Investigating the Use of Circles in Social Networks to Support Independence of Individuals with Autism

Hwajung Hong[1], Svetlana Yarosh[2], Jennifer G. Kim[3], Gregory D. Abowd[1], Rosa I. Arriaga[1]

[1]Georgia Institute of Technology {hwajung, abowd, arriaga}@gatech.edu

[2]AT&T Research Labs lana@research.att.com

[3]University of Illinois at Urbana-Champaign jgkim2@illinois.edu

ABSTRACT

Building social support networks is crucial both for less-independent individuals with autism and for their primary caregivers. In this paper, we describe a four-week exploratory study of a social network service (SNS) that allows young adults with autism to garner support from their family and friends. We explore the unique benefits and challenges of using SNSs to mediate requests for help or advice. In particular, we examine the extent to which specialized features of an SNS can engage users in communicating with their network members to get advice in varied situations. Our findings indicate that technology-supported communication particularly strengthened the relationship between the individual and extended network members, mitigating concerns about over-reliance on primary caregivers. Our work identifies implications for the design of social networking services tailored to meet the needs of this special needs population.

Author Keywords

Social networks, social support, autism, independence

ACM Classification Keywords

H.5.3. Information interfaces and presentation (e.g., HCI): Group and Organization Interfaces

General Terms

Human Factors; Design;

INTRODUCTION

Like all young people, youth with autism face life transitions when they leave school or home. An adolescent with autism and her family face many challenges on the way to attaining a satisfying independent life for that individual [12]. One of those challenges is developing a robust and sufficiently large network of people who can provide advice about everyday situations. These situations vary in terms of the immediacy of the need for an answer and the topic addressed (e.g., health, grooming and dressing, home upkeep, school or work relationships, financial planning and management and leisure activities [25]). Over-reliance on a small set of people, typically a primary caregiver, is a barrier to independence and a burden on the caregiver [3]. Thus, having access to social support networks with people who can provide help is crucial both for the individual and for the primary caregivers [23].

CHI 2013, April 27–May 2, 2013, Paris, France.

Social networking services (SNSs) are used widely today as a way for an individual to communicate with a wide set of people. In particular, over the past years interesting new features to SNS have been introduced to encourage and support different communicative patterns. One of those specialized features, the focused communication circle [14], is of particular interest to the work presented here. The ability to direct conversations either to a set of people with a common social connection (e.g., family, friends, co-workers) or to those interested in a particular topic (e.g., health, job coaching) may be a promising way to break the trend of over-reliance on the primary caregivers for individuals with special needs.

Our research goal is to identify opportunities and challenges of the use of SNS to support independence for adolescents and young adults with autism[1]. The study reported here recruited individuals having Asperger's Syndrome, a diagnosis that reflects an individual with average or above average language skills, but with qualitative impairments in social interaction and restricted, and stereotyped patterns of behavior, interests, and activities. Of particular interest here is the support SNS provide for individuals who seek information, advice and support for specific life transitions and social problems.

In this paper, we explore a particular feature of SNSs, and that is the ability to define a small set of members, a "circle" to participate in shared discussions. We want to see how the use of these circles influences how an individual with autism might reach out to people beyond a primary caregiver (e.g., a mother) for advice on everyday life skills. Using a commercial, cross-platform social networking service, GroupMe [24], we supported three individuals with Asperger's Syndrome and their primary caregivers with the ability to set up multiple communication circles. Over the course of 4 weeks, we examined 1) how the use of the communication circle impacted the initiation and topics of requests for help and 2) how the technology-supported communication impacted the existing support practice as well as the strength of the relationship between the individual and the network of friends and family.

The contribution of our work is twofold. First, we provide an in-depth analysis of the interplay between independent skills and social support with the use of SNS. Our study shows how a focused communication circle and other related SNS features impact important social problems (i.e., over-reliance on a small

[1] Throughout this paper, we will use the term "autism" to refer to individuals who either self-diagnose or have an official diagnosis of autism, as defined in the DSM-IV criteria for Pervasive Developmental Disorders.

set of caregivers and social isolation) by increasing social connections with other circle members. Second, we identify two key challenges: managing circle membership and balancing communication load within a circle. These challenges should open up design opportunities for the development of future systems that support individuals with autism online. The features we propose include tools that help users build and shape circles that will allow them to receive immediate and adequate advice on daily activities.

RELATED WORK

Autism Context: Towards Building a Support Network

Attaining independence may be more difficult for those with autism because of their limited ability with self-determination [11]. Lower self-determination ability leads to over-reliance on caregiver prompting and continuous assistance in everyday situations ranging from very simple operations to complex social activities [12]. Over-reliance on a primary caregiver also leads to problems such as difficulty broadening one's social network, reaching out to appropriate people to get advice about specific topic, and tapping into other available resources [3].

Increasingly, the use of technology for fostering social support for individuals with special needs, such as those with autism [8,10,17] or other cognitive disabilities [18,23], has been the focus of considerable research within the HCI research community. A notable example of the technology-mediated social support includes a mobile-based prompting system that provides individuals affected by cognitive disabilities with detailed protocols created by a set of caregivers to perform activities such as using public transportation [7]. One recent study explored the role of computer-mediated communication (CMC) and available social media for the support of individuals with high functioning autism, particularly those having a social communication difficulty [6]. Additionally, a human-computation approach that harnesses the ability of distributed workers has been investigated as a means to develop software to teach adolescents with autism problem-solving skills [1]. However, much of the previous research in this area has focused on the technology design itself rather than any potential interventions or ecological approaches that benefit the community of people who are involved in the care of individuals with autism.

