…*Interviewer: It can get better…… … At the beginning it’s all new, meeting new people, new activities …*

*Ron: Yes [nods]*

*Interviewer: It’s all—it can be very overwhelming.*

Only Daisy indicated she wouldn’t attend a similar group in future; this was based on her experience of group interaction as “bad” more broadly. Recommendations for improvement came from each of the men. In terms of programing, these included: having more time on Life Book work, omitting yoga, having more frequent combinations of art, yoga, and conversation, adding sport-based activity, and adjusting the format of the initial sessions to promote increased understanding. Preferences regarding dose were mixed, with Simon keen for longer and more frequent sessions, and Max open to fortnightly sessions of the same duration rather than weekly.

Spouses

The major themes and subthemes for the spouses are shown in Figure 4. Themes representing the spouses are marked with an S in the text. Illustrative quotes are found throughout the text and in Table 5.

Theme S1. Logistics

Subtheme 1. Programming content and format.
The spouses referred positively to the activities overall, highlighting in particular, the focus on Life Books and the art session. They discussed the relationship between programing and the purpose of the group, and whether this was commensurate with or different from their expectations of the program. For instance, Heidi described it as “different”, including alternative approaches to communication and addressing “life skills” as opposed to the communication impairment-based focus she had been anticipating. Similarly, Felix discussed a focus on socialization and conversation rather than improving verbal output. Take-home materials were viewed as helpful for aiding memory (Fiona) and providing a “good framework” in relation to Life Book content (Heidi), while Felix noted a lack of follow-up around Action Plan task reflections he had been completing throughout the program. When discussing some programing elements Melissa and Heidi seemed to perceive that the model was in some ways fixed with the belief (in the context of a research trial) there were particular goals to be addressed or something specific being studied. However, this did not necessarily appear to be perceived as negative.

Regarding the spouse-only sessions, Fiona was the only spouse to refer to expectations, indicating that she had imagined they would receive more support-related information given a social worker was involved. There were mixed responses to the format. Heidi had perceived the group’s primary focus would be to support the spouses with aphasia and thus was disappointed at not being able to observe the member with aphasia-only sessions more frequently (see also Overarching theme 2). Similarly, Felix
Theme S1: Logistics

1. Programming content and format:
   ‘…the idea of having a Life Book… I thought, ‘how didn’t I come up with that, thinking of that… earlier?’…’ Michelle [speech-language pathologist] showed us the video, the lady [with aphasia], that how she did painting to explain her situation… like, Life Book, and I found that interesting…” (Fiona)

Theme S2: Group dynamics and environment
   ‘Always very welcoming when you’d go in. You know, always, ‘Hello’, ‘how are you?’, ‘would you like a coffee’, ‘come over here’, ‘you know’, ‘would you like this’, ‘I’ll get the chair for you’, ‘I’ll put the cushion under your [arm]—very caring, very caring of everyone’s different needs, so they really made us at ease” (Heidi)

Theme S3: Impacts
1. For self: “Felix: So, my general impression as I said was that the activities were… nothing new… but as I said I enjoyed the experience of it. There’s a difference between gaining something and just enjoying what you’re doing.
   Interviewer: And having some pleasure from the experience? Felix: Yeah. Exactly”

2. For spouses with aphasia: “… I think it’s a learning experience [for Ron], you can get into a different group and you can make some connections there” (Heidi)

Theme S4: Evaluation

1. Value of Interdisciplinary Community Aphasia Group model: “… um… we had more… personal time … with [the Interdisciplinary Community Aphasia Group], it was more um… it was more the carers— I mean, when we used to go to the groups with Simon at [place], nine times out of ten, we’d go away and just come back and maybe have half an hour at the end [to observe]. So if the carers came in you, you didn’t really didn’t get a chance to talk to them and find out what life was like” (Melissa)

