

Social media experiences of adolescents and young adults with cerebral palsy who use augmentative and alternative communication

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Abstract

Purpose: This pilot study aimed to expand the current understanding of how adolescents and young adults with cerebral palsy (CP) and complex communication needs use social media.

Method: An online focus group was used to investigate the social media experiences of seven individuals with CP who used Augmentative and Alternative Communication (AAC). Questions posed to the group related to social media: (a) advantages; (b) disadvantages; (c) barriers; (d) supports; and (e) recommendations.

Result: Adolescents with CP who use AAC used a range of communication media to participate in daily interactions, including social media. An analysis of the focus group interaction revealed that the participants used social media to: bypass the constraints of face-to-face interactions; communicate for a number of reasons (e.g. maintain relationships, share experiences); and support independent leisure (e.g. playing games, looking at pictures/videos). Despite the advantages, the participants discussed barriers including limitations related to AAC technologies, social media sites and literacy skills.

Conclusion: The results suggest that service providers should implement interventions to support social media use, including enhancement of linguistic, operational and strategic competence. Technology manufacturers should focus on improving the designs of AAC apps and social media sites to facilitate access by individuals who require AAC.

Keywords: Social media, augmentative and alternative communication, cerebral palsy, focus group, adolescents, Facebook

Introduction

At the core of human connection is communication (Chayko, 2002). Implicit in this view, communication occurs when individuals engage in a dynamic and transactional process with a partner or partners (Kent-Walsh & McNaughton, 2005). Some individuals with cerebral palsy (CP) have significant speech and language impairments and require the use of augmentative and alternative communication (AAC) (such as signs/gestures, low-tech communication boards or books, speech generating devices and mobile technologies with AAC applications) to maximise their communication participation (Beukelman & Mirenda, 2013). For individuals with and without disabilities, communication environments have changed in the last 5 years, with increased recognition that maximising communication participation extends well beyond face-to-face interactions (Shane, Blackstone, Vanderheiden, Williams, & DeRuyter, 2012). Individuals who use AAC are expected to participate in a variety of communication environments, with a wide range of communication partners (Williams, Krezman, & McNaughton, 2008). Communicating through email and cell phones, as well as social media, are

all important activities in the 21st century and support full participation in society (DeRuyter, McNaughton, Caves, Bryen, & Williams, 2007; Light & McNaughton, 2014).

The number of individuals who participate in social media sites (e.g. Facebook, Twitter) has grown rapidly over the past 5 years (Duggan & Smith, 2013). Adolescents and young adults have embraced social media use and make up the largest demographic that uses these sites (Pew Research, 2010). A survey conducted by Pew Researchers (2010) indicated that 73% of American teenagers (12–18 years) and 72% of American young adults (18–9 years) participated in at least one social network (Lenhart, Purcell, Smith, & Zickuhr, 2010). Tsitsika, et al. (2014) surveyed adolescents in six European countries (Greece, Spain, Poland, the Netherlands, Romania, and Iceland; $n = 109\ 300$) and found 70% of adolescents used online communication tools every day. The Australian Communication and Media Authority (ACMA) found, as reported by Raghavendra, Newman, Grace, and Wood (2015), most typically developing young people are familiar with social networking sites, with 97% of 14–15 year old and 99% of 16–17

year old Internet users reporting that they have used some form of social networking online.

In 2014, Pew Researchers saw significant membership growth from previous years in the range of social media platforms used (e.g. Pinterest¹, Instagram², Twitter³), with Facebook⁴ continuing as the most used site for American Internet users aged 18 and older. Most recently, Pew Researchers (2015) found that the majority (71%) of American teens (aged 13–17) use more than one social media site. The top five social media platforms included Facebook (71%), Instagram (52%), Snapchat⁵ (41%), Twitter (33%), and Google+⁶ (33%); with Facebook remaining the most used social media site (Lenhart, 2015).

As Internet use continues to diffuse into daily routines, individuals are finding it easier to interact with their acquaintances (what Granovetter (1973) calls “weak ties”) and use the Internet to strengthen connections with their close friends (“strong ties”). Yet, interaction with others may not be the driving force of social media use, especially for adolescents. Hoffman and Novak (2012) extend this theory of increased participation in online environments, arguing that social networking and sharing behaviours have increased because social media offers the ability to connect (interact with people), create (post, upload pictures), consume (read or watch content), and control (tag, block, rate). Bolton, et al. (2013) noted that adolescents use social media to contribute, share, consume content, and play.

Despite the reasons for use, the popularity and pervasive use of a variety of social media platforms by adolescents and young adults has potential challenges and benefits for individuals who use AAC. Documented challenges that potentially impact successful social media for individuals who use AAC include poor literacy skills, reduced communication opportunities, communication partner supports, and physical access (Grace, Raghavendra, Newman, Wood, & Connell, 2014; Hynan, Goldbart, & Murray, 2015). Despite the challenges, communication via social media may offer some unique benefits to individuals who use AAC. For example, social media has the potential to: (a) provide users with access to a range of partners without the constraints of time and geographic location (Caron & Light, 2015); (b) reduce operational and linguistic demands with short text-based messages (Hemsley, Dann, Palmer, Allan, & Balandin, 2015) or photographs/videos; (c) give individuals a sense of achievement, confidence and competency (Hynan et al., 2015; Raghavendra et al.,

2015); and (d) increase communication opportunities and networks (Raghavendra et al., 2015).

