

Connection and Cohesion in a Co-designed Virtual World: Experience of Online Aphasia Groups

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Abstract. People who have aphasia report having reduced social networks and social activity. This paper introduces and explores experiences in EVA Park, an accessible multi-user virtual world, co-designed with people with aphasia. The study reports 16 people with aphasia taking part in virtual world social support groups in EVA Park, exploring their experience through self-reported measures of connectedness, structured observations of cohesion, and interviews. Self-report outcomes suggest that virtual social support groups fostered feelings of social connection and observation analyses indicate consistent evidence of group cohesion across time. Interview outcomes reveal largely positive experiences of being part of an aphasia group in the virtual world but caution that such groups should represent an addition to and not a replacement for real-world connections. Findings suggest that social support groups delivered in a co-designed virtual world, offer users with aphasia a space in which to foster consistent levels of social connection.

Keywords: Aphasia, Virtual Worlds, Social Connectedness, Group Cohesion.

1 Introduction

1.1 Aphasia

Aphasia is a language disability. It occurs because of damage to the brain due, for example to a brain tumour, head injury, dementia or, most commonly, stroke. At least a quarter of stroke survivors acquire aphasia [9]. Aphasia affects speech, reading, writing and the understanding of speech. Symptoms vary across individuals but can have a devastating effect on everyday communication such as conversation, following TV and radio and accessing social media.

Aphasia has many negative consequences: for example, it affects social engagement and quality of life. Interventions have been developed that aim to improve social and emotional outcomes in aphasia, such as social support groups. These aim to foster social connections and enhance wellbeing.

There has been increasing interest in delivering such aphasia support groups online, spurred on by the Covid-19 pandemic and the widespread acceptance of online video-

conferencing platforms as part of our everyday technology landscape in the post-pandemic world. Pitt et al [10, 12] showed that aphasia social support groups run on a video conferencing platform were feasible and acceptable to service providers. Virtual reality (VR) platforms have been used successfully with other communities for online support groups, e.g. see [3], but have not previously been used for people with aphasia. This work explores participants' experiences of connectedness in aphasia groups within the co-designed virtual world EVA Park.

1.2 EVA Park

EVA Park is a multi-user virtual island that was co-designed to be accessible to people with aphasia. The environment was co-designed with five collaborators with aphasia through a series of 10 co-design workshops which took place over 12 months [18]. It has a range of locations, including houses, a restaurant, a café, bar, health centre, hair salon, open green spaces and a tree house. It is not a sophisticated "game" environment; rather it is an engaging online space where users, represented by personalized avatars, can meet and communicate via voice and text. EVA Park includes water features and fantastical elements, such as a Tardis and planetarium.

Quirky features aim to promote humour and stimulate discussion, for example, the lake is home to a giant yellow duck and a mermaid can be found beneath the surface. Users of EVA Park communicate synchronously through speech or typed messages. The co-design process influenced the choice of settings for conversation, simplified the nature of interactions and led to a strong shift from the implementation of functional spaces such as a clinic to the inclusion of more playful elements. Accordingly, several features support and encourage collaboration between users. There are spaces that encourage groups to gather because there are seats for avatars such as sun loungers by the lake, the café, pizza restaurant and tree house (see Figure 1 for examples). Similarly, interactive features, such as display boards, the disco and musical instruments, encourage people to gather to do something. Users can animate their avatars using a range of pre-programmed gestures, such as a wave, dancing, and an elaborate belly laugh; these are frequently used to amuse others or to communicate without words. Simplified navigation features, such as the "home" button which transports the user's avatar back to the town square and a map to find other avatars, help groups to gather.

1.3 Aims of This Work

This study explores the experience of aphasia support groups within EVA Park. Specific research questions were:

1. Do people with aphasia perceive that EVA Park social support groups foster social connections and does this change over time?
2. Is there cohesion in EVA Park social support groups for people with aphasia and does this change over time?
3. What is the experience of people with aphasia of participating in EVA Park social support groups?



Fig. 1. Two scenes from online aphasia groups in EVA Park. 1: Group members seated on sun loungers, discussing life with aphasia. 2: Talking in small groups in the café.