2. Recommendations for improvement: “Fiona: … I thought we’re going to have all this information about the carers and all that… something more for carers… you know, like information where we can get help or… you know… Interviewer: So some more sort of practical assistance, you would have liked that? if that could have been something added into it. Fiona: [nods] if we had” “… in a way, I think it would have been much better even if we were sitting there watching what [the people with aphasia] were doing [in the split sessions]… So that it was more open, that you actually got to experience what they experienced, as well, because I’m sure… that we didn’t get much of an opportunity to see, say, Greg [aide] and Michelle [speech-language pathologist] interacting with each—the four people” (Heidi)

experienced dissonance given his desire to support Daisy to communicate:
   “…I’m happy to do a separate session, but I wanted to know what Daisy was doing in her session—that’s only from my point of view because I know… she struggles, and I want to be there for her, I suppose that’s what it is. However, maybe she needs that, so she doesn’t keep turning and relying on me—it’s just a mixed emotion, that’s all.”

In contrast, Melissa and Fiona perceived the spouse-only time as wholly positive for both themselves and their spouses with aphasia. Heidi’s concerns also related to the focus on life narratives including the topics of “life before the stroke” and “the stroke event”, which she was not comfortable revisiting. The remaining spouses were positive about the content covered within their split sessions, as illustrated by Felix: “… I think… the sessions that I was with the other… carers were helpful” (see also Theme 3, 4).

Subtheme 2. Staff.
   The spouses conveyed a sense of value in the staff team and referred to each individual positively overall, acknowledging their specific input linked to their roles and professional backgrounds as well as their personal qualities (more in Themes S2–4, Overarching theme 2).
   “having um… Greg [aide] there was great. It was good to sort of speak to him from what his background in linguistics is. We had a lot of talks about um… how hard it is to make a sound… once you’ve had a stroke (Melissa)

Subtheme 3. Location and scheduling.
   Two of the spouses living close to the venue referred positively to the group location, while the two who had a farther distance to drive noted the tediousness of being caught in traffic and that much of the day was taken up with travel. They considered the session length to be ideal, though in terms of program duration two were happy with 12 weeks and two were more partial to an ongoing program.

Theme S2. Group dynamics and environment
   The spouses reflected on a range of aspects of the group dynamics and environment, which were positive overall. In relation to the members, Felix described diversity in professional and personal backgrounds while Melissa referred to commonalities. Spouses described the Interdisciplinary Community Aphasia Group as “a good group” that “gelled quite well”, and that once they got to know each other everyone was “lovely”, “caring”, and “friendly as anything”. Heidi described a mix of structure and flexibility in Michelle’s [speech-language pathologist] facilitation style. Also linking to the staff member’s qualities (Theme S1 subtheme 2), members felt welcomed, valued, and well looked after. However, Melissa and Heidi acknowledged that Don’s (the peer aide) high expectations and recurring encouragement to focus on rehabilitation could be “a bit off-putting” at times (see also Overarching theme 2). Nevertheless, Melissa referred to differences of opinion as a healthy occurrence within the group:
   “You know… … ‘I don’t agree with that,’ or ‘I haven’t found that in my… or our process,’ I think that was good. You can’t all be the same, so…

The group was also described as “relaxed” and informal, particularly in relation to break time where members could “chat”. Felix highlighted his distinct efforts to interact with all the members with aphasia, though perceived limited engagement between the members with aphasia themselves. The atmosphere of the spouse-only sessions was mixed overall. Spouses felt that they were able to discuss anything and express any emotion freely without any judgments. At the same time, one spouse perceived another to dominate the interactions (as well as during whole-group time), Felix noted feeling a little uneasy as “the only bloke”, and for Heidi (as noted in Theme S1 subtheme 1), experiencing her peers cry and swear and having to re-live “the bad times” in the context of life narrative discussions was unpleasant and contributed to a feeling of “being psychoanalyzed.”
Theme S3. Impacts

Subtheme 1. For self
The spouses highlighted a range of impact areas through their own attendance at the program. Participation was raised most commonly, with a mix of positive experiences shared by one to two spouses each. These included looking forward to the group each week, trying new activities and having fun/enjoying them, experiencing a positive change of routine, maintaining engagement around the group focus, and having “personal time”. Two spouses noted that participating disrupted managing other roles/obligations and usual participation preferences for the day. With regards to interpersonal relations and socialization, spouses described meeting new people, getting to know one another, and forming bonds, as well as enjoying conversation and laughs together. Two spouses conveyed a desire to continue socializing with the group outside of the research program. Support was experienced through gaining knowledge about resources in the community, as well as hearing and learning from one another’s sharing (addressed further in Overarching theme 2) in a space of mutual understanding and acceptance. For instance, Fiona describes the group’s response to her black humor:

… I say … I say ’I’m going to kill Max’ maybe … at least three times a day. But I can’t say that to people who don’t… you know? But in the group, I said that and… everybody laughed. If you say to someone else, “I’m gonna—” I say three times a day, and say, 'What’s wrong with [you] that you’d like to kill him?’ [laughs].

In relation to communication skill, the women highlighted the benefit of exploring different ways of communicating and applying these at home. For example, Heidi described experiencing a shift in communication-based expectations about “what is important”, feeling “affirmed” that she and Ron could maximize his strength for drawing to improve their interactions. Identity was another area of focus, with two spouses discussing, reflecting on their and their spouse with aphasia’s situations and preexisting perspectives (see Overarching theme 3 for more). This was to some degree linked with the experience of positive feelings such as hope and an acknowledgment of progress, as well as difficult feelings (including during spouse-only sessions, which have been addressed for Heidi and Felix above).

Subtheme 2. For spouses with aphasia
Perceived gains for the spouses with aphasia mirrored the aspects raised in Subtheme 1. Everyone felt their spouses enjoyed the group activities. Felix noted the contrast between Daisy’s report and his own observation of her participation:

… Daisy loves singing… she used to be in the choir and she used to love it. They had this singing thing [in the group] and when you ask her… she didn’t like it… but she did, I mean, you just gotta look at the movie [clip] of it [that Michelle, speech-language pathologist, shared in the last session] [chuckles]

Additional points of interest across one to two members include having a sense of purpose through participation, including working towards a product through the art session and Life Book project; experiencing pre-stroke activities as well as trying new activities; developing a routine of independence with getting to the room; and having increased participation options such as art classes and choir to explore in future. References to existing transfer were mixed. For instance, Melissa observed Simon “doing more things” including pre-stroke activities; while Fiona described Max’s indifference to her recent suggestions to try new activities, and Heidi suggested Ron’s social networks and overall independence remained stable given their tendency to stick to a routine.

Spouses also highlighted the benefit of opportunities for the members with aphasia to communicate, with the overall perception they engaged well within the group. Fiona felt Max socialized more there given his ease with the others, relying less on her; similarly, Heidi attributed Ron’s growing comfort levels with the staff’s welcoming nature. Three spouses indicated the Interdisciplinary Community Aphasia Group focus was “not really speech oriented” and anticipated that gains in verbal output for their spouse with aphasia would be unlikely. However, Melissa reported observing increases and Fiona discussed receiving positive feedback from close others. Finally, identity-based gains included feeling motivated and empowered, and a sense of hope through participation and social comparison (see Overarching theme 2 for more).

Theme S4. Evaluation: Something for everyone, though not a one-stop shop

Subtheme 1. Interdisciplinary community aphasia group value
All spouses stated they would recommend the Interdisciplinary Community Aphasia Group to others. Their sense of value in the program was related in part to it meeting some or all expectations and/or leading to positive outcomes. Different areas of value included: the researchers’ goal to develop a manual for guiding future community aphasia group facilitators; having a peer aide as part of the staff; having the opportunity to explore whether “there was anything there” for their spouses with aphasia regarding different activities; experiencing enjoyment and pleasure in participating irrespective of other gains; learning; and the program’s holistic foci in “looking outside the square” to address a broad range of areas of life beyond “speech skills” as well as involving family. Despite Felix’s appreciation of the focus on socialization and activity engagement, he was interested in a model aiming to increase conversation practice for people with chronic, severe aphasia. In terms of its context, Heidi valued it specifically “as something added to what we’ve already been doing” from a communication therapy angle. Similarly, Fiona took the approach of wanting to “participate in everything” that may have potential benefit. Melissa raised its likely usefulness for supporting people earlier post-stroke “to know that, you know, other things are out there for people” and that “it’s changed, but it’s not the end”. For Fiona, the group’s finite nature was a limitation of its value (also see Subtheme 2 below; the Overarching themes address content from the present subtheme in more detail). Spouses also contextualized the model by contrasting it with limitations of previous groups their spouses with aphasia had attended, including where the family was not involved or the composition was not aphasia-specific.