There is growing but limited research about the advantages and challenges of social media use for adolescents and young adults who use AAC. Raghavendra, Wood, Newman, and Lawry (2012) interviewed 15 participants (mean age = 14 years) with physical disabilities, five of whom had communication disabilities and one who used AAC about Internet use. Hynan, Murray and Goldbart (2014), interviewed 25 adolescents and young adults (mean age = 20 years) who use AAC. Both studies found benefits and barriers to social media use. Participants, through self-report, shared that social media provided a means to keep in touch with people and allowed them to express themselves more fully. The main barriers the participants faced included reliance on family members to support set up/use of sites, lack of specialised equipment, difficulty with physical access and limited literacy skills. Raghavendra et al. (2015) found similar barriers when investigating the effectiveness of a home-based intervention using social media, in rural Australia, on enhancement of social networks. The study included eight adolescents and young adults (mean age = 15 years) with communication difficulties (two participants identified as currently using AAC strategies). Raghavendra et al. reported that learning to use social media leads to increased social participation, yet parents and service providers need more knowledge and training to integrate assistive technology with the Internet.

This emerging research evidence highlights some of the benefits and barriers of using social media for increasing social connections and bypassing challenges in face-to-face interaction for young people who use AAC. Given the importance of social media in the lives of individuals who do and do not use AAC and the limited research to date, the current study solicited the views and experiences of adolescents and young adults with cerebral palsy who use AAC and social media. The overall aim of the pilot study was to investigate these experiences, using a different research methodology from previous studies (i.e. online focus group instead of interviews), to inform AAC service providers and develop future AAC social media interventions.

Method

Research design

Ethics approval was obtained from the Human Research Protection Program prior to

¹Pinterest allows sharing and collecting through visual bookmarks (also called boards). Additional information is available from <http://www.pinterest.com/>

²Instagram is a social networking services that allows sharing of photos and videos. Additional information is available from <http://www.instagram.com/>

³Twitter is a social networking site that allows users to send and read messages with a maximum of 140 characters. Additional information is available from <https://twitter.com/>

⁴Facebook is an online social networking service. Additional information is available from www.facebook.com

⁵Snapchat is a video messaging application in which users can take photos, videos, and add text or drawings, and send them to recipients. Additional information is available from <https://www.snapchat.com/>

⁶Google + is a social network for Google services. Additional information is available from <https://www.google.com/>

commencement of the study. The current study employed a qualitative research design, as qualitative research supports exploration of new or under-researched areas in order to attempt to understand the unique interactions and experiences that occur within a particular situation (Balandin & Goldbart, 2011; Tracy, 2012). This research design allowed for the exploration of attitudes, perspectives and impressions of individuals who come from similar backgrounds and share common experiences (Tracy, 2012).

More specifically, the current pilot study employed the use of one online focus group. According to Tracy (2012), focus groups are “a group interview with 3–12 participants and marked by guided group discussion, questions and answer, interactive dialogue, and other activities” (p. 167). Online focus groups have emerged as a valuable research method (Stewart & Williams, 2005). In AAC research, especially, the use of online focus groups has led to the inclusion of individuals who use AAC in research, as both moderators and participants, in order to understand experiences of people using AAC (e.g. Caron & Light, 2015; McNaughton, Light, & Groszyk, 2001). Given the low incidence and geographic dispersion of the target population (i.e. adolescents and young adults with cerebral palsy who use AAC and are independently using social media), an asynchronous online focus group was used. The asynchronous nature of the discussion permitted the seven participants to participate with anonymity at their personal communication rate, during times that were convenient for them, despite their different geographic locations (Caron & Light, 2015; Hemsley, Balandin, & Togher, 2008).

Participants

Criteria for participation. The participants met seven inclusion criteria: (a) diagnosis of cerebral palsy; (b) under the age of 21; (c) complex communication needs whereby their speech was inadequate to meet all their needs and, therefore, AAC was used for some portion of the day; (d) able to independently produce written text, including in English; (e) access to the Internet and a means to participate in a text-based discussion online; (f) independent use of at least one form of social media (e.g. Facebook, Snapchat, Twitter) at least three times per week; and (g) willingness to commit to an online forum for 6–8 weeks.

Recruitment. Recruitment of participants was conducted through various means. Messages and materials were sent to three sources: (a) emails directly to researchers and clinicians in the field of AAC; (b)

web postings (i.e. Listservs for Speech-Language Pathologists or individuals who use AAC); and (c) social media sites (e.g. Facebook and Twitter). Once in touch with interested participants, information regarding the objectives of the study, requirements, and Wikispace⁷ (the forum for the focus group) were provided via email.

Participant description. A total of 11 adolescents and young adults responded to the recruitment invitations. Seven met the inclusion criteria and agreed to participate in the online focus group. Table I presents demographic information for the seven participants involved in the focus group discussion based on self-report. Participants included four females and three males, ranging in age from 14–21 (mean age=18). All participants had been diagnosed with cerebral palsy and used a variety of means to communicate. More specifically, all participants used high-tech speech generating devices and five out of seven participants used alternative access strategies when using social media and their AAC devices. As seen in Table I, five participants used more than one form of social media (e.g. Facebook, Twitter, Instagram), but all participants identified Facebook as their preferred social media site.