Our work complements these efforts, focusing on empowering young adults with autism and their caregivers in a style that differs from most assistive technologies. To foster social support, we emphasize leveraging existing connections for the practical and social assistance that appeal to individuals with autism as well as caregivers. Individuals with autism naturally form small social support circles that typically consist of immediate family members and close friends [3]. However, such support can also be provided by others, perhaps using a technology such as an online social networking system. While research has explored the design of a special purpose social networking system for connecting individuals with autism to a wider set of people online [10], such a system has not been actually deployed.

Our work investigates the use of an SNS as a social support system for this special population in real world settings. In particular, we wanted to explore how a specific feature of SNS, the communication circle, enables individuals to initiate communication or request help, and ultimately whether this system can be used by overburdened caregivers to distribute their responsibility to others in the network.

Communication Circles on Social Networking Services

boyd and Ellison [2] defined social network sites as a multidimensional construct that allows users to build a profile, to represent their list of contacts within a system, and to form relationships with their contacts. We consider Social Networking Services (SNS) a subset of social network sites to the extent that they particularly facilitate communication and collaboration across networks of contacts online with a variety of different technical features. Outside of networking with friends or everyone, SNSs also offer a novel setting in which one can build sub-groups for specific purposes [14] and solicit help or information from the group members [9]. These features are explicitly presented as "lists" or "groups" in Facebook or "circles" in Google+.

Morris et al. [19] conducted a survey that examined the use of personal connections within an SNS for asking questions. They found that more than half of participants reported that they asked questions on people's Facebook statuses on various topics such as technology, leisure and social activities, and philosophical inquires. The study also revealed that many questions were likely to be answered by close friends. However, asking overly personal inquiries about topics such as health, dating, religion, and finance, seems to be inappropriate within the SNS context or at least through the mechanisms revealed in this study.

The disclosure of highly personal information is sometimes necessary when seeking help or advice, but it inevitably raises tensions around one's privacy and social identity. To tackle this social dilemma, Newman et al. [20] proposed a mechanism that builds customized support groups for focused communication, for example, groups consisting of individuals that a user selects for the health-related goal. This approach is echoed by recent work investigating selective and targeted sharing practice in Google+ [14]. In that study, participants generated custom circles across life facets (professional life), tie strength, and topical interest. More importantly, the result showed these groups are utilized for specific purposes (e.g., selectively sharing health and nutrition content with those who might be interested.)

A key benefit of soliciting help or information through a focused communication circle is that they provide an individual with access to direct communication to the right set of people. Building upon the previous work, we seek to explore how the mechanism of pre-defined groups or circles in a specific social networking service, GroupMe, influences an individual with autism in seeking advice on everyday activities.

METHODS

Our aim was to understand the impact of the SNS's communication circle on the patterns of support and the relationship between an individual with autism and his or her caregivers. To that end we enrolled three groups that were comprised of an individual with autism, their primary caregiver, and a flexible number of extended network members.

Technology Probes

Technology probes [13] have been adopted as a methodology that allows researchers to investigate the daily activities for children with autism and their families [17]. We also used this approach as well. We installed a social network application into a real-use context to observe how it is used over a period of time. Instead of seeding "new" technology in the existing context, we explored the repurposing of a general online social networking application for a specific situation, the day-to-day support of individuals with autism. We expected the participants to provide us with feedback on how the use of the social network application may or may not have addressed their needs and concerns and to critique the technology by describing their experiences with it.

The cross-platform social networking application, GroupMe (see Figure 1) [24], was used in the study for three reasons. First, it facilitates the network creation process. Users can smoothly transfer existing connections offline to GroupMe members using contact information (e.g., phone number, email address) stored in their communication devices. It allowed the researchers to track those who were already involved in offline support and how they moved to online support. Another reason for choosing GroupMe was that it facilitates user-generated groupings of contacts (which we refer to "focused communication circle"). It enables users to sort their contacts so that they can selectively communicate with circle members and to broadcast messages to circles they wish to communicate with. This mechanism shapes GroupMe as a more synchronized group chat system. We expected to observe what kinds of circles the study participants created and what interactions would evolve within each circle. The main reason

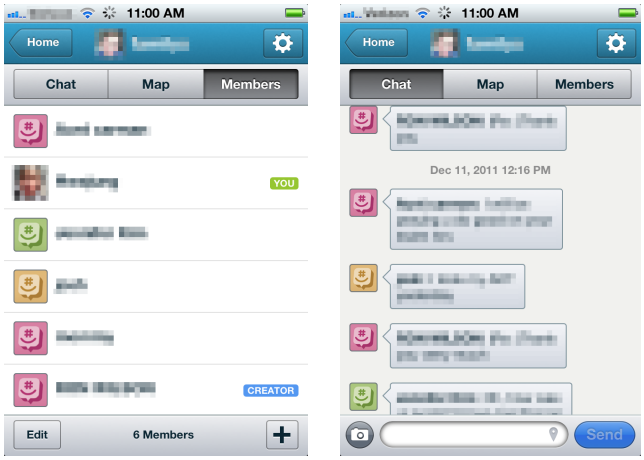


Figure 1. Two screen shots from GroupMe mobile app: Members view of G1's circle (left); Chat view of G1's circle

we chose to explore GroupMe was because of its unique communication mode. Users can access GroupMe not only through a web interface but also on mobile phones. GroupMe also integrates mobile telephony features into social networking by assigning a proxy phone number to each circle. Even if users do not have a smartphone, they can still broadcast messages through text via a feature cellphone. The use of various communication modes in GroupMe allowed us to determine effective ways of asking and providing support in various situations.

Participants

We solicited participants through word-of-mouth, mailing lists, and public events. We recruited three young adults (Andrew, Sarah, and Paul)[2] who self-identified as having Asperger's Syndrome (AS) and whose primary caregivers were their mothers (see the demographic summary in Table 1). All three pairs invited their existing networks such as other family members, relatives, and friends (Total: 20) to join the GroupMe system. Each pair was compensated $30 for completing four weeks of the field study phase plus $20 for completing the pre- and post-study questionnaires. We decided to approach only three groups for this study because this number was sufficient to address our research questions and because it was consistent with previous technology probe studies in this domain (e.g., [16], [17]). Keeping the number of deployments fairly small allowed us to conduct a more in-depth qualitative analysis focusing on the lived experiences of each participant.

During the study, two researchers joined as members of all three groups in GroupMe because researchers were interested in determining how young adults react to the inclusion of someone that they do not know well in their existing network. To authenticate the researchers' presence in the group, the researchers asked the participants to consider them as proxies for community volunteers (e.g., church youth group members) who could be invited to participate in future studies.

The first group (**G1**) consisted of a moderately independent college student (Andrew) with AS who was in his late teens and his immediate family members. Although he managed his daily chores under his mother's proactive guidance, he was less confident about staying on a schedule. He lived with his mother, a leader of a local autism awareness group, and his younger brother who was 17 years old. The family members also included an aunt whom they met once a month. Since G1 was the first group with whom we deployed the social network application for the study, we wanted to identify technical and behavioral challenges and to use insights to revise our study procedure during the study period. Furthermore, Andrew was unfamiliar with social networking tools unlike Sarah and Paul. Hence, researchers were more actively involved the G1's communication than those of others.

The second group (**G2**) consisted of "Sarah," a 16-year-old female middle school student with AS, her extended family and their friends. Members lived in in multiple states. Outside

[2] Names are pseudonyms.

of school, Sarah spent most of the time with her mother, who assisted her with maintaining her appearance, managing her schedule, and making friends. During the study period, one of the mother's friends dropped out of the group because of personal circumstances. Two weeks after the beginning of the study, the mother invited Andrew (from the first group study described above) because he attended an autistic teen and adult transition group with Sarah. She also invited Andrew's mother to join G2.

The third group (**G3**) consisted of a 28-year-old moderately independent adult (Paul) with AS who was employed as a technical assistant in a local IT company, and extended family members including an aunt and a cousin in their late twenties that lived in a remote part of the same state. A week after the beginning of the study, a family friend was added as a group member. Although Paul was described as very organized and routine-oriented, his mother was concerned about his limited social interaction skills. He tended to engage in solitary activities such as watching television or listening to music. He lived in a metropolitan city with his mother, his father, and his 17-year-old younger brother, who often asked Paul for rides to his high school and who played baseball in a local league.

Procedure

The study consisted of three phases: the pre-study, the field study, and the post-study.

Pre-Study Individual with autism and their primary caregiver took part in an opening interview, a questionnaire, and a tutorial. The questionnaire included the following:

1. Information about current needs and concerns associated with independence with perceived levels of importance and competency independent living skills in seven areas defined by the Virginia Education Department (VED) transition guidebook [25]: maintaining good hygiene, staying on schedule, good health habits, work and professional life, financial management, leisure and social activity, and managing household chores.
2. A form on which both listed known relatives and friends who had helped or who would be able to help the individual acquire these living skills.
3. Information about the relationship with each person on the list and the individual's perceived strength of the relationship in terms of closeness (Likert scale 1-5) and intensity (i.e., the frequency of contact with each person on the list).

Participants were asked to create groups on GroupMe using the list they had developed (see #2 above). We asked the participants to invite two of us so we could join their GroupMe conversations. This approach allowed us to capture data and the context in which the participants sent messages and any changes that they made to group memberships.

Field Study Over the course of 4 weeks, Participant interacted with invited members through GroupMe. Log data from the GroupMe system was collected during this period.

Post Study After the fourth week, each participant with AS and his/her primary caregiver took part in debriefing

Network	Individuals with Asperger's	GroupMe Members	Changes in Closeness (Post – Pre)	Intensity	
				Frequency of contact before the study	# of Message that the member sent to Group during the study
G1 18 threads 147 messages	**Andrew** (age: 19 | College student | AS) - Moderately independent - Less confident (2 out of 5) about staying on schedule - Feature cellphone user - Recently joined Facebook (FB), access weekly - Created 69 out of 147 messages (50%) - Initiated 11 out of 18 threads (61%)	Mother	-1	Hourly	16
		Brother	0	Daily	6
		Aunt	0	Weekly	13
		Researcher 1	2	Never met before	33
		Researcher 2	2	Never met before	10
G2 32 threads 186 messages	**Sarah** (age: 16 | Middle school student | AS) - Less independent - Not confident (1 out of 5) about managing good hygiene and leisure and social activities - Feature cellphone user - Access Facebook daily, produce a number of videos on her YouTube channel - Created 81 out of 186 messages (43%) - Initiated 7 out of 23 threads (30%)	Mother	0	Hourly	25
		Father	0	Daily	9
		Mother's friend1	N/A (removed immediately)		
		Mother's friend2	2	Not often	12
		Family friend	1	Not often	12
		Friend*	2	Weekly	34
		Friend's mother*	2	Weekly	12
G3 23 threads 250 messages	**Paul** (age: 28 | Technical assistant | AS) - Moderately independent - Less confident (2 out of 5) about social activities - Smartphone user - Access FB daily, but do not write on the wall - Created 69 out of 250 messages (28%) - Initiated 8 out of 32 thread (25%)	Mother	0	Daily	41
		Father	0	Daily	25
		Aunt	1	Not often	61
		Cousin	0.5	Not often	39
		Family friend*	0	Not often	15

*: Members who invited after pre-study phase

Table 1. Summary of participants' profile, questionnaire result, and usage logs.

interviews and filled out post-study questionnaires, which included the same form (see #3 above). We then conducted semi-structured interviews with each group, asking them about their overall experience interacting on GroupMe, the benefits of using GroupMe, its technical and social barriers, and the effects of the application on their support activities and interpersonal relationships. The materials used during the debriefing included lists of the group members that they had invited and the messages they generated. The purpose of the debriefing was to encourage the participants to reflect on the use of GroupMe, to explore the rationale for their interaction with the system, and to expand on the context of specific message threads pulled from the log.

Analysis

We conducted two phases of analysis of the logs and questionnaire responses. First, we conducted a descriptive analysis to examine the relationship between questionnaire responses and the overall communication patterns generated from GroupMe use. We also collected fine-granularity scale conversational data such as messages exchanged on GroupMe. We then grouped the messages by VED skill topics area, and defined the group of messages as a conversation thread. We examined the relationship between the conversation threads and the concerns around independence which participants reported.

Concurrently, we conducted in-depth qualitative analysis of transcribed interview data and logged messages. Two of the authors conducted an initial round of open coding and memoing to create thematic connections using a data-driven approach [22]. We extracted statements of interest and grouped them according to theme, conducting two such passes through all of the data. We refined the themes through affinity diagramming until a set of distinct themes emerged. By applying a triangulation of descriptive quantitative analysis of the system logs and questionnaires and the interviews, we were able not only to assess the functional value of the technology but also to understand the social value from the perspective of daily interaction.

RESULTS

Questionnaire

Skill Importance and Competency. Managing hygiene and attire was considered as the most (Andrew, Sarah) or the second most (Paul) important skill in a self-reported ranking of the seven skill areas from the VED guidebook [25]. The self-reported level of competency differed from the level of importance. Schedule management (Andrew: 2 out of 5), attire-and hygiene-management (Sarah: 1 out of 5), social and leisure activities (Sarah: 1 out of 5 & Paul: 2 out of 5) are the skills individuals were least confident in being able to perform.

The Sense of Closeness. Pre and post assessments of the closeness showed that all three participants had an increase perception of closeness to the extended network members (61%, 8 out of 13 relationships). Two of the three participants showed no change in the closeness to their primary caregivers and one showed a decrease in closeness (see Table 1).

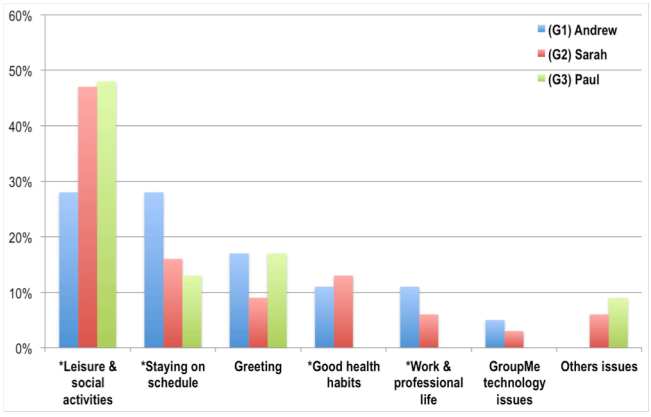
Log Analysis

In the following section, we begin by describing the general patterns of communication extracted from the GroupMe usage logs. We recorded a total of 73 threads (583 messages) from our three participants' groups.

Membership. All three groups communicated within a single focused communication circle of GroupMe that consisted of five to seven members. In the pre-study, we worked with participants to create their first social support circle in GroupMe; we also encouraged them to add new members and create additional circles as the study progressed. However, we observed only a few instances in which new people were added to existing groups (two new members to G1 and one new member to G3), and none of the participants created new circles during the study.

Patterns. The three groups showed both common and distinct patterns of communication. All three individuals with autism were the most active communication participants in their groups (Andrew: 50%, 69 out of 147 messages, Sarah: 43%, 81 out of 186 messages, Paul: 28%, 69 out of 250 messages). Of the three young adults, Andrew was the most active communication initiator (61%, 11 out of 18 threads) followed by Paul (30%, 7 out of 23) and Sarah (25%, 8 out of 32). The initiation in both Sarah's and Paul's groups were more evenly distributed among the members of their groups. We found that the mothers, who were providing prompts both online and offline in all of the groups, were more engaged during the first week, but they reduced their engagement in the remaining weeks when invited group members increased their activity. For instance, Andrew's mother participated in 75% threads at the first week, but 2% of threads the remaining weeks (Sarah's mother: 43% to 36%, Paul's mother: 88% to 64%).

Topics. Overall, the system addressed an ongoing issue that all of the participants with autism faced—that of socializing (see Figure 2). Social and leisure activity was the dominant theme. The second most frequently discussed topic was schedule management. Participants also generated phatic communication or greetings almost every day and it often emerged as other topics such as social activity planning. Two participants discussed health-related concern such as physical discomfort, sickness, and hospital visit. Those two participants



* VED Seven Skills

Figure 2. Topics discussed on GroupMe

had conversations related to job and professional life, such as upcoming job interview. However, none of participant discussed house chores and attire- or hygiene-related issues through GroupMe. We also looked at the association between the skill importance and competency questionnaire response and the topics of communication participants generated. Sara and Paul reported that they had least confidence in social and leisure activities among the seven skills area. We found that almost half of Sarah's (47%) and Paul's (48%) threads were related to social activities (e.g., offering a movie night, buying a gift for a friend, planning a potluck party). Andrew ranked schedule management as the skill that he was least confident in and it was one of the most frequently discussed topics (28%) in his group threads.

Summary of Results

We make the following four observations about the characteristics and the impact of the communication circle. First, participants made limited changes to the membership in the circles following the initial deployment and they did not add any new circles. The members were, however, actively engaged in communicating within a single circle. The circle was based on their social connections rather than on a particular topic. Next, GroupMe motivated participants to initiate communication and the responsibility for responding was shared among the members. Thirdly, the application was utilized to address some of the participants' ongoing needs, but some sensitive topics were not broached on the system. Lastly, the participants perceived that their engagement with the various members of their extended network, but not their primary caregiver, was improved between pre- and post-study.

Building upon the results from the survey and log data, we were interested in whether the use of GroupMe impacted existing support practices and therefore mitigated the over-reliance on the primary caregiver. Keeping these high-level findings in mind, we move on to data collected through the qualitative study, through which we aim to gain a detailed understanding of the contexts in which these patterns occurred.

QUALITATIVE ANALYSIS

We analyzed the interview data, logged messages, and written responses from a few members. The findings indicated that participants were highly motivated to engage in GroupMe that they perceived that the application was beneficial for both improving the care network and extending social relationships.

The Comfort of the Small Circle

GroupMe was perceived as a comfort zone in which the individuals could extend conversations to a controlled set of individuals. Though some participants also had access to other social media, the prescribed nature of GroupMe appears to have ameliorated some of the social anxiety related to communicating with a large group. Sarah complained: *"I have too many people on Facebook, but I'm not actually comfortable talking with them."* She reported feeling more comfortable sharing on GroupMe: *"I'm still at the point where I'm afraid to walk up to somebody, get their attention, and say this is what I need. I'm learning that it's easier when I know the people are there for me."* Paul's mother stated that she and Paul liked GroupMe because it provided them with a safe place in which to engage people they felt comfortable asking for help: *"The resources are there, and the families and friends are on."*

Our participants, both individuals with autism and their caregivers, reported that they were satisfied communicating with those in the circle they first created, so they did not want to create more circles. In the study, we saw incidences that might explain why no more circles were created. While family members understood the purpose of using GroupMe and knew how to use it in advance, friends could not acquire information about how to participate. In addition, participants had difficulty inviting others to GroupMe because of strict social norms that managed certain relationships (e.g., the teacher-student relationship). For example, Andrew asked his teacher to join GroupMe, but teachers were not allowed to contact students through personal social media.

Immediacy of Response

An individual and his primary caregiver valued the focused communication circle because of the immediacy of the response. Participants noted positive feelings about GroupMe as a personalized Q&A system. For example, Andrew had a job interview and asked a question: `[Message] I have an interview tonight and I need to know some questions to ask what should I ask.`

Shortly thereafter, his aunt responded: `[Message] Ask for details regarding their training for new employees. […] They might ask u for 2 or 3 of your best and worst qualities and why[,] so be prepared to tell them what they are. I would say one is that you are creative […] and another is trusting of people. That one can be a positive and [a] negative.`

Andrew emphasized that the immediacy of GroupMe was his favorite feature: *"It makes everything a lot quicker […] I don't have to keep going to my contacts to find someone. I just got an answer to what I needed. Quicker!"* Andrew's mother added: *"He liked the dialog in GroupMe because it is faster and convenient and because I'm very long [winded]. When I teach, I will go from the very beginning to the end, like a half hour answer, like 'Andrew, you are going for an interview. Make sure that you have eye contact, be sure to shake hands, be sure that you say thank you.' […] GroupMe response, when he asked, was very simple and concise."*

Although we were concerned that members might be less inclined to respond to posts and instead rely upon others to take responsibility, we observed no such reluctance during the study period. All queries were answered by at least one group member within an hour. The average response time was 10.3 minutes. Members with existing relationships tended to make the networks more responsive and supportive. Further, participation in the same circle allowed members to expedite action on an individual's request because they could determine immediately whether the request had been handled by others or whether the poster was still awaiting a response.

Instrumental Support

Individuals and their primary caregivers adopted GroupMe for providing and receiving practical support. For example, schedule management was a skill Andrew admitted he always needed help with. Andrew's mother and his brother often had to remind him about upcoming events such as a final exam, a

hospital visit, or a family gathering. The distinct qualities of GroupMe, near-synchronous communication and the group-broadcasting feature, facilitated schedule coordination activities in which multiple members were involved.

Through the instrumental support seeking process, individuals could harness various ideas and perspectives. Sarah's mother commented: *"I liked GroupMe because when she [Sarah] posted something I didn't feel that I had an answer, but the other people that I trusted were able to answer."* Andrew's mother noted advice from members helped Andrew prepare for various scenarios he and the mother never expected: *"Information is very different coming from me than from his peers on GroupMe. The best thing was when he was going for the interview, he got replies from everyone and they were all different. It was very, very helpful for him during this interview. So, he wasn't just relying on me, my own experiences and my ideas. But, he got his aunt's, yours, and everybody's."* On another day Andrew asked a question: `[Message] I am at a grocery store and what should I get my friend who is in the hospital.` Everyone told him different gift ideas. For example, his mother suggested: `[Message] Chocolates, flowers, cards.` A researcher in his group asked a question to understand details: `[Message] How sick was your friend? If it's severe, snacks might not be a good idea.` Andrew chose to wait awhile in order to collect ideas and then decided to buy a card. His mother valued GroupMe because he no longer was dependent solely on her opinion. More importantly, Andrew and his mother appreciated that the opportunity to weigh a variety of ideas could lead to more flexible decision-making, an important step toward independence.

There were instances where individuals with autism reported needing support in a given area but failed to address this concern via GroupMe. Most notably hygiene- and attire-related matters were never discussed. For example, during the pre-interview Sarah said: *"It's really hard to keep up my hygiene. I mean, I have a lot of trouble with it."* Our findings from her post-study interview revealed that these were still issues that her mother was helping her deal with.

Learning by Lurking

GroupMe members can choose not to respond to conversation threads. We found that in these situation individuals with autism were able to observe how dialog evolved among the different members. The passive engagement allowed participants to learn communication norms that were often opaque to them. Such silent observation also gave them access to various styles of interaction that they could later mimic.

All individuals reported that in some cases others' posts on GroupMe gave them ideas for future interaction. When Andrew engaged in Sarah's group, for example, he observed that Sarah brought up various topics about herself instead of just saying "Hi, how are you?" Thus, learning occurred even when individuals merely lurked within a communication thread. An individual indicated that they enjoyed being silent while other members developed multiple dialogs. For example, Paul followed a thread where his aunt and cousin discussed an outing and was then motivated to ask his group members about going to a concert the following month: *"I love the fact that people actually want to go on and talk more. I start a question, people can talk about it, and I can jump in and add what I want."*

On another occasion Paul simply posed a question about a boxing match: `[Message]Question: Mayweather or Cotto?` The thread evolved and ultimately Paul's family and friends gathered to watch the fight. Paul remained quiet while others exchanged messages to coordinate a potluck. At that point, he joined the conversation: `[Message] I will handle dessert.` He commented later that this dialog was the highlight of his GroupMe trial. By providing the opportunity for such silent participation, GroupMe could help individuals learn communication skills that may enrich their future interactions. This finding echoes Burke *et al* 's conclusion that passive consumption of others' communication has a greater impact on those with low social skills [5].

Opening up Richer Social interaction

All individuals lived in their parents' homes. One of the concerns often reported was that the individual's social interaction was very dependent on their primary caregivers. Thus, mothers expressed concerns that their children might be socially isolated if they moved away from home. For example, in the pre-interview, Paul's mother was worried that: *"He tends to isolate in his room, listening to music… Having access to people, knowing how to go and find activity is crucial."*

As conversations grew and expanded, opportunities arose for enriched social relations. For example, Paul's mother appreciated the fact that GroupMe increased interaction between Paul and his aunt: *"They're close in age. She lives on the south side of the town. Paul and [his aunt] didn't even talk that often. But, I think he would see her at Thanksgiving or Christmas. I feel there's more interaction. So, I think that's the best part of it."* Consequently, these GroupMe conversations led Paul and his aunt to attend a concert together. Paul confirmed the use of GroupMe made the social event happen: *"It was the first time we actually talked about it. We never did it before. It was the first time that I invited her to go to a concert."* Paul's mother reported that GroupMe fostered improved interaction between her son and other members and, in turn, helped Paul interact with others more spontaneously than before.

The conversations on GroupMe also helped to identify and meet individual needs even primary caregivers had overlooked. For instance, a friend of Sarah's mother treated her to an age appropriate treat: `[Message] Hey Sarah, you know I'm a nail tech so I'd love for you to come get your nails done and get to know you:-) let's plan something!` Sarah's reaction was one of delight: *"[When I got this message] I felt 'Oh, I want to do that.' Honestly, I never really had friends ask me if I can go with them for the nail stuffs. So, I felt like 'WOW'. I never thought of that. So, it was surprising to me."*

Sarah's mother found that GroupMe also provided members with a different view of her daughter: *"I think [GroupMe] gives [other members] a little more insight into her, like how she thinks. I think this is a good way for them to see her as more a person coming into the adulthood and to see that she's just not a kid playing. I think it helped them to see her as more mature and older."* This positive experience increased Sarah's sense of closeness to the mother's friend. In fact, Sarah rated her closeness with the

mother's friend as 2 ("I barely know this person") in the pre-questionnaire, but listed a 5 ("we're very close") after the study.

Challenge: Managing Circle Membership

Individuals and primary caregivers did not always assign the same significance to relationships or value the same method of maintaining contact with others. Some individuals expressed a willingness to defer to the caregiver for most of these decisions. Sarah explained that she did not object to her mother's addition of a friend to GroupMe: *"I honestly don't know [mom's friend], but I trust my mom enough to let her help me."* However, in other situations, participants wished to exclude members who were close to the caregiver but not to the individual. Sarah noted that: *"This is my stepfather. I just didn't put him on because it isn't comfortable at the moment, but not all the time"* Nevertheless, individuals relied heavily on their mother's input in selecting network members at the pre-study and did not make any change in members or circles by themselves.

Questions exist, therefore, about who should control the social network, the individual or the primary caregiver, or both. Because the goal is to support an individual's transition to independence and adulthood, conflicts between the individual and the caregiver will inevitably emerge. Disagreements could arise in situations where the caregiver may invite a person with whom the individual is not comfortable or, alternatively, where an individual with autism may seek to include a person whom the parent does not see as being *"on the same page [with] our beliefs."* In fact, the mothers did not think they needed to have complete authority of managing membership. Rather, they anticipated that their children could develop an ability to create a social network on their own through GroupMe: *"I want him to be outside of family and friends … I want him to be able to develop his own network of friends." (Paul's mom)*

Another issue to consider is an inevitable tension between creating a circle of known and trusted participants versus extending participation to less known others to increase social opportunities, such as the diversity of relationships and ideas presented above. Sarah's mother noted that open participation in the network might lead her to worry about the quality of the provided responses: *"When she posts something on Facebook, she could get a ton of friends she does not know well. So the younger kids may not have quite thought out their answers."* She noted that members of the network needed to be vetted on a number of characteristics including: *"[their ability to] understand her strength and her weaknesses with Asperger's … They need to understand what our religious beliefs are so that they don't suggest for her to do things that we wouldn't allow…"*

Challenge: Managing and Distributing Communication

GroupMe is basically a group broadcasting system. Participants used the technology appropriately to address the whole group (e.g., `[Paul's Message] what are all your plans for this weekend?`). However, group broadcasts and the resulting responses created significant message volume, which proved problematic for some members. This led one member to drop out on the first day. During the post interview, Sarah's mother noted: *"I had one person at the first day who said that 'take me off.' […] When you're getting responses from everybody, that can get to be way too much."* She tried to ameliorate the traffic flow: *"There was a couple of times that I was supposed to respond to say something, but I didn't because I thought, 'well, I don't want to bother everyone with this.'"* To cope with the group format, if a conversation between others became irrelevant or uninteresting, participants often stopped conversation on GroupMe and switched to other channels (e.g., phone call) to directly communicate with a selected person. Participants had to negotiate when they needed to sign off GroupMe and to determine to whom to direct their message, but it was not easy to determine whether a member was available for such communication.

DISCUSSION

In this paper, we investigated the opportunities and challenges of fostering the independence of young adults with autism. We investigated a specific feature, the focused communication circle that enables broadcast communication to a pre-defined set of people, particularly in the context of requesting help or advice. Our results suggest that this feature can be adopted for the specialized purpose of helping young adults with autism to seek help from individuals other than primary caregivers. In this section we will revisit our original research questions and propose a set of design alternatives to augment SNS to better serve individuals that have disabilities such as autism.

How does a single communication circle impact the type of topics and requests for help?

As we discussed in related work, general SNS users create diverse circles by reflecting their facets of life, tie-strength, and topical interests [14]. We expected to observe the similar behavior from our participants, but found that instead they created a unified circle and posted a variety of queries and comments. In the first few days or week, the individuals relied on their mothers' prompts to initiate conversations or to request help, but the participation of the primary caregivers dwindled as that of others increased. This demonstrates a distribution of responsibility for answering requests of help among friends and family members. Thus, it is seen that SNS may indeed lessen the previously reported over-reliance on primary caregivers.

Because social isolation impacts the independence of young adults with disabilities [15] and since SNS is inherently social and informal, it is therefore an appropriate outlet for discourse on social and leisure topics. However, request for help on other areas requiring more instrumental assistance, such as hygiene or attire management, did not occur. One explanation is that such questions may have been too sensitive to share in an SNS setting, or the individuals may not have known how to articulate the problem (e.g., a question about a romantic relationship that the individual does not want to ask parents, a number of questions about cosmetics that a woman would only want to ask a female). The unified circle may not always be suitable for discussing those unique questions. Some questions or requests would be applicable to only few members in the circle. We consider a design opportunity that could address this challenge by proposing an alternative way to create circles in the existing system.

How does the technology-supported communication impact existing practices? And how does it impact the strength of the relationship between the individual and the network of friends and family?

Our findings support the notion that SNSs mediate participants' communicative expression in two ways: passive engagement and active involvement. First, our findings resonate with the conclusion arising from past research that found that SNSs afford opportunities for passive engagement [21] that confers informational and social benefits to those with low self-esteem [5] or on the autism spectrum [6]. The three young adults in our study reported that they sometimes neither initiated a group conversation nor participated in it extensively, but they actually read the stream and sought to understand the intentions of other members as they communicated. By allowing them to passively observe how people initiate a discussion topic and respond to others, a shared discussion thread itself may serve as a tool for individuals with autism to learn social skills. Conversely, observing threads helped members understand some facts about the individual with autism. Thus, the discussion thread could also be a tool for critical reflection of an individual's emerging needs and concerns.

Next, active involvement allowed participants to receive both immediate responses, and over time, multiple responses to a request. While a previous study speculated about the possible risk of conflicting advice among SNS members holding different perspectives [10], we saw no evidence of this potential conflict in practice. However, caregivers still raised concerns about including members that do not share the caregivers' values. They wanted others to understand the specific attributes of their children such as their strengths and weaknesses related to Asperger's. Thus, in the next section, we will explore a way of improving value transparency and accountability.

GroupMe facilitated various communication practices that led to an increased sense of closeness to their group members whom they did not know well before the study. Our four-week field study also revealed that online interaction led to offline socialization, which was clearly a positive experience for both the young adults and their caregivers who wanted their children to seek social opportunities. However, in the long term, the use of the circle could have an unexpected impact on network relationships. One can imagine that being in a circle that centers around supporting the needs of one individual and that includes all of the other members' messages directed to the individual can become quite overwhelming and burdensome to the group members. Therefore, the long-term outcomes of SNS use within the perspective of network membership should be studied in more depth.

Design Opportunities

GroupMe was appealing to use for this investigation because it was freely available and offered cross-platform support for desktop, smartphone, and feature phone users. Having conducted this exploratory study, we see several opportunities for building specific features on the top of circle services.

Prompting contextual circle formation

Current approaches to creating circles focus on setting up groups for the purpose of controlling who receives particular messages during the early stages of system use. At the outset of our study, it was not clear to our participants whether and to what extent they should assign their family and friends to different circles. Furthermore, inexperienced individuals may not know what types of questions their social network members are willing to answer. Therefore, one design recommendation is to have the system suggest both themes for various circles and ideal members for focused communication within each circle. Future systems could, at any time, explicitly aid in circle creation by suggesting topics and inviting people that the user might find easier to discuss a topic with. Initially, a basic set of topics for circles could come from the seven independence skill areas, and group members could be invited to join any of the circles they wished. Additional circle topics may also evolve in the context of ongoing conversations within the system. Therefore, a circle may not be a permanent entity but rather a more contextual or perhaps ephemeral one as an individual's concerns or interests change. One direction for future work, then, will be to determine the factors and mechanisms that will produce valuable suggestions for circle formation and membership.

Profile articulation: Requesting and offering help

Knowledge about the individual's personality, personal and professional goals, and interests may help group members provide more effective support. To that end, a system could prompt and help young adults with autism to openly advertise their limitations so that group members can proactively provide advice or suggestions on those topics. This mechanism can be embedded in SNS profile management since a profile does not just depict one's identity, but mediates communication [4]. A young adult could thus identify skill areas that they want to improve. Conversely, the system may allow members to browse the needs articulated by the individual and choose which topics they would like to support. Other relevant system features could include prompts to group members regarding the areas that the individual identified as ones in which he or she has limited capabilities. These reminders could lead the members to reach out to the individual with specific information or suggestions.

Another profile idea is one expressed by primary caregivers who want to ensure that a member giving advice shares values and priorities similar to those of the primary caregiver's family. The primary caregiver may be aware of this information about individuals they already know outside of the SNS, but they would want some form of profile information about those they do not know, making the process more transparent.

Fine-grained communication control

As we discussed above, the downside of GroupMe included a high volume of messages. Since individuals had no way of knowing whether members' were available to communicate, they tended to broadcast a message to the entire group first, and only directed subsequent messages to a particular

individual once someone responded to the initial broadcasted message. Thus, tensions arose as the individual generated significant message volumes at times when members were not available to provide support. The current all-or-nothing mechanism for participation in the discussions within a circle is inadequate. We see the need for more fine-grained controls on discussion threads that enable a circle participant to opt in and out of various discussion threads, or allow active participants in a thread discussion to limit those who can see further messages.

The ability for group members to signal their availability for real-time support might help to ensure that a request for help is targeted at the right people at the right time. For example, a simple feature that turned off the network participation temporarily could serve both to signal to the individual that particular group member is not available, while simultaneously encouraging other members to make themselves available to cover for the diminished network size. Intelligence embedded in the system could also play a role; for example, recurring "unavailability" could be predicted based on the members' past behavior within the circle. A new design could attempt to handle the situation when too few members are available to participate. One possibility we have explored is the creation of a service of "trusted stranger," volunteers willing to provide input but who remain anonymous to members of a circle.

CONCLUSION

The goal of this study was to determine if specific communication features of a cross-platform social networking system such as GroupMe could reduce the barriers to independence experienced by individuals with autism. Our findings showed that circles of communication helped individuals overcome their over-reliance on their primary caregivers by increasing social closeness to others after a month of use. The identified design features, including contextual circle formation, profile articulation, and delicate communication control mechanisms, which have implications for adopting a system that supports independence, represent a promising direction for future work. These implications may also encourage researchers to explore issues faced by groups of users who would benefit from support for independent living.

ACKNOWLEDGEMENT

We thank all of our participants for making this study possible. We also thank UbiComp lab members and the many readers for their incredibly helpful comments. This research was supported by the Samsung Fellowship awarded to the first author.

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