Subtheme 2. Recommendations for improvement
All suggestions for adjusting the program related to logistics and were highly individual. Elements included staffing (adding another peer aide to the staff); location (closer to home); and scheduling (feedback covered a mix of options for session frequency, program length, and time of day). Program content was discussed most. Spouse-only session recommendations (each raised by one spouse) included: omitting focus on stroke/aphasia experience, additional opportunities for open discussion and sharing about practicalities and resources (with less of a need for direct facilitation), and additional resources from the social worker. General program content recommendations with a focus on communication (from one to two spouses) included: adding the opportunity to observe their spouses with aphasia engaging in session
Spouse overarching theme: Therapy and recovery

1. Role of peers: “…having people with the same problems as Daisy has, I think that helps her in realizing that … that there is a way ahead and that there are other people with the same problems that she has, and they’re learning to cope with it and so it might help her to learn to cope as well” (Felix)

2. Spouse views: “…sometimes I have that time when I don’t want to do exercises with [Max], I don’t want to practice anything with him, I just want to be by myself …”; “…you say—they can’t move their hand but they don’t want to, they can move their leg but they don’t want to and they can talk but they’re just too lazy to try … it’s hard to understand … how hard is for him to express himself” (Fiona)

“…they [health professionals] gave no hope for [Daisy] whatsoever. And I was lucky enough to be given the book by Norman Doidge; I read it, and so I applied strategies from the spouses” (Don)

Spouses shared different views relating to therapy and recovery. Impairment was explored as a barrier (by all but Melissa). For some, addressing communication and/or physical impairment and maintaining hope for improvement was a primary issue—though this sat in the context of other, seemingly dissonant views, including awareness and/or views that progress can be stilted “if you don’t keep up” with therapies; recovery outcomes are uncertain and everyone is different; mechanisms for regaining expressive language are not clearly established; speech-language therapy does not focus sufficiently on restoring language function; and variables such as chance and spouses with aphasia’s drive/wishes also play a part. Fiona also conveyed the challenge of balancing her hopes and expectations with trying to understand Max’s situation and allowing herself “me time”. Some referred to goals around their spouse’s improved communication, with Felix conveying the responsibility he had taken over the past 7 years for assisting Daisy to make continued gains himself. Speech-language therapy was discussed as highly valuable (“I would take [Max] to speech therapy every day [if it were possible”]; Fiona). In relation to gains expected from the Interdisciplinary Community Aphasia Group, Felix and Fiona noted their low initial expectations were in part “since it was a research group” (and thus efficacy was not established), and “assisting others in the future” was Felix and Daisy’s primary motivation for joining the study. As noted in Theme S1 and S4, Heidi’s expectations based on previous speech-language therapy for “number one: more articulation, more expressive” from the Interdisciplinary Community Aphasia Group were not met “but from that we’ve gone in a different [and nevertheless positive] direction”.

Subtheme 2. Spouse views

Comments from the subtheme above and others still link to aspects of both the spouses’ and their partners’ sense of identity, which includes various forms of coping and adaptation. Here we outline some illustrative examples. Several of the spouses highlighted their partner’s intelligence in the context of their communication impairments, and described aspects of communication strength (including compensatory strategies) and limitations which in turn facilitate or hinder participation. They referred to activities and participation, both shared and undertaken individually. For instance, Heidi described Ron’s mix of existing social networks and activities along with a busy therapy schedule in addition to her own work roles: “I’m not just Ron’s carer. And his...
wife”. As “Max doesn’t do much” in contrast to a very involved pre-stroke work life, Fiona described her directive approach in encouraging his participation, though she conceded this was not always successful. She considered Max’s focus on returning to his work at the cost of participating in alternative activities to be overly rigid and perhaps unrealistic, though acknowledged that optimism and hope are important coping mechanisms:

> [previously] I wanted to—[encourage Max to try painting] and he was like, ‘off’ [dismissive gesture]. I think he’s just too, yeah. Too concentrated on his… profession, that’s the only thing that he wants to go back and do, nothing else… … he thinks he doesn’t have a problem, he thinks everything is fine, or just pretends, I don’t know, he’s very positive, that’s the good thing that’s helping him… get through this

An additional coping mechanism Fiona described was the couple’s tendency to “leave things to the past”—in relation to both earlier life experiences (such as the dire circumstances leading to their migration to Australia) and the stroke event. Despite this, Fiona had “no problem expressing my… emotions” in the spouse-only sessions given the sense of universality she felt; and Melissa considered sharing and discussion to be part of the coping process. In contrast (as noted in Theme S4), Heidi was wholly in favor of not “dwelling on… those bad times”. The notions of loss and growth were also discussed regarding their current situations. For instance, Heidi acknowledged one benefit of looking back: “it probably makes you realize things aren’t quite so bad now”; Melissa described viewing the stroke and aphasia as “a bump in the road”; and Felix and Fiona reflected on the experience of loss, including emotional reactions such as regret and black humor. Finally, some of the spouses addressed various barriers they face. These included feelings of worry regarding their partner’s health and limited communication independence, others’ behaviors or responses to their partner’s aphasia, and a need for therapy services that were inaccessible (private/outpatient speech-language therapy) or limited (community aphasia groups).

**Discussion**

This paper reports on the experiences of people with severe aphasia and their spouses attending the Interdisciplinary Community Aphasia Group program. The findings depict an interaction between logistics, and group dynamics and environment creating impacts, through which members evaluated the program. An overarching area in the spouses’ experience pertains to therapy and recovery.

**Factors mediating impacts of Interdisciplinary Community Aphasia Group**

**Logistics, and group dynamics and environment**

The members with aphasia’s experience of logistics were specific to programing, while the spouses addressed additional aspects. To our knowledge, the present study is unique in exploring both people with aphasia’s and spouses’ own experiences of involvement in community aphasia groups, as well as their perception of their partner’s experience. These combined sets of perspectives allow for additional depth in understanding of the experience and impacts of community aphasia groups. Previous community aphasia groups participants have highlighted activities that are varied and stimulating as well as needs-based and tailored to serve as facilitators to accessing community aphasia groups [9] and managing existing participation barriers [11,21]. All Interdisciplinary Community Aphasia Group members favored the art session and identity-oriented Life Book work. Such activities enable creativity and self-expression, and the powerful opportunity to explore, affirm, and represent aspects of the past, present, and future. Importantly, this is done in a concrete fashion without a reliance on language, thus promoting inclusion and access for individuals with communication impairment [35]. References to the activities as enjoyable, exciting, and motivating (along with the recommendation that these be extended within the program) highlight the sense of purpose, empowerment, and value people with aphasia were able to derive. This is also particularly the case, given the activities were novel (or had not been undertaken by members in some time). Similar positive outcomes are reported in the qualitative community aphasia group literature for both structured and/or project-based biographic activities including group sharing (as the primary focus) [12,36] as well as other participation-based activities [11,15,37,38]. At the same time, the potential for personal reflection to raise difficult emotions has been acknowledged [12], with other studies reporting members perceiving sensitive topics as barriers [11] or recommending they be removed [39]. In practice, incorporation of biographic activities in current group practice is difficult to quantify: while a survey study of Australian speech-language pathologist’s community aphasia group practice suggests “telling personal stories” and “sharing biographical information” occurs in over 90% of the 86 active groups, the format and level of structure is unclear [3]. In addition, non-verbal leisure and creative pursuits including art were reported as present in less than 15% of the groups [3].

While the opportunity to socialize was highlighted by most members, spouses with needs regarding their partner’s improved verbal output acknowledged these were not addressed by the Interdisciplinary Community Aphasia Group. It is possible that these expectations were in part based on previous experiences with 1:1 or group speech-language therapy. While the members with aphasia did not refer to communication skill gains overall, most spouses described the inclusion of communication strategy-based programming as helpful and reported some changes in the way they now view and/or use communication with their partner. Similar experiences of the latter have been described by members of community aphasia groups dedicated to family members [39–42] and some for people with aphasia [15,22,43], suggesting that a greater communication skills focus in the Interdisciplinary Community Aphasia Group may have further increased benefits. Little reference was made to the stroke and aphasia information provided in the group, though the spouses’ desire for content regarding practical services and supports within the chronic stage supports existing literature [44–46].

Experiences of logistical elements such as location and scheduling reflect existing findings [11,12,23,36], along with the difficulty in achieving a combination that suits most [3]. Members reported a mix of format preferences and needs. Simon and Max’s rationale for favoring whole-group sessions supports other findings regarding people with moderate and severe aphasia [26], while (as for Ron) small-group time can facilitate the propensity for member inclusion [11,38]. Spouses’ experience as centered on the people with aphasia, including a desire to support their partner during communication breakdown/speak on their behalf and oversee/gain additional insights into their interaction and participation, has been described in qualitative research investigating significant others’ experience of aphasia and rehabilitation [47] and reflected in qualitative community aphasia group research [11,15,41]. However, the benefits of having dedicated family member time with peers (as described by Fiona and Melissa, who expressed greater support needs) are also commonly noted.
Other aspects of group composition were discussed only briefly, with both similarity and diversity perceived positively; however, this area is complex, with a mix of stakeholder views in the literature [11,26,36]. Positive references to staff reflect the importance of relationship-centered experience, with strong links to group dynamics and environment. Indeed, effective leadership; engagement and investment in the group; and positive interactional style and personality (all described by Interdisciplinary Community Aphasia Group spouses) are recognized as key factors of shaping community aphasia group culture [26]; and staff friendliness and understanding [11] and members having trust in the therapy team [25] have been deemed important facilitators to community aphasia group participation. However, the challenge of establishing “joint aims in therapeutic relationship” has been acknowledged in the context of family emphasis on verbal communication and holistic speech-language pathology approaches to living with aphasia [20]. In contrast, the poor communication access Ron experienced in early didactic Interdisciplinary Community Aphasia Group sessions mirrors staff-based barriers reported previously [11,26]. Along with Heidi’s feeling of “being psychoanalyzed” in some social worker-led sessions, such experiences could, for those perceiving more risks than benefits, contribute to withdrawal. In addition, the strong value that members placed on the peer aide’s inclusion reinforces the valuable role people with aphasia can contribute to mentoring and support [13,38,48]. Community group type (including facilitator type, group composition, and programing) is a variable found to produce different outcomes as perceived by people with aphasia and family members [15]. While peer-led community aphasia groups have been reported to a small degree [15,23,24], health professional and peer collaboration appears even less common [5]. The phenomenon of peer facilitators expecting (with good intentions) others to adopt a similar narrative or coping style (e.g., that of a “fighter”) and its potential to be counterproductive to peer support has been described [49]. The different responses Interdisciplinary Community Aphasia Group members had to the “restitution” narrative [50] our peer aide shared, may have been in part contingent on their own narratives. Indeed, reflections on, or evaluations of, community aphasia group participation naturally connect with the broader life narrative, including experiences with the health system and coping and adjustment processes [21,24,39]. For instance, Felix’s account reflects a desire for the hope that, in contrast to earlier experiences of health care during Daisy’s recovery, Don’s approach appeared to reinforce. Other experiences occurring at the time of the program may have also contributed to member responses; for instance, Heidi described competing for physical needs and health issues as a major focus in Ron’s life that Don had potentially discounted.

Next, members also indicated that contributions to a relaxed and non-threatening environment came not only from staff but from fellow members as well as suitable structures. For our members and others in the community aphasia group literature [11,51], the latter is particularly associated with the morning tea break. This offered particular opportunities for members to share, learn about one another, and connect. Lanyon and colleagues [26] describe the use of ritual and structure, including regular opportunities for sharing and partaking in a refreshment break, as an important factor associated with community aphasia group member perceptions of cohesion. However, the dominance described by one Interdisciplinary Community Aphasia Group spouse regarding another represents an imbalanced interactional pattern potentially contributing to the opposite. Examples of problems with community aphasia group discourse equality experienced by members with aphasia also exist in the literature [13,26]. Of interest, the notion that the mixed-group structure may contribute to a degree of reduced responsibility for communication on the part of members with aphasia was viewed positively (Simon’s preference for large-group time) as well as negatively (Felix’s perception of limited interaction between members with aphasia).

**Interdisciplinary Community Aphasia Group value**

Previous community aphasia group studies have reported program value as a theme [13,21]; this is reinforced by the present findings where members based the Interdisciplinary Community Aphasia Group’s perceived value on the impacts they derived. The spouses entering with needs additional to/other than impairment-based gains tended to report on a wider range of benefits overall. For others, membership appeared motivated and defined by their partner’s communication impairment (for Felix, this linked to contributing to research towards improving others’ outcomes). The Interdisciplinary Community Aphasia Group’s value was thus framed based on this absence and reframed based on other—sometimes unexpected—impacts. Experiencing community aphasia group activities as exemplifying living well with aphasia and the associated novelty of this is also reported by Purves [38]. In line with this, as demonstrated by Mumby and Whitworth [52], part of the Interdisciplinary Community Aphasia Group’s impact appears to relate towards contributing facilitators that mediate the barriers raised (in this case by spouses regarding themselves and their partner with aphasia) in their narratives. Next, in relation to whether they would attend a similar group again, spouses demonstrated a process of weighing up the benefits in the context of various personal and environmental factors (e.g., needs; group programing, scheduling, and location), as has been reported for people with aphasia [25].

**Clinical implications**

The present study’s findings offer many implications for clinical practice. The most prominent is people with aphasia’s and family members’ need for community aphasia group services to support living with chronic aphasia [11,21,23]. While not unexpected, the finding that groups like the Interdisciplinary Community Aphasia Group offer something for everyone but are not a one-stop shop [14] reinforces the issue that aphasia rehabilitation faces more broadly. Not only is there a paucity of community aphasia groups, intensive and/or 1:1 speech-language pathology service is also highly limited; given the desire for 1:1 therapy [11,38], access to each of these services would likely allow for the composite benefit. Given the inherent barriers here, at least in relation to community aphasia groups, there is the need to proliferate a range of groups that meet a range of member needs (including impairment- and functional communication-based goals) across a range of geographical areas, allowing members to attend multiple groups to suit their preferences. Such proliferation would also likely reduce the scheduling and transport issues common to many [25].

Experiencing hesitancy in relation to community aphasia group attendance appears somewhat common for people with aphasia [25], and particularly so for those with severe aphasia [27]. People with aphasia may make the decision to attend community aphasia groups primarily at the initiative and/or encouragement of a significant other or speech-language pathologist; such
environmental influence has the potential to serve as both a facilitator and a barrier to participation [25]. As illustrated by the cases of Ron and Daisy, this may lead to differing outcomes and evaluations of the group experience. Having a sense of members’ feelings and concerns as they come into a group can help staff minimize barriers where possible [25] and optimize the dynamics and environment to be reinforcing, with the aim of helping to develop people with aphasia’s sense of group value and ownership. Given the important role that time and “gradual integration” play in allowing members to find their place in a group, getting to know one another, and identifying relevant benefits [25], it is likely that this becomes less feasible with shorter running groups. As members with aphasia (severe or otherwise) are more likely to participate in community aphasia groups when they can identify tangible benefits [25], an awareness of potential mechanisms for member dissatisfaction with community aphasia groups may assist in identifying members who may perceive greater levels of cost than benefit in attending. Daisy and Ron are examples of individuals who perceived a “high cost” associated with community aphasia group attendance. In contrast to Ron, Daisy did not appear to experience a shift in motivation and view of group participation (community aphasia-based and otherwise) over time. For some individuals, groups will never be desirable. It is important to tease out the causes of dissatisfaction or lack of motivation, and whether any adjustments in group processes could optimize the experience. In addition, to promote the participation of people with severe aphasia and the group’s capacity to serve as a bridge to community access [52,53], including more accessible and meaningful verbal and non-verbal activities alongside traditional activities is suggested (e.g., photography, book club, outings). Facilitators may draw on existing aphasia-friendly biographic-based activities [35] or, where present, the expertise of other staff including art and occupational therapists, and community integration and leisure teams.

Community aphasia groups also offer an ideal opportunity to address the personal and relational needs of significant others [47,54,55]—needs which may not be properly addressed earlier in the rehabilitation continuum [47]. However, including family members as genuine recipients of rehabilitation appears to require a balance between encouraging (1) family members to experience guilt-free focus on themselves, as well as to meet their own and people with aphasia’s needs for the latter’s independence and autonomy, in order to minimize burden and increase quality of life; and (2) acknowledging their caregiver role and associated protection and participation needs and benefits [11,47,55,56]. Focused communication skills training as part of a broader program is indicated as a key consideration for the latter. Further, a greater balance of mixed- as well as split-group time may allow spouses to observe members with aphasia interacting with one another (with appropriate scaffolding from the staff but without direct spouse support), as well as allowing these members the opportunity to undertake both speaker and listener roles. The contribution to communicative acts and demonstration of competence associated with the active listener role often assumed by people with severe aphasia has been discussed as part of recent findings exploring this subpopulation’s group experience [27]; it may benefit both spouses and members with aphasia to have the value of different roles explicitly acknowledged throughout a program. In addition, as suggested through this research, incorporating people with severe aphasia into mixed-severity groups with appropriate structures may better reinforce a range of communication roles for all members [25].

Next, the present findings, as well as existing research [39] regarding member expectations and preferences for topic coverage, highlight the need to reinforce the rationale for and negotiate community aphasia group programming and format prior to commencement. This will help to make clearer “the intention and potential benefits” [47], with an ongoing dialog to check the relevance and appropriateness of these aspects in the context of members’ needs. Indeed, in community aphasia groups that are somewhat structured, it may be beneficial to reinforce the capacity for programming flexibility with members over time to promote feedback and suggestions for adjustment during the program. Obtaining a more detailed sense of the experiences of members with severe aphasia could be achieved by offering a short rating scale questionnaire for completion after each/selected sessions, based on relevant concepts accepted by members before the program (e.g., overall experience of session; facilitators to group participation: I had opportunities to communicate; the staff were friendly and helpful, etc.).

In community aphasia groups with a mix of health-professional, peer, and volunteer facilitators present, it is possible the various benefits associated with each type (e.g., as depicted by Rotherham [15]) are merged. A range of staff types appears useful to members. While arguments for the benefits and outcomes of both professional and peer facilitation exist in the aphasia and other caregiving literature [41,57,58], the support and understanding and opportunities for social comparison that are unique to peers’ position contribute particular value in the context of limited speech-language pathologist person-power.

Recommendations for future research

While challenges associated with interviewing people with severe communication impairment have been acknowledged [59], the voices of individuals from this subpopulation are important and must continue to be shared. Our study sample is small; understanding in more depth the experiences of individuals representing a broader range of demographics (including, for significant others, other family members and friends; and for members with aphasia, comparisons and contrasts of particular group experiences across various aphasia types and severities) will build generalizability of the findings and further inform the contexts for optimal group processes for different members. Future research could include explorations of member experiences both at community aphasia group commencement and at various time points [39] including, where applicable, group attrition, as well as within existing ongoing/block-based community aphasia groups [11,23,37].

Conclusion

While not “a one-stop shop”, the Interdisciplinary Community Aphasia Group model has overall acceptability as perceived by four members with chronic, severe aphasia and their spouses. Members’ preferences varied regarding logistical components including staffing and program format, duration, and content; these aspects appear to directly influence member perceptions of the group dynamic and environment, and impacts for the self and spouse. With the capacity to adapt program elements as required, the Interdisciplinary Community Aphasia Group model has feasibility in clinical practice for contributing to living well for people with chronic aphasia and their spouses. Integration/metasynthesis of results from quantitative and qualitative investigations will provide a more complete picture of the efficacy and
utility of community aphasia groups for this heterogeneous population living with a chronic communication disability.

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