Materials

A Wikispace was used for the online discussion. A Wikispace is a website that allows for creation of interactive webpages, supports easy authoring and permits text-based discussion. This format allowed participants to post on the discussion topics, read others' comments and contributions and add comments within a discussion thread.

The investigators developed the questions posted to the Wikispace before the focus group began. Question development was based on a review of research related to cerebral palsy and AAC, as well as social media use by adolescents with and without disabilities (e.g. Hynan et al., 2015; Madden, et al., 2013). Before beginning the focus group, the primary author invited researchers and clinicians with experience working with adolescents and young adults with cerebral palsy to review the questions to confirm their relevance. In addition, readability statistics (in Microsoft Word) were run on the proposed questions, yielding a Flesch-Kincaid Level of grade 4.0. Questions posed to the focus group (available upon request) related to: (a) advantages of social media; (b) disadvantages to social media; (c) barriers to successful use; (d) supports to successful use; and (e) recommendations for other adolescents and young adults with cerebral palsy who use AAC and technology developers.

⁷Wikispace is a web application that allows collaborative modification, extension, or deletion of content. Information is available from <https://www.wikispaces.com/>

Table I. Characteristics of the participants.

Gender	Participant						
	Mary Female	Rita Female	Jenna Female	Sara Female	Tim Male	Nate Male	Ross Male
Age	20	14	18	18	21	19	20
Disability	Cerebral palsy	Cerebral palsy	Cerebral palsy	Cerebral palsy	Cerebral palsy	Cerebral palsy	Cerebral palsy
Educational placement	Special needs school	Mainstream Secondary iPad with Predictable app ^a	Special needs school PRC Accent 1000 + iPad ^b	Mainstream Secondary iPhone/iPad with Assistive Express app ^c	Special needs school Dynavox Vmax ^d	Special needs school PRC ECO2 ^e with ECOpoint	Did not report Tobii I-12
Means of communication	Tobii C-12	iPad with Predictable app ^a	1000 + iPad ^b	Assistive Express app ^c	Dynavox Vmax ^d	PRC ECO2 ^e with ECOpoint	Tobii I-12
Access	Scanning with headswitch	Scanning with hand switch and direct selection	Direct selection with hand	Direct selection with hand	Scanning with headswitch	Eye gaze	Eye gaze
Social media sites	Facebook, SnapChat	Facebook, Instagram	Facebook, Pinterest, Twitter	Facebook, Twitter, SnapChat, Instagram	Facebook	Facebook	Facebook, Vine
Preferred social media site	Facebook	Facebook	Facebook	Facebook	Facebook	Facebook	Facebook

^aPredictable App is a voice output application. Additional information is available from <https://itunes.apple.com/us/app/predictable/id404445007?mt=8>

^bThe PRC Accent is a voice output communication device. Additional information is available from the Prentke Romich Company at www.prentrom.com

^cAssistive Express App is a voice output application. Additional information is available from <https://itunes.apple.com/us/app/assistive-express/id379891874?mt=8>

^dThe Dynavox Vmax is a voice output communication device. Additional information is available from <http://www.dynavoxtech.com/tobii-dynavox/>

^eThe Eco2 is a voice output communication device. Additional information is available from the Prentke Romich Company at www.prentrom.com

Procedure

A short questionnaire was emailed to participants to gather background information related to current communication modalities and social media use. Upon completing and returning the background questionnaire, an email message was sent summarising participation requirements, which included: (a) visiting the Wikispace 2–3-times per week; (b) contributing to each topic's discussion by posting a minimum of three sentences; (c) commenting on other participant's posts when relevant; and (d) being respectful to other participants' ideas and experiences. Upon acknowledgement of the study requirements, participants were provided information about the Wikispace.

Participants were required to post an introductory message to the Wikispace. Additionally, they were encouraged to comment on at least one post, demonstrating that they knew how to participate. The moderator and participants sorted through any technological questions and barriers. After all participants had posted their introductory messages, the moderator presented the first question. A new question was introduced on the site after the majority of group members responded to the discussion topic (approximately one new question per 7–10 day period).

The first author served as the moderator and was responsible for maintaining the Wikispace (e.g. deletion of accidental multiple posts), presenting the discussion topics, and facilitating the discussion through probing questions (as needed), and sending out reminders to participants who did not respond and encouragement to those who did. At the end of the 6 weeks, the moderator reminded participants that the forum was closing and participants were asked to respond to any unanswered questions. After the forum was closed, an email was sent to all participants thanking them for their participation and summarising the themes discussed. This email served as a member check (Tracy, 2012). All seven participants verified that the emailed summary was accurate and no participants added additional comments.

Data analysis

As summarised by Balandin and Goldbart (2011), to insure the rigour of qualitative research, we analysed the data using four procedures recommended by Creswell (2007). The data were triangulated through crystallisation, peer review, an external audit and a member-check.