2 Methods

We undertook a study with support from four real-world community aphasia groups to address the research questions. The groups were designated as Jupiter, Saturn, Mercury and Venus, and were based in different geographical locations in the UK. For participant recruitment the real-world group coordinators invited their existing members to take part in online virtual groups. In some cases, participants knew each other prior to the virtual group. However, contacts who could not travel to real-world groups were recruited and recruitment was widened if numbers were not reached. Thus, each virtual group had a range of known and unknown members. A separate, larger study with these groups has elsewhere investigated the feasibility of running online support groups to promote wellbeing for people with aphasia [8]. Using rating and interview data here we examined whether participating in support groups in EVA Park promoted feelings of social connection, for example with the other group members, and analyses of sessions explored social cohesiveness. The study was given ethical approval by the Ethics Committee of the School of Health Sciences, City, University of London (Language and Communication Science Proportionate Review) LCS/PR/Staff/16-17/06. All participants gave informed consent. The study was registered with ClinicalTrials.gov (NCT03115268)

2.1 Participants

Each community group included between six and nine people with aphasia (34 in total), at least one Coordinator (6 in total) and two volunteers (10 in total) [8]. Four people with aphasia were randomly selected from each group to participate in the study reported here (16 people in total). 6 female and 10 male participants took part. Participants' mean age was 61 years (range: 40-77), mean time post stroke was 56 months (range: 9-192), and mean Aphasia Quotient 70 (range: 42-96) [The Western Aphasia Battery [6] is a standardized assessment of language which can be used to calculate an

individual's 'Aphasia Quotient' on a scale of 1 to 100. Lower numbers indicate higher degrees of language impairment]. An Aphasia Quotient score of 70 indicates moderate aphasia. For example, while able to talk the person may experience word finding difficulties and struggle to produce grammatically correct sentences. Word comprehension is relatively retained, but understanding of complex sentences and discourse is likely to be impaired. For reference, the mean aphasia quotient for the community group as a whole (i.e., all 34 participants in the wider study) was 74 (range 42-96), indicating that the aphasia levels of the sample included here are representative of the wider group.

2.2 Groups Procedure

Each group met for 14 sessions in EVA Park over a period of 6 months. Sessions lasted around 90 minutes (21 hours in total) and each group was facilitated by trained volunteers who followed a pre-devised program of activities. Group members with aphasia accessed EVA Park using a computer in their home. Coordinators and volunteers accessed EVA Park from either a computer in their home or from a computer in their community centre. Everyone was represented by a personalized avatar.

All groups followed a programme developed by a research team, specified in a manual, which provided detailed session plans. Each session addressed a specific topic. The first session introduced EVA Park. Several sessions enabled group members to share their experiences of living and coping with aphasia. Other sessions aimed to stimulate social connections and provided opportunities for group members to express opinions and convey aspects of their personality, for example These topics included 'Comedy', 'Music', 'Art', 'Literature' and 'Eating Out'. In the final session, group members reviewed the program and had a party in EVA Park.

Sessions were held in various locations in EVA Park and made use of features such as animating avatars and playing video clips on media screens in the virtual world. In addition to attending fortnightly group meetings, group members were able to drop-in to EVA Park at any other time.

2.3 Data and Analysis

Each of the 16 participants in this study was visited at home at two time points (T1 and T2). The T1 visit took place during session 2, 3, 4 or 5. The T2 visit took place during session 11, 12 or 13. 12 of 16 participants completed visits at both T1 and T2. Three participants dropped out of the study before T2. One participant completed the wider study but opted not to complete the T2 visit.

At each time point, researchers collected session screen recordings and interview data as follows:

1. A self-report measure of the participant's connectedness to others, using social connectedness circles (based on [17]). This is a visual representation of social connectedness, appropriate for participants with a communication impairment. Participants rated their connectedness to other people in their group and to the volunteers who ran the groups by pointing at a pair of circles which overlap to a greater or lesser

extent. Mean ratings for self-reported connectedness to other group members with aphasia and to volunteers/facilitators were calculated for both time points.

2. An interview about the participant's experience of the session. Participants responded to questions using rating scales and short answer responses. Interviews were audio-recorded and short answer responses transcribed. Means were calculated for rating scale responses and qualitative short answer data were summarized into categories for reporting.

To ensure the accessibility of the interview and self-reports, all researchers conducting data collection were trained speech and language therapists, experienced in supporting the expression and understanding of people living with aphasia. Using established aphasia data collection methods, all questions were read aloud by the researcher and presented alongside visual support such as a pictorial rating scale [4, 13]. If necessary, questions were repeated and/or rephrased in simplified language.

Group cohesion:

Screen capture videos were analysed for group cohesion (RQ2) by an independent researcher using a protocol described by [16] and adapted from [2]. Eighteen screen capture recordings were included in this analysis with three ten-minute segments selected from each one (at minutes 10-20, 40-50 and 70-80), giving a total of 54 excerpts.

Using a standard operating procedure [15], excerpts were rated by a researcher blind to the study design and time point. Ratings for each excerpt were made on 6 dimensions, using bipolar scales (table 1).

The end points of the dimension scales were labelled with contrasting characteristics (e.g. withdrawal (negative) vs interest (positive)) and ratings ranged from -5 to -1 on the negative side of the scale and from +1 to +5 on the positive side of the scale. Zero indicated that the researcher found no evidence of the characteristic. The researcher coded excerpts using a detailed reference list of behaviours [2]. Following coding, an average rating score for each dimension was calculated for all sessions from T1 and for all sessions from T2.

3 Results

3.1 Research Question 1: Social Connectedness

Participant self-report: social connectedness circles

Comparison of ratings for perceived connectedness to other group members with aphasia at the early time point ($M = 4.08$, $SD = 1.44$) and the later time point ($M = 4.85$, $SD = 1.63$) indicate a significant increase in perceived connectedness over time ($t(12) = -2.245$, $p = 0.044^*$). Comparison of ratings for perceived connectedness to volunteers/facilitators at early ($M = 5.08$, $SD = 1.75$) vs late ($M = 5.69$, $SD = 1.60$) time points demonstrates an increase which is not significant ($t(12) = -1.075$, $p = 0.303$).

3.2 Research Question 2: Group Cohesion

External rating: global cohesion

Using the external rating scale reported by [15] we see mean outcomes for all 6 dimensions were in the positive range (i.e. between +1 and +5) as opposed to a negative range (from -1 to -5). See Table 1. This suggests observable evidence of the 6 positive components of each dimension: Interest and Involvement, Trust, Cooperation, Expressed Caring, Focus and Group Cohesion.

Video data, however, included more evidence for some dimensions than others. There was most evidence for observations pertaining to dimension 6 (Fragmentation vs Cohesion Rating), which was observed in 85% or more of the video excerpts. In contrast, only 37% or less showed evidence pertaining to dimension 3 (Disruption vs Cooperation).

Table 1. Mean ratings for each dimension of the Group Cohesion measure at T1 and T2, percentage of data points where evidence was observed for each dimension and change in mean rating over time for each dimension. 1. Withdrawal and Self-absorption vs Interest and Involvement; 2. Mistrust vs Trust; 3. Disruption vs Cooperation; 4. Abusiveness vs Expressed Caring; 5. Unfocused vs Focused; 6. Fragmentation vs Cohesion.

	1.	2.	3.	4.	5.	6.
T1 Mean rating (SD) and % of data points with evidence	3.45 (1.71) 81%	3.67 (1.40) 56%	2.44 (1.81) 33%	3.31 (1.38) 48%	4.10 (1.45) 78%	3.09 (1.44) 85%
T2 Mean rating (SD) and % of data points with evidence	3.85 (0.88) 96%	3.53 (1.33) 63%	2.70 (1.70) 37%	2.92 (1.62) 44%	4.12 (1.37) 96%	3.46 (0.90) 96%
Change in mean rating over time (T2-T1)	+0.39	-0.14	+0.26	-0.39	+0.02	+0.37

If we consider average ratings for these dimensions at early vs late time points, we observe marginal changes between T1 and T2 in both negative and positive directions. This indicates relative stability of the observed positive cohesion over time.

Dimension 6, (cohesion) is only the dimension where there was evidence for 85% or more data points at T1 and T2. An independent samples t-test reveals no significant difference between observed measures of global cohesion at T2 versus T1 ($t(36) = -1.102, p = 0.28$) indicating that the cohesion observed at T1 is maintained at T2.

3.3 Research Question 3: Experience of Participating in Virtual World Social Support Groups

Participant Experience: Interview data

All 16 participants completed the initial interview at T1. 12 participants completed it twice at T1 and T2 (three had discontinued the wider study and one completed the study but opted not to complete the final interview).

Question 1. “How does this compare to being in a group meeting in real-life? (not on the computer)?” Interview data show a mix of feelings about how the online experience compares to the real-life group experience.

Table 2. Examples of responses to interview question 1.

Computer group better	Real life group better	Computer and real life similar	Computer and real life different	Other
<p>“This is better. We can take time. I can talk to [Jupiter group member 1] more than in real life.” (T1)</p> <p>“EVA Park is better because it's closer contact than to travel.” (T2)</p>	<p>“[real life Mercury group] group is better. Much better speaking and listening [real life Mercury group] best. Sometimes I listen and talking a little. Don't know what's different. Computer speaking difficult. Understanding others and being understood is better at [real life Mercury group]” (T2)</p>	<p>“Found real-world group and EVA Park group good. Not really any differences. Probably slightly better at the face-to-face group but EVA Park still very good. Not quite the same relationship as in the real world. I seem to be able to speak more easily in EVA Park” (T2)</p>	<p>“Very different. Face to face group tight - know beforehand. Here 'loose'. this is 'see what comes up' explore thinking” (T1)</p> <p>“Different. Not in a good way or a bad way. Just different” (T1)</p>	<p>“If I was in EVA Park non-stop and I didn't go out of the house, I'd be a hermit. I like what it does but only for a short time.” (T1)</p> <p>“Computer, headphones, OK, talking, talking, better, better.” (T2)</p> <p>“Pub. [being in EVA Park is] like being in the pub having fun.” (T2)</p>

Q2. “How do you find being in EVA Park with your group? (1. Not Like > 5. Like)” Participants rated their experience positively at both time points (mean of 4.67 (SD 0.65) at T1 and 4.50 (SD 0.90) at T2). Differences between time points were not significant. Comments largely related to other people or the space: “Helpers are good, and people are good. Not scared of anything.” (T1); “Very good yes, supportive everybody.” (T2). One participant identified that the sound in the group context sometimes made things difficult: “More sound issues and more difficult when in the larger group compared to the smaller group.” (T2).

4 Discussion

The language disability aphasia negatively affects a person's social connectedness [5], and quality of life [7]. Interventions that support these are a priority [14]. This study explores the extent to which EVA Park aphasia groups can foster social connectedness, allow group cohesion and provide positive experiences. Here we discuss responses to our research question and consider the wider implications of these findings.

4.1 Research Question 1: Social Connectedness

Data from social connectedness circles reveals that participants felt connected to their fellow group members in the virtual world setting and also to the volunteers leading the group. Participants experienced a development in the strength of their relationship with peers during the course of the group sessions.

4.2 Research Question 2: Group Cohesion

Our second research question asked whether cohesion was observed in the VR social support groups and whether this changed over time. On the 11-point scale (running from -5 to + 5) all scores were comfortably within positive range, with none of the means falling below 2.44. Thus, cohesion was clearly observed. The final domain, 'Fragmentation/Cohesion', has been described as a global measure of cohesion [16], and here mean scores were above 3. The final cohesion score reported by Tarrant et al for a weekly, face-to-face singing group was also just over 3. It is encouraging that we achieved similar levels of cohesion in a group that only met remotely in VR.

4.3 Research Question 3: Experience of Participating in Virtual World Social Support Groups

When asked about their perspectives of the virtual group vs real life groups, some participants favoured a real-life group experience, and some preferred the virtual world group. Others highlighted differences and similarities between the two contexts. The mixed responses here indicate that both real-world and virtual world groups have a place in supporting people with aphasia to connect and each might convey its own benefits and challenges. When asked how they found the experience of being in EVA Park with other group members with aphasia most participants responded positively - largely justifying this in relation to their connections to other people in the group. This suggests that it is the space for connection with other people that the virtual world provides which is perceived as most valuable – beyond the novelty of the space on its own.

4.4 Fostering Connections in the Virtual World

Given our data, we can conclude that the VR environment was not a barrier to cohesion. Rather, features of EVA Park may have been facilitatory. In interviews, some group members commented that they gained confidence from being in the VR environment and felt able to communicate more freely there than in the real world.

4.5 Challenges of the Virtual World

Despite our generally positive findings, there were negative comments from some group members. For example, some experienced communication barriers in EVA Park, or commented that they preferred face to face interactions. Many of those who enjoyed meeting virtually also emphasized their appreciation of face-to-face meetings. These comments underscore the need for diverse provision in aphasia, and the value given to

‘traditional’ face to face contact. Our data suggest that technological applications, such as using VR, offer a valuable means to augment rather than replace this contact, perhaps indicating a case for hybrid models which include both.

4.6 Wellbeing in the Virtual World

Early work exploring how in-person social support groups impact wellbeing has been done by [1] in Australia, who propose that the mechanism that mediates change in psychological wellbeing is “opportunities for support, learning and communication”. Positive preliminary findings have been achieved in language and wellbeing from a videoconferencing-delivered aphasia group [11]. This study goes some way to show that these opportunities for support and connection are possible online in virtual spaces where participants are represented by avatars.

4.7 Limitations

The data represent a sample of perspectives from a wider group cohort, and it is important to recognize that they do not cover all sessions for all participants taking part. Findings therefore may not capture the full range of perspectives and experiences encountered. Nonetheless, global cohesion findings for the group data appear to echo those within a separate study of face-to-face singing groups for people with aphasia [16], indicating the presence of sufficient data to capture group cohesion effects observed elsewhere. It is also worth noting that participants in this study generally had mild or moderate aphasia (with a mean aphasia quotient of 70). Those with a lower aphasia quotient, who are more severely impaired might struggle to communicate in EVA Park, particularly if they have minimal speech. Future research with EVA Park might explore take up with a wider range of participants.

5 Conclusions

A co-designed, accessible virtual world such as EVA Park can offer a space to foster connection and an experience of group cohesion for people with aphasia. Participants in our study used this space to learn about others and connect with new people. Findings illuminate the valuable contribution a virtual world can offer to augment social connection for people with aphasia.

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