

# AphasiaWeb: A Social Network for Individuals with Aphasia

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## ABSTRACT

With the rise of social networks like Facebook and Twitter, it might seem that our opportunity to communicate with others is limited only by our access to smart phones and computers. However, most social networks are not designed with complete accessibility in mind. In particular, these networks' chronological organization of news items, abundant feature sets, and busy presentation can make these tools unusable to individuals with aphasia, an acquired language disorder that compromises an individual's ability to speak, write, and recognize language. This is unfortunate, as one of the primary means of managing aphasia is to keep individuals in community. To counter this, we have developed AphasiaWeb, a social network designed exclusively for keeping individuals with aphasia and their friends and families connected. In this paper we describe the social network and share findings from a two-month trial program conducted with a local aphasia support group.

## Categories and Subject Descriptors

K.4.2 [Computers and Society]: Social issues—*Assistive technologies for persons with disabilities*

## Keywords

aphasia, social networks

## 1. INTRODUCTION

Aphasia is an acquired language impairment often associated with stroke or head injury. Affected individuals have difficulty speaking, writing, and comprehending. In contexts of high language input, such as crowded social settings or complex web pages, this difficulty is made especially prominent. Individuals with aphasia are likely to withdraw and experience a decrease in friendships [9]. As a result, they are

at risk for social exclusion [20]. Currently, socially-focused approaches are being used to manage aphasia, with a particular emphasis on placing individuals in "authentic, relevant, and natural contexts" [21].

With the explosion of social networking technologies like Facebook and Twitter, it would seem that the opportunities for individuals with aphasia to stay socially connected are increasing. However, based on the findings of human-computer interaction researchers [15] and on our personal experiences in a local aphasia support group, most software is not aphasia-aware. Non-intuitive terminology, non-topical organization, crowded layouts, and small user interface elements limit these networks' usability [4].

Despite the current limitations of mainstream social software, we believe social networks present real opportunities for minimizing social exclusion. A primary benefit of an accessible social network would be feelings of connectedness that extend beyond the successful face-to-face treatments currently used for managing aphasia. Group therapy sessions are common in managing aphasia, as they provide members with opportunities to be socially active in a natural environment and with a support system that may improve the individual's psychosocial functioning [10]. The authors hold an annual aphasia summer camp, which offers attendees a chance to meet others with aphasia. Given that campers come from a broad geographic region, attendees find it difficult to keep in contact with others after the camp is over. A free and accessible social network would allow these individuals to grow and maintain relationships with these support groups.

In this paper we describe AphasiaWeb, an early implementation of an aphasia-aware social network. The network is made accessible through an app for tablet devices. The app was designed in a participatory fashion with input from a group of four individuals with aphasia. It supports the exchange of topic-oriented communication through textual and photographic posts, to which members may respond with comments. A two-month trial study with seven participants was conducted to determine the network's usability and effectiveness.

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## 2. RELATED WORK

Most previous work falls under two categories: using technology specifically to manage aphasia and the human factors that describe how individuals with aphasia interact with technology in general.

### 2.1 Assistive Technology

Technology has frequently been used to manage aphasia. Modern mobile devices installed with software that facilitates communication allow users to maintain their independence and avoid social exclusion, two of the primary features Newell et al. [18] identify as hallmarks of supportive technologies.

#### 2.1.1 Applications for Independence

Early work by McGrenere et al. [16] evaluated prototypes of aphasia-aware software for mobile devices. Participants reported that they could not read long streams of text like those found in recipes. This led the authors to develop a recipe book app, which replaced ingredient text with pictures, and a planner [17], which annotated each calendar event with photographs of the place and people associated with the event. AphasiaWeb similarly makes heavy use of visual imagery. Icons and shared photographs guide users through interaction.

#### 2.1.2 Applications for Communication

AphasiaWeb is in some sense an augmented and alternative communication (AAC) system, which guides users through a conversation with audio and visual prompts. A comprehensive treatment of AAC systems is given by Beukelman and Mirenda [5]. Kane et al. [13] describe an AAC system specific to aphasia. Their TalkAbout system runs on a mobile device and provides context-aware prompting. In a cafe, for example, the device's screen will automatically present the user with words related to ordering coffee. The system provides audio and visual cues that guide the user through a conversation. AphasiaWeb similarly relies on photographs and coherent organization of discussion topics to facilitate conversation. However, the two projects have very different motivations and therefore very different feature sets. AphasiaWeb's primary goal is to support asynchronous online communication, whereas TalkAbout targets face-to-face synchronous communication.

Daemen et al. [8] describe a system for telling stories through pictures, sounds, emotion icons, and written annotations. Each participant in the study responded differently to the software, revealing the difficulty of designing a comprehensive system to manage aphasia. For example, one participant valued sound as the most important input method, while another favored pictures. As AphasiaWeb is intended for asynchronous and not face-to-face communication, we do not currently support audio recording. We do expect this to change in a future release.

Many other mobile AAC systems have been developed [23, 4, 3, 22, 14]. AphasiaWeb is distinct from these earlier works in that its major premise is to provide an online community. We considered the findings reported in these works in our design, but our application is to create a communication channel for individuals with aphasia.

### 2.2 Human Factors of Aphasia Technology

Researchers have also used technology to gain insight on the impacts of aphasia. For example, Nicolau and Jorge [19] measured the typing performance of 15 elderly adults on mobile devices. The most encountered error was omitted text, with spaces between words being the most frequent omission. In some cases, omissions were caused by multiple simultaneous touches on the screen. Based on these findings and our own formative study with participants, we've targeted third-generation iPads because of their high-quality speech recognition capabilities. We have not evaluated if speaking the text reduces error rates. For traditional typed input, AphasiaWeb currently makes use of the device's native software keyboard and does not try to correct any errors.

The current focus in AphasiaWeb's development is to provide an accessible commons. Members enter the commons to share of themselves and read and see what others have posted. Currently, no effort is made to ensure that the content is appropriate and error-free. However, Kalman et al. [12] suggest that there are significant, identifying features present in the online writing of individuals with aphasia. Future versions of AphasiaWeb may attempt to detect and address these features.

## 3. DESCRIPTION

The development of AphasiaWeb consisted of two primary phases: design using a participatory action model and implementation of the application.

### 3.1 Participatory Action Design

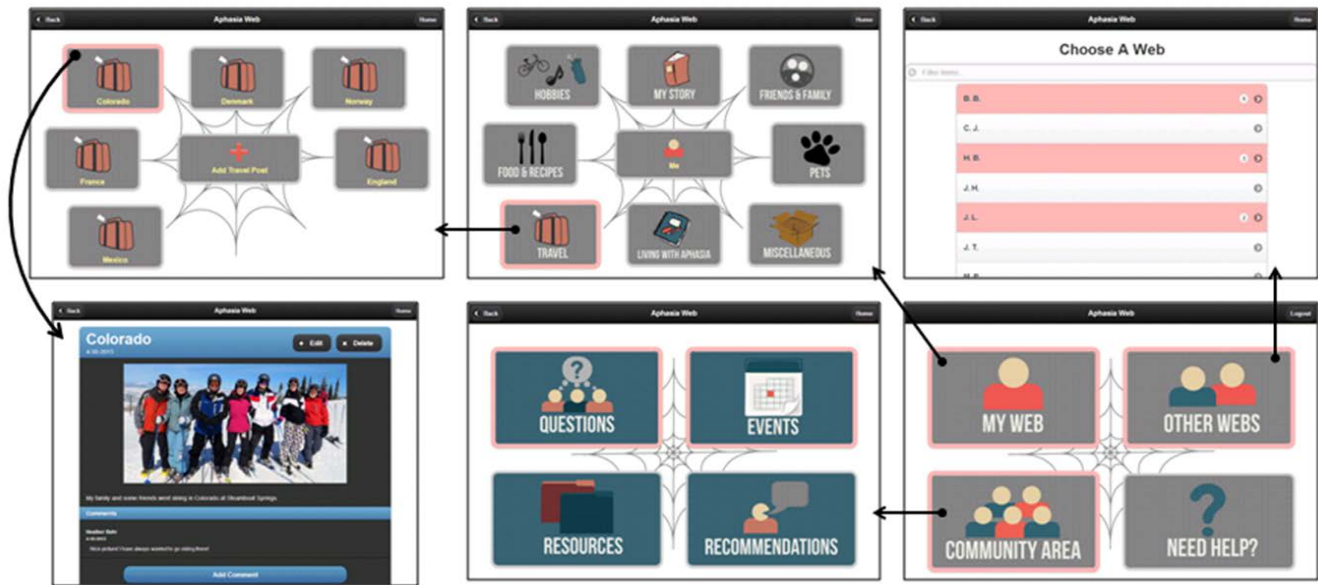
In designing the application, we employed the use of a participatory action model by including four individuals with aphasia in the design process. We gathered their input in a pre-design interview, designed the interface and developed an initial prototype, and then visited them again for their input midway through the implementation process.

#### 3.1.1 Pre-Design Interview

The pre-design interview provided us with insight in how to manage logging in, maintain users' privacy, and structure the layout of our application.

Since using pictures has been proven helpful for individuals with aphasia [4, 17, 13], we considered an alternative to a typed login password: a keypad of pictures which a user would tap on in the correct order to log in. However, when this option was posed to the participants, they indicated that whether the password was a string of letters or a string of pictures, they would have to write it down to remember it. We did not test this empirically, though password usability has been extensively researched [6]. More important to our participants was that the app would allow them to save their password after a successful login, so that when they revisited the app they would not have to log in again. AphasiaWeb incorporates this capability.

Another topic discussed in the interview was privacy within the social network. The participants stated that they would like to be able to decide which other users could see their content. Several options for supporting this were discussed, but we ultimately decided to exclude privacy control from



**Figure 1: Final user interface in AphasiaWeb.** The bottom right screen is the home screen, which is seen immediately after a user logs in. From this screen, users can navigate to another user’s web to look at (top right), to the community area (bottom middle), to a page of tutorial videos (not shown), or to the user’s own *webpage* (top middle). In the user’s webpage, she can select a category, bringing up a category web (top left) where posts for that category fill the web. Finally, the user can add or click on a post to view it and any comments that have been added (bottom left). Highlighting and alternate shading guide users to newly-added or edited content.

AphasiaWeb because we viewed it as a possible barrier to open communication. Consequently, content added to AphasiaWeb is currently visible to all AphasiaWeb users. For future releases, we intend to further evaluate privacy control.

Dialog at the interview provided much insight into the overall design of AphasiaWeb. Essentially, we asked the focus group what they wanted in the application, what features they would use the most, and what they would find the most helpful. Their responses directly inspired features eventually built into AphasiaWeb. The group said the most valued aspect of the application would be the ability to connect with other individuals—specifically those with aphasia. This is not only a feature, but the purpose of the application. They wanted to be able to ask and answer questions and participate in discussion relevant to the aphasia community. This led us to create a Community Area in AphasiaWeb. Further, the group expressed a desire to share their individual stories, describing how they acquired aphasia and how they have managed and coped with it. To facilitate discussion in these two areas, we created sections My Story and Living with Aphasia in AphasiaWeb.

A final capability they requested in the app was having multiple modes of input. They wanted to express themselves, and therefore needed the ability to do so in the form that worked best for them. AphasiaWeb allows for image uploads and text input. We specifically targeted the third-generation iPad, as it supports high quality speech recognition. Whenever the native keyboard appears in any app,

users can instead speak into the microphone and have their speech translated into text. We intended to support the recording and uploading of videos as well. This feature was not completed in time for our trial, through we expect to implement it for the next release.

### 3.1.2 Interface Design

Following the interview, the authors determined the encompassing design of the interface and the core features comprising the application. Since non-topical organization and crowded layouts are known limitations of current social networks’ usability [4], goals of our interface were to provide topical organization and a non-crowded layout.

The design process began by examining Facebook pages on a large computer screen. The challenge stared back at us: how does one take the social networking functionality exemplified by Facebook on a large screen, and redesign it to be very simple, clean, and not so heavily congested on a small iPad screen? The answer came to us when considering how communication can be facilitated with individuals with aphasia. The authors had described a communication technique they use with aphasia patients known as *written choice*, a method of conversation in which patients are asked questions and then provided with anticipated written choices to choose from [11]. We retain this concept of guiding a conversation by asking what the user wants to accomplish on a given screen and providing options of actions for the user to take.

We considered this guided methodology only necessary when users were adding or editing content in AphasiaWeb. Accordingly, we laid out the process of editing a post or comment in a chronological series of questions, such as “What will the title of this post be?” and “What type of post will this be?” with options for text and photograph provided. Our initial formative evaluation led us to this question-and-answer type navigation throughout the application, but later evaluation of this design—described below—resulted in this navigation not being used throughout the application.

Originally, the four core communication areas that were to be supported in the application emerged directly from the feedback of the participant pre-design survey: My Story, Others’ Stories, Questions for the Community, and Community Conversation. These areas would allow users to add and edit their own stories, view other users’ stories, pose and answer questions in the community, and participate in community discussion. However, our evaluation of these very loosely-defined areas showed that they did not fit the guidance model.

First, we were concerned that the Community Conversation area was too general to stimulate actual conversation. Topical organization has been shown to help facilitate conversation [4], but the original requested areas were vaguely defined. Accordingly, the Community Conversation area was removed and categories were added to a user’s story. Beyond just telling her story, a user could also make posts in a number of other categories, like Friends and Family, Hobbies, and Travel. Adding categories provided the topical organization which we expected would help guide conversation.

Second, we expected that with only four conversation areas, users would have to navigate too much chronological content. Research into visual communication with individuals with aphasia led us to an alternative to chronological display of content: a web. Individuals with aphasia prefer viewing an array of information in a circular, web-like format as opposed to a chronological list [7]. Thus, we invoked the use of a web-like interface wherein each user has a *webpage*. In a user’s webpage, there are eight categories under which content can be added. Selecting a category brings the user to that category’s web for that user, in which the user can add a new post, view posts he or she has already added, and view comments that have been added on these posts. An illustration of these webpages can be seen in the final implementation interface in figure 1. The web concept not only inspired the layout, but also the theme and name of the application.

Another problem we considered was how to guide users to new content. By highlighting areas containing new content, users can follow the highlights to either a new or edited post or a post with a new or edited comment. This creates a truly guided experience for users as it steers them clearly to areas of interest within the application. This highlighting is illustrated in the final implementation interface in figure 1.

At this stage of the design, a prototype was implemented. We then showed this prototype to the focus group and requested their feedback.

### 3.1.3 Mid-Design Interview

Demonstrating the prototype to the focus group confirmed our design reasoning. However, the individuals were concerned about the various categories and knowing what to put in them or how to follow them. They were especially concerned about the Questions for the Community area, because they wondered, “What if I want to post something for the community that is not a question?” This discussion produced a Community Area broken down further into four categories for the community: Questions, Events, Resources, and Recommendations. Each of these categories has its own web in which all users can add posts, view posts, and add comments. The participants also determined the final categories included in the user webs: Hobbies, My Story, Friends and Family, Pets, Miscellaneous, Living with Aphasia, Travel, and Food and Recipes.

## 3.2 Implementation

Following the design process, AphasiaWeb was implemented with the user interface depicted in figure 1. The AphasiaWeb client software was developed using JQuery Mobile [2], a framework for designing mobile webpages, and Apache Cordova [1], a tool which lets developers convert web-based apps into native ones—which have access to the cameras frequently found on mobile devices. Behind the scenes, a central database stores posts, comments, and other user data.

## 4. RESULTS

To evaluate AphasiaWeb, we released it to a local aphasia support group for a trial run. Following the trial period, we calculated various usage statistics to determine the effectiveness of the application.

### 4.1 Trial

Seven individuals with aphasia agreed to participate in the trial of AphasiaWeb. Each of the participants was given an iPad with the application already installed. We showed them how to view, add to, and edit their webs, view others’ webs and comment on others’ posts, and enter and contribute to the community area. The participants used AphasiaWeb for a two-month trial period.

The participants were recruited from two regional aphasia groups. Ages varied from early 30s to late 60s, and both sexes were represented. Severity of aphasia varied across participants, as did the time elapsed from stroke or precipitating event. However, the majority of participants were at least a few years post-stroke. In the authors’ experience, this variance is typical for an aphasia support group.

### 4.2 Quantitative Results

After the trial period ended, we collected the iPads from the participants and analyzed their use of AphasiaWeb. We examined how they used the application in several ways.

We first looked at each user’s activity of adding posts and comments throughout the trial. The total posts and comments added per day is shown in figure 2. This activity timeline show that the participants definitely used the application, as there were posts and comments added throughout the trial.

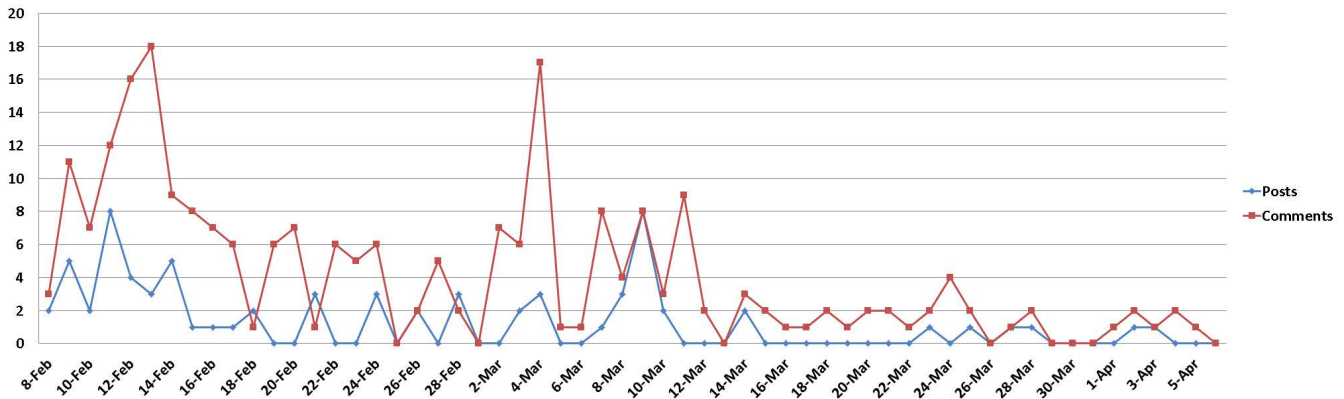


Figure 2: Posts and comments inserted into AphasiasWeb during the trial.

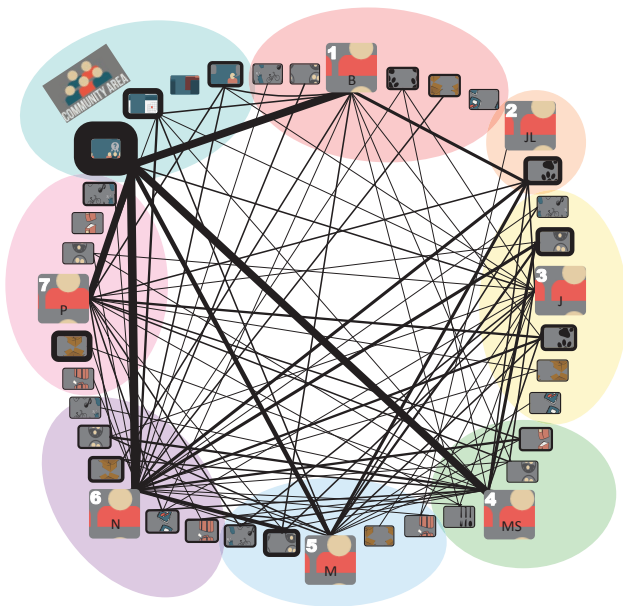


Figure 3: Interactions on AphasiasWeb

Originally the trial period was to last just one month. At the end of this period, we decided to extend the trial to a second month. We note that less activity occurred during this second month, during which we focused less on the app in regular support group meetings.

Figure 2 also shows that the users do a lot more commenting than posting and that users tend to comment more when posts are added. Posts provided the stimulus for conversation. It appears that the participants were less eager to start new conversations, but they actively participated in conversations that had already started. This suggests that AphasiasWeb may be more effective and may elicit more interaction if family members and therapists also participate by seeding conversation with posts.

Figure 3 shows how the participants communicated with each other and what areas of the application they used.

First, the categories in each user’s bubble are the categories they added posts to on their own web. The thickness of the outline of each category indicates the relative number of posts the user added to that category. Therefore, by looking at each user, we can see the variety of categories he or she decided to use and which of those he or she used the most.

Also in figure 3, a line connecting a user to another user’s category indicates that the user commented on at least one post in that user’s category. The thickness of the line denotes the relative number of comments the user contributed to the other user’s posts. The resulting web of connections shows the level of interaction between the users by showing which participants communicated with each other and how much they contributed to the conversation. For example, participant six has many lines stemming from her figure and several of them are thicker, showing that she commented on many other users’ posts. Participant two, on the other hand, presents the opposite case—having little interaction with other users. This was expected as this participant did not have Internet access in his home and could not freely access AphasiasWeb.

While figure 3 illustrates the category usage on an individual basis, we wanted to examine how the different categories were used overall. The weighted bigraph featured in figure 4 shows the category use in aggregate. As explained above, the individual user webs had eight categories that could be posted in and the community area had four. These twelve categories are shown on the right of the graph and are, from top to bottom, Hobbies, My Story, Family and Friends, Pets, Miscellaneous, Living with Aphasia, Travel, Food and Recipes, Questions, Events, Resources, and Recommendations. The last four are those from the Community Area.

This graph, like figure 3, shows which categories each participant contributed to. The relative thickness of the lines shows the frequency of contribution. We can see, for example, that participant seven contributed to seven different categories while participant four contributed to only three. Several categories had few or no posts.

Figure 4 also shows the aggregate usage of each category

Category	Participant							Totals
	B.	J.L.	J.	M.S.	M.	N.	P.	
Hobbies	1	0	1	0	2	1	2	7
My Story	0	0	0	2	0	0	1	3
Friends & Family	1	0	4	1	4	2	1	13
Pets	2	4	3	0	0	0	0	9
Miscellaneous	2	0	1	0	1	3	4	11
Living with Aphasia	1	0	1	0	0	2	0	4
Travel	0	0	0	0	1	2	1	4
Food & Recipes	0	0	0	1	0	0	0	1
Questions	1	0	0	0	0	5	2	8
Events	0	0	0	0	1	0	2	3
Resources	0	0	0	0	0	0	0	0
Recommendations	0	0	0	0	0	1	0	1
Totals	8	4	10	4	9	16	13	64

**Figure 4: Numbers of posts in each category and by each AphasiaWeb participant. Comments are not included.**

by showing the total post count for each category by each participant. We can see which categories were favored and used the most and which may not have been necessary as contribution to them was minimal. The popular categories from individual user webs seem to be Family and Friends, Miscellaneous, Pets, and Hobbies. Questions and Events were the most used categories from the Community Area.

Finding the optimum set of useful categories is a major area of focus for the next release of AphasiaWeb. By eliminating several of the less popular categories, we expect AphasiaWeb to be easier to navigate.

We next consider the types of contributions made by the participants. First, as figure 2 showed, there were a lot more comments added than posts. During the two months, participants added 64 posts and 237 comments. Participants contributed 27 text posts and 37 picture posts. Though the majority of the posts were pictures, we looked at the participants' postings individually to see if they all preferred posting pictures. What we found, shown in figure 5, was that the type of post preferred varied from participant to participant: three posted a majority of picture posts, two a majority of text posts, and two equal of each. We interpret this as the users appreciating having the multiple modes of communication, and we plan to expand upon this concept in future releases by enabling posting of videos.

Lastly, the authors observed the conversations taking place in the application. Specifically, they looked at the length of the conversations, measured by the number of comments on each post. Figure 6 presents this by showing how many posts had a given number of comments. For example, there were two posts with nine comments on them, two with eight, and so on. The average was about three comments per post.

We also considered how effective each type of post was at provoking conversation. This is shown in figure 7. The average number of comments per text post was about 2.5 comments, while the average number of comments per picture post was about 3.5 comments. Though the averages only differed by one comment we see that, in general, the longer conversations are elicited from picture posts.

### 4.3 Qualitative Results

In addition to the usage analysis, we conducted a followup qualitative interview with the participants. We informally asked them in a round-table discussion how they felt about the app's features, its navigability, and their likelihood to continue using this kind of app. Following are a handful of their responses.

- "I couldn't remember where I put [my posts]."
- "People were putting things under questions that weren't really questions."
- "I wanna know if this is going to continue... I don't want it to die. I mean this is a wonderful site. Cause I never got to talk to M. and find out what she's up and find out that she's going snowshoeing."
- "I love Aphasia group and that's like what this is."

The content that participants shared with each other also provides some insight into how the app was used. Following is a sample of exchanges showing different levels of conversation. All excerpts are taken directly as entered into AphasiaWeb.

Popular Internet memes were posted:

- J: (picture of a squirrel meme)
- J: look at Squirrel on my web! Funny!!!
- N: I like this poster
- M: That's cute J.
- P: You better feed him, he looks hungry

A number of conversations, like this one, had a casual tone:

- M: To all my friends. Happy Valentines' Day to all.
- B: M! Right back at you!
- J: Happy V-Day friend!!!!
- N: Happy Valentines Day to you too.

Participants inspired each other with stories and pictures from their life:



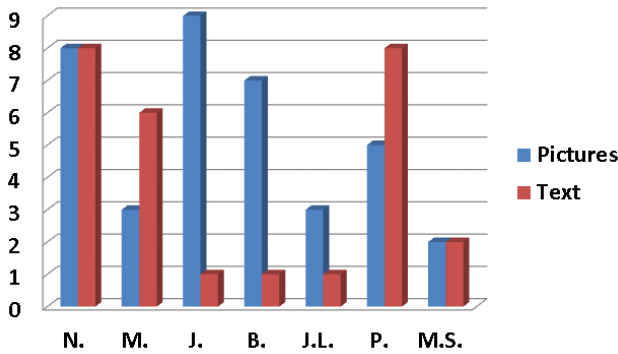


Figure 5: Types of posts added by each user.

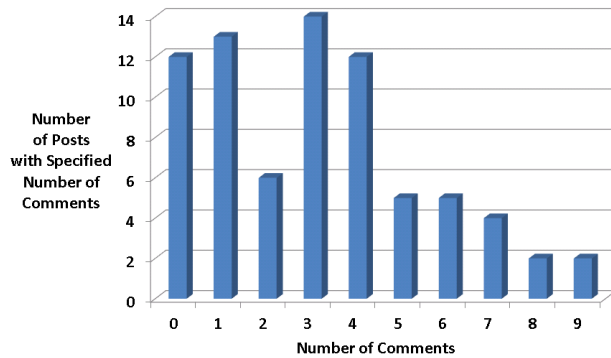


Figure 6: Frequency of Number of Comments per Post

- B: Things i saw while on my walk today! (picture of snowmen)
- JH: Awesome. A whole family of snowmen! I like the pine skirt! looks like a good walk B!
- N: Cool picture. How far do you walk?
- B: I walk 4 miles a day. 5 or 6 days each week.
- N: Wow! I need to do that.

AphasiaWeb also provided a channel for sharing emotions about aphasia itself:

- N: Frustrating!!! I have so many idea in my head. But they wont' come out in an organize fashion!
- P: How well I know that is so true
- MS: I am too!
- J: Me too!!!

## 5. CONCLUSION

We have implemented AphasiaWeb, a social network for individuals with aphasia. It makes use of proven therapeutic techniques including written-choice, web layouts, and multiple modes of input. AphasiaWeb has the potential to strengthen relationships between members of a support group by allowing more frequent informal conversation beyond regular face-to-face meetings.

Based on feedback from the participants and our analysis of their contributions in a two-month trial, we conclude

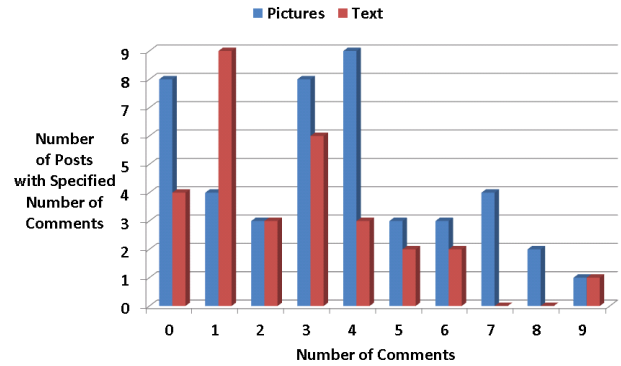


Figure 7: Frequency of Number of Comments per Post Type

that AphasiaWeb was successful in facilitating interaction amongst individuals with aphasia. With continued development and usability refinements, we expect this tool to reduce the feelings of social exclusion that may accompany aphasia.

## 6. FUTURE WORK

The authors plan to continue the development of AphasiaWeb, with a long-term goal of releasing the app for public use. Before this is possible, AphasiaWeb needs some core functionality added to it and the interface needs to be modified to be more accessible to individuals with aphasia.

We would like to increase the number of input and output modes in AphasiaWeb. Currently the app supports text, photo, and speech-to-text input. The next release will incorporate video recording and uploading. Additionally, we hope to include text-to-speech functionality, which would allow users to have content read back to them.

The guidance model built into the interface will be evaluated as we prepare the next release. While the guidance model was effective in promoting interaction, we believe improvements can be made and the model can be applied more consistently. For example, highlighting guides users to new activity, but once a user views and subsequently leaves this activity, there is no indication to the user about what they had been looking at previously. Also, while the categories guide a user to a location to add a post and begin a conversation, when the user revisits the app, she finds herself unable to remember where she added posts. Essentially, our guidance model is forward-facing—it guides users to new activity they have not seen before. A goal of the next iteration of AphasiaWeb is to round out our guidance model to be backward-facing as well, guiding users back to where they had previously contributed or viewed content.

Not all categories contained content, and some were used much more heavily than others. In the next release we will prune and combine several categories.

The participants expressed a desire to be able to chat directly with other users. On several occasions, participants set up posts entitled “Chatting” or another participant’s name in the hopes of starting conversation with the other

participant. These conversations were visible to all users. Support one-on-one conversation without complicating the interface is a future challenge we hope to overcome.

Before widespread release, the application needs some more formal privacy protection in place. The participants from our trial indicated that if AphasiaWeb were to be offered publicly, they would want some privacy from individuals they have never met before. It's also not clear that a single AphasiaWeb would be effective on a large scale. Many AphasiaWebs, one for each group, might be more likely to promote conversation.

The authors believe that AphasiaWeb has strong potential to be an empowering, aphasia-friendly social network, and we look forward to continuing with future releases.

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