Crystallisation. The first procedure we used in data analysis was crystallisation. Crystallisation involves reflecting on the contributions by the participants to identify themes and patterns emerging from the data (Balandin & Goldbart, 2011). For crystallisation, the first author and a graduate student (trained in the process) first "unitised" the participants'

contributions to the discussion pages. The first author and graduate student then independently reviewed, sorted and organised the unitised thought units based on shared content of the message. The first author and a graduate student then independently developed themes post-hoc, based on their reviews of the participants' contributions. After discussion and review, we identified six themes that emerged from the data. The same process was completed for each theme separately to identify the sub-themes. Next, the first author developed operational definitions for the coding themes (Tracy, 2012). After trial coding and discussion between the first author and graduate student, each theme was designated a numeric code, based on the content and the operational definitions. The first author and graduate student independently re-coded the data based on the operational definitions of the themes and then compared the data to achieve agreement for the coding procedures.

Peer review. A peer review is the review of the data and process by someone who is familiar with the research or the phenomenon being explored (Lincoln & Guba, 1985). The second author served as the peer reviewer by asking questions about methods and interpretations and serving as a sounding board for ideas (Lincoln & Guba, 1985). This procedure was used over time, throughout the process of the entire study.

External audit. In order to examine both the process and product of the inquiry, a second graduate student, not involved in the crystallisation process, participated in an external audit (Balandin & Goldbart, 2011; Creswell, 2007). A graduate student was trained in the coding procedures. Once the graduate student achieved greater than 90% agreement with the standard, a randomly selected sample (representing 20% of the unitised data) was independently reviewed and coded by the first author and the trained graduate student. Cohen's Kappa was calculated, based on agreement of the first author and graduate student for the 20% of the total data, and resulted in an agreement of 0.90. Viera and Garrett (2005) consider kappa values above 0.60 satisfactory agreements and values above 0.80 as nearly perfect agreements.

Member check. As a final step of data triangulation, a member check was performed. With member checking, the validity procedure shifts from the researchers to participants in the study, as the interpretations are discussed with the participants (Balandin & Goldbart, 2011; Creswell, 2007). The first author sent an email to all the

participants thanking them and summarising the themes and sub-themes from the focus group. The member check allowed for respondent validation and discussion of interpretations with participants (Creswell, 2007). All seven participants verified that the emailed summary was accurate, based on their comments and experiences with social media.

Result

During the 7-week period of the focus group, the participants posted a total of 54 times and 2277 words (range of 6–11 posts per participant), to seven different discussion topics. Six of the seven participants posted responses for all seven questions posed by the moderator. One participant posted to six of the seven questions. In addition to addressing the questions initiated by the moderator, some participants posted comments and questions in reaction to the posts of others (e.g. "I use that site too" and "[participant] is right"). Table II provides a summary of the themes, sub-themes and examples of specific issues discussed by the participants. The results of this study are presented as per the six major coding themes that emerged from the data: patterns of social media use, advantages to social media, disadvantages, barriers to social media use, supports and recommendations to service providers, technology developers and other individuals with cerebral palsy. Pseudonyms have been used throughout the text to protect confidentiality of the participants⁸.

Patterns of use

All of the participants discussed the social media sites they used. Facebook was their preferred social media site and was used by all seven participants. Additionally, the participants discussed features that they used frequently and especially enjoyed (e.g. videos, instant messages, pictures, games). For example, Sara said:

I have Twitter, Instagram, Facebook, [Apple] Messages and Snapchat. I write posts on my Facebook [wall], but I use the message [feature] with my school friends. We talk about school and private things we can't talk about while at school. I also put pictures on my Instagram [page].

Mary and Nate used Facebook in similar ways to each other. Mary said, "I use Facebook on my iPad and Tobii⁹ to see pictures of my friends and talk to my sister at college. It is easy. I also like to post pictures of the cool things I do." Nate shared, "On Facebook I post pictures of my friends and the memories we made." One participant, Rita, shared that she uses Facebook differently. She used specific features that Facebook has to offer. She said,

⁸The Web-based discussion did not easily support proofreading and editing as participants posted, we have made minor corrections of spelling and grammatical errors.

⁹The Tobii -12 is a voice output communication device. Additional information is available at <http://www.tobii.com/en/assistive-technology/north-america/>

Table II. Summary of coding themes and sub-themes and examples from participants.

Themes	Sub-themes	Examples from participants
Patterns of use		I use Facebook to post pictures of my friends and the memories we made.
Advantages	Keep in touch with family and friends Meet new people	I use social media to talk to friends who I go to college with.
	Entertainment	Social media helps me to connect to other people that like the same things. Social media also helps me to find new fun things. For example, I play games on Facebook all the time. You can also post and see pictures, videos and other cool stuff.
Disadvantages	Inappropriate use by members	The worst thing about social media is sometimes people use it inappropriately. Some people use it to pick on others and to make them feel hurt.
Barriers	Lack of direct contact Technology	I'd rather see and talk to people in person. Sometimes I get cut off [the social media site] if the Internet connection is bad on my device.
	Social media site Literacy	I cannot use Snapchat or Vine because I cannot get on the app[s]. I don't always know the word and know how to spell it. I don't always know if my posts are okay because of this.
Supports	Technology	I sometimes use prediction on my iPhone to help with my spelling of posts.
	Learning	I started using Facebook before I got my Tobii. I watched my dad and brother. They showed me a lot about Facebook. When I got my Tobii, my dad and brother helped me set it up. Then I surfed around on it [Facebook] and talked to my friends.
Recommendations	Technology	I wish for people who have speech problems to have an individualised dragon-like program that could understand their kind of speech.
	Adolescents with cerebral palsy	I think Instagram is the easiest to start. It's quick. You can post pictures and write as much as you want. You can start by sharing pictures of family, friends and activities you like.
Unrelated statements		Have a good day!

"I don't post a lot, but I 'like' photos and like to see what others have posted. I like that you can show off your favourite things (like TV shows, movies, music, games, sports and other things too). I like to watch the videos people post."

Advantages

The participants expressed three main advantages of using social media. These themes included use of social media to: (a) keep in touch with family and friends; (b) meet new people; and (c) entertain themselves.

Keep in touch with family and friends

Six of the seven participants discussed the use of social media to interact with friends and family. For example, Tim said, "I use social media to talk to friends who I go to college with." Jenna commented, "I use Facebook to talk with my friends and family as well." Nate expanded on Tim and Jenna's comments and shared that social media helped him maintain relationships over a distance. He said, "I like Facebook because I can talk to and see pictures of friends and family who live far away, who I cannot see [in person] all the time." Sara also shared how she used social media and the advantages of being able to communicate with lots of people easily. She said:

I use Facebook the most because its helps me know what is happening with my family and friends [through the use of] pictures and messages. I will continue to use

[social media] sites because they change everyday because people add new posts. I also like that if I send a message it can go to a lot of people not just one. I went to the prom and I sent my pictures to a lot of people not just one [person]. It was easy and I liked the comments [that others posted on the shared pictures].

Meet new people. Two participants discussed how social media allowed them to meet new people. These new connections expanded their personal networks. Rita discussed how social media allowed her to meet people with similar interests. She said, "Social media helps me to connect to other people that like the same thing. For example, you get to meet new people from many different countries and talk about things you both like." Social media also offered an avenue to find and give support to others with similar disabilities or life experiences. Ross said, "I think an advantage of using social media is you get to make new friends. It is a way of communication ... I will continue to use social media. I enjoy it and I can meet and encourage people with disabilities through it."

Entertainment. In addition to the benefits of social media related to maintaining and expanding social networks, participants discussed the use of social media for entertainment and leisure. Rita said, "Social media also helps me to find new fun things. For example, I play games on Facebook all the time. You can also post and see pictures, videos and other cool stuff." The multi-media features were also a draw for Tim. He said, "For me, I talk to people about the same things on Facebook [and in person]

... but I like that you can look through different things like pictures and videos.” Sara added, “I like to use social media because it’s fun!”

Disadvantages

Despite the advantages of using social media, participants also discussed some disadvantages of using social media. Two sub-themes emerged from the discussion, including: (a) inappropriate use by members of social media sites and (b) lack of direct contact.

Inappropriate use by members. The first sub-theme was about issues surrounding behaviour in cyber environments. Participants shared stories about how social media can hurt others’ feelings. Rita said, “The worst thing about social media is sometimes people use it inappropriately. Some people use it to pick on others and to make them feel hurt. I try to block those people.” Nate added, “You can post things that upset people and everyone will see it. You need to be careful what you post.” Jenna shared about a time that she posted something to social media that hurt her friend’s feelings:

I had a bad experience. I got in a big fight with one of my good friends. I posted some things on Facebook that I am not proud I wrote. Everyone saw what I had posted. I felt so bad.

Social media presents opportunities for people that you do not like or know well to interact with you. Sara shared her experience with members contacting her when she did not want to talk to them. She said:

The bad thing about social media is that people you don’t want to talk to or know can contact you. This is annoying. They ask me questions I don’t want to answer. If it keeps happening, and I don’t know or like them, I block them on Facebook.

Lack of direct contact. Participants highlighted the differences between interactions over digital media and those involving direct face-to-face contact and described some of the challenges in interactions via social media. Mary said, “I’d rather see and talk to people in person.” Like Mary, Nate preferred face-to-face communication. He said, “People can lie easier online because you don’t see them. Talking in person is better because you have to be more honest.”

Jenna shared her perspective, “Talking on Facebook and talking with a person face-to-face have their differences (like if you are talking to a friend on Facebook you cannot see their face and that can be hard), but I like to use both!” Sara made similar observations related to direct contact and the use of facial expressions supporting communication interactions. She also highlighted the

asynchronous nature of social media interactions. She said:

Sometimes I need to see person’s face when I talk with them. It lets them know how I feel or how they feel. Also, I don’t like how sometimes it can take a person a long time to respond to me on social media. In face-to-face communication that doesn’t happen.

Barriers

Although the participants discussed many benefits to using social media, they also highlighted barriers that prohibited their full use. Some participants shared that they were not able to access certain social media sites, other participants shared that they needed help to use certain features on the sites. Three sub-themes emerged from the discussion including: (a) technology barriers; (b) social media site barriers; and (c) literacy barriers.

Technology barriers. The first sub-theme addressed the technology barriers that were encountered by participants when using social media, ranging from portability issues to access problems and specific AAC software features. Related to portability, Tim said, “My AAC device is old. I cannot take it with me anymore when I am on the move. Therefore, I cannot go on my social media websites everywhere.” Mary added to Tim’s comment, sharing that at times she has issues with consistent access to social media. She said, “Sometimes I get cut off [the social media site] if the Internet connection is bad on my device.”

Mary and Rita shared their experiences with barriers related to access. Both Mary and Rita use a switch to access their AAC devices and social media. Mary said, “It is hard for me to use my switch with Facebook.” Rita agreed stating, “It’s hard to get around on Facebook because I can’t use my switch with it easily.”

Mary elaborated on the barriers she faced. She compared using dedicated technology vs mainstream technology. Currently Mary is not independent in using Facebook on mainstream technology [iPad], but can independently upload pictures and post to Facebook on her Tobii [speech-generating device]. She said:

I use Facebook through my Tobii. I don’t like that it doesn’t notify me of my messages. It is a lot of steps to post pictures on Facebook through my Tobii. It is hard but I can do it by myself. When I use Facebook on my iPad, I need to have someone else do it for me.

Social media site barriers. Participants also raised issues concerning social media sites. Five of the participants discussed social media sites they would like to use, but could not access for reasons related

to motor control or features within social media sites that were challenging. Tim said, “I cannot use Snapchat or Vine¹⁰ because I cannot get on the app[s].” Ross echoed Tim’s thoughts, “I wish I could do Snapchat. Also, I wish I could do Instagram. Right now I can’t do those [on my Tobii].” Jenna wrote more generally about her observations of some of the social media sites, “There are some sites and apps out there that are good; people who have disabilities can use them. Other sites and apps are not good for people who have disabilities. That can be frustrating.”

Three participants discussed barriers when social media sites change and are constantly updating. As Jenna said, “Facebook changes so much. It can be a good change or a bad change.” Nate said, “Sometimes I find Facebook hard to use when they update the website and change it around. I am good at picking up on technology, so I don’t think it is very hard. Just sometimes, it is difficult to get used to.” Sara added, “Sometimes it takes a lot of time to keep up my [social media] pages. When the sites change, I need to figure out how to post my pictures and comments again.”

Literacy barriers. In the last sub-theme, three of the participants identified their literacy skills as a barrier to using the full range of features provided within social media. Sara and Jenna shared their personal experiences related to literacy barriers. Sara said:

I use Snapchat, Facebook, Instagram, and Twitter. I don’t have trouble getting on to sites I want to. I don’t have a problem understanding how the sites work, but sometimes it’s hard to write because I don’t have spell check. I don’t always know the word and know how to spell it. I don’t always know if my posts are okay because of this. Also, sometimes I don’t understand posts because the words that are used are hard for me.

Jenna shared a similar experience:

I have a hard time using Facebook with my reading and my spelling. With my hard time reading, it is not easy for me to read other people’s posts on Facebook. [I either need] someone to read the posts to me or I use the help of a disability app on my computer, iPad or iPhone. With my spelling, sometimes my posts do not come out right. I sometimes need to ask someone to spell a word for me or I use a disability device [PRC Accent¹¹].

Supports

All participants discussed how they were supported in learning to use social media. Additionally, some participants mentioned technology supports that were used to mitigate some of the barriers and

challenges that they faced when using social media. Based on the discussion, two sub-themes were identified in this topic: technology and learning supports.

Technology supports. Technology supports were available and utilised on both mainstream and dedicated devices. These technology supports allowed some participants to independently access social media despite literacy and access issues. As Jenna said:

I use many different devices to use Facebook. I have an iPad, iPhone and Accent [AAC device]. The iPad/iPhone help me to use Facebook everywhere I go. I also have a device called the Accent that helps me write what I want to say and then send it to Facebook. This makes it easier to talk to my friends on Facebook ... When I don’t use this [the Accent], because of my spelling, sometimes my posts do not come out right. These devices make it so much easier.”

Sara added, “I sometimes use prediction on my iPhone to help with my spelling.”

Learning supports. Five of the seven participants said that they learned how to use social media by themselves. All of the participants added that they watched friends or family members use social media and learned through observation. Sara said, “I learned [how to use] social media by myself. My sister and brother use it too so I watched them.” Similarly, Rita shared, “I first learned how to use Facebook by playing games with my dad on my dad’s account.” Jenna discussed her perspective, sharing that she learned by herself but had some help getting her AAC device to work with social media:

I think that the new generation just knows how to use social media. They do not need somebody to teach them how to use it because everyone is using social media today. I learned how to use social media just by watching my friends. Then my teachers taught me how to use [access and integrate] social media with my devices.

Like Jenna, Ross shared a similar learning experience. He said:

I started using Facebook before I got my Tobii. I watched my dad and brother. They showed me a lot about Facebook. When I got my Tobii, my dad and brother helped me set it up. Then I surfed around [Facebook] and talked to my friends.

Tim shared a different view. He shared about his learning experiences at school. He said, “In school I learned about being safe when I go online. That was good, but I did not learn about the things you can do when you go on social media.”

¹⁰Vine is a video sharing service where users videos are published. Additional information is available at <https://vine.com>

¹¹The PRC Accent is a voice output communication device. Additional information is available from the Prentke Romich Company at www.prentrom.com.

Recommendations

All participants were successful users of social media, yet they reported that they had to overcome a variety of barriers to do so. In reflecting on their learning experiences and current social media usage, two sub-themes emerged: (a) recommendations for technology developers and (b) recommendations for adolescents with young adults with cerebral palsy.

Technology developers. The participants provided suggestions for mainstream social media technology developers and assistive technology manufacturers regarding ways to improve access and use. One participant commented about his hope for mainstream technology developers to collaborate more with assistive technology developers. Ross said:

I wish to [have more] integration of things like Snapchat, Instagram, and Vine in my device. The little short videos are usually funny. Things like that would be great. My thoughts on how to make this happen ... get developers of [social media] sites and developers of communication devices to talk. If they talk, they can make it happen.

The recommendations for assistive technology manufacturers ranged from personalised speech to text dictation programs to better alternative access and more literacy supports. Rita shared "I wish for people who have speech problems to have an individualised dragon-like [Dragon Dictation] program that could understand their kind of speech. That would make it faster and easier for communicating with other people all over the Internet." Rita also added comments related to access. She said, "I want Facebook and other social media websites to work better with my switches." Sara wished for spelling supports. She said:

I would like spell-check and prediction on social media sites because sometimes I don't know [how to] spell [a word]. I also would like the sites to read to me. Sometimes the letters would be easier to read if they were bigger.

Participants additionally made recommendations to mainstream technology developers, specifically to social media site developers. Nate said, "It would be cool if Facebook had slide shows of your pictures. This would make it easier to just click once and see all of your friends' pictures." Mary also made a comment related to making social media sites easier to use; she said, "I want social media sites that are simpler and easier to be scan-able. Also all the links are sometimes overwhelming."

Jenna had a different view in regards to recommendations for future social media designs. Jenna shared about the different supports that social media could offer to individuals with disabilities. She said:

My one big thing that I want to see in social media is more support and ways for kids with disabilities to

express [themselves]. I think that kids who have a disability get left in the dark and they need to come out from that darkness and tell their stories about having a disability. They need to share with one another and with people that do not have a disability. I want to see social media apps for people who have a disability.

Individuals with cerebral palsy. In addition to recommendations to developers, participants provided recommendations for other adolescents and young adults with cerebral palsy related to social media. The participants encouraged others to join social media. As Tim said, "I wish that more people used social media. It is frustrating when my friends don't have social media because I cannot talk to them as much. I would tell people to join. It is easy." Sara gave an idea of how individuals can start using social media. She said, "I think Instagram is the easiest to start. It's quick. You can post pictures and write as much as you want. You can start by sharing pictures of family, friends, and activities you like." Rita also encouraged others to join. She said, "You can do lots of different things, like look at pictures and play games. You should do it because it is fun!"

Discussion

The results of this study demonstrate that social media played an important role in the lives of all seven of the participants who had cerebral palsy and communicated with AAC.

Patterns of use

Previous research related to social media use by adolescents who use AAC (e.g. Hynan et al. 2015; Raghavendra et al., 2012) has not included detailed information in regards to number and variety of social media sites used by adolescent participants. Yet, this study's findings were similar to recent Pew Researcher's (2014, 2015) findings with Facebook as the most preferred and used site for all participants. This study and Pew Researchers (2015) also found that 71% of the participants (five out of seven participants in this study) used more than one social media site. This study did differ from Pew Research findings in regards to use of popular social media sites. For example, the seven participants used less of the social media sites suggested as popular in the Pew Research study (e.g. Twitter) and reported no use of certain popular social sites (Google+). In addition to a potentially biased sample and small sample size (only seven participants), challenges with literacy, physical access, and technology compatibility might account for the differences between this study and Pew Researchers' findings. The participants' documented challenges with literacy and physical access could potentially explain why they talked about more visual-based social media sites, like Instagram, rather than more text-based

sites, like Twitter or Google+. In addition, participants reported the inability to use certain social media sites with their AAC devices (e.g. SnapChat).

The main uses of social media sites by adolescents, as documented by Bolton et al. (2013), included contributing, sharing, consuming content, and playing. The results from the seven participants, and previous social media research with individuals who use AAC, were consistent with this finding (Hynan et al., 2015; Raghavendra et al., 2012). For example, the participants discussed how they contributed by posting new status updates, shared by adding photos, consumed content by looking at photos and following pages and people, and played games with others through social media. These results differ slightly from research with older individuals who use AAC and social media (e.g. Caron & Light, 2015; Hemsley et al., 2015), as these participants' experiences focused on social media use for sharing and consuming information and did not talk about social media use for playing games (e.g. Farmville).

Benefits

There has been limited prior research investigating the benefits of social media specifically by adolescents and young adults with cerebral palsy who use AAC; just three prior studies including information from less than 30 individuals. Even so, the findings of this study, related to the benefits of social media, are relatively consistent with the findings of prior studies that have investigated social media use by individuals who require AAC.

Prior research has found that individuals who use AAC primarily use social media for the purpose of connecting to others (Caron & Light, 2015; Hynan et al., 2014; Raghavendra et al., 2012, 2015). Additionally, prior research also reported that social media has supported participation, increased inclusion in social communities, reduced isolation and increased social network, and increased self-representation and confidence (Caron & Light, 2015; Hemsley et al., 2015; Hynan et al., 2015). Participants in this study reported similar findings, including the focus of social media for connection, participation, and inclusion. Participants in this study did not discuss feelings of isolation or increased self-representation and confidence due to social media use.

In addition, previous studies of social media use by individuals who use AAC found that social media was used to overcome the constraints faced within other communication modalities (e.g. face-to-face interactions) (Caron & Light, 2015; Raghavendra et al., 2012; Sundqvist & Ronnberg, 2010) and to minimise interaction effort (Caron & Light, 2015; Hemsley, Palmer, & Balandin, 2013; Shpigelman & Gill, 2014). Unique to this study, individuals with cerebral palsy who use AAC provided more detailed

strategies of how they overcome some of the constraints of face-to-face interactions. Challenges of face-to-face interactions included the synchronicity of communication, time for composition and linguistic demands. Participants commented that they were able to communicate when they wanted, with time to compose their thoughts on social media, capitalising the asynchronous nature of social media sites. Additionally they capitalised on reduced linguistic demands by using only short segments of text, benefitted from the reduced importance of spelling and increased reliance on photos and videos and used acceptable social media shortcuts (e.g. "like" button to comment or "retweet" to share information).

Similar to findings by Hynan et al. (2015) and Caron and Light (2015), although all the participants liked and used social media, they also valued face-to-face communication and did not want social media to replace face-to-face interactions. As one participant said, "social media is a way of communication." It is one way, or one communication option, of many that the seven participants with cerebral palsy used.

Barriers

Despite the many benefits, the participants noted barriers that prevent them from maximising social media use. The seven participants in this study discussed barriers related to their AAC technology, physical access, preferred social media sites and poor literacy skills. These barriers are similar to those reported by previous researchers (e.g. Grace et al., 2014; Hynan et al., 2015). Participants shared that their AAC technology does not easily integrate with all the social media sites they wanted to use. Additionally, all three of the participants who use scanning as an access method made comments about how hard it was to use their switches with social media sites. Many participants shared that their preferred social media sites update and make changes, therefore increasing operational demands as they learn to re-navigate the site. As Hynan et al. (2015) and Grace et al. (2014) reported, the orthographic demands of many social media sites pose barriers to independent and maximised use of social media. As society becomes increasingly text-based and technology reliant, these barriers have implications on service provision, technology development and the type of social media participation by adolescents with cerebral palsy who use AAC.

Implications for practise and technology development

Despite facing barriers, all the participants liked and independently used social media. In addition, they also valued face-to-face communication and did not want social media to replace face-to-face interactions. The experiences of the seven participants

contributed to the growing body of research documenting that having only one communication mode, partner or communication environment is insufficient for full participation in today's society (Caron & Light, 2015; Light & McNaughton, 2014; Williams et al., 2008). However, the increased expectations for participation in a variety of communication environments by adolescents and young adults who use AAC have posed implications for practise and technology development. These implications are explored in relation to recommendations from participants and previous research.

Implications for practise

Society, and adolescents in particular, have embraced the trend of multimodal communication, including on and offline communication (e.g. emailing, texting, blogging and posting to social media sites). Despite the importance of social media for adolescents, six of the seven participants in this study reported that they had had to learn to use social media on their own; relying on family or friends for guidance and support. Speech-language pathologists need to be aware of the significant benefits of social media for adolescents and young adults who require the support of AAC due to complex communication needs. Yet, recognition of the benefits of social media is not enough.

With the expansion of communication environments, the skills required to become a competent communicator increases (Light & McNaughton, 2014). Due to this, AAC intervention should extend beyond the traditional focus on face-to-face interactions to attain communicative competence across a broad range of online and offline situations (Caron & Light, 2015; Raghavendra et al., 2015). Participants in this study and previous research indicates that people who use AAC and social media need information and guidance on strategies for utilising all communicative functions and purposes of social media platforms (Hemsley et al., 2015). Emerging research has demonstrated that young people with disabilities, some of whom use AAC, can learn to use the Internet and social media, in turn having a positive impact on their social networks (Raghavendra et al., 2015).

Service providers need to consider intervention in social media use not only with adolescents and young adults who use AAC, but also with their families and AAC service providers (Raghavendra et al., 2015). The participants in this study relied on their families to assist them in social media use. Research suggests that families need and want support from professionals in the use of mobile and other technologies (Meder & Wegner, 2015); yet families may have concerns about social media. They may not see any benefit to social media use or they may be nervous about allowing their children to be online independently (Raghavendra et al., 2015).

Families may require training and support to understand potential applications of social media for adolescents and young adults who use AAC and may need assistance with technical operation and set up of AAC technologies and social media sites to ensure reliable access.

Implications for technology developers

The attainment of communicative competence requires not only intervention to teach individuals who use AAC the necessary linguistic, operational, social and strategic skills, but also concerted intervention to eliminate barriers that impede communication (Beukelman & Mirenda, 2013; Light & McNaughton, 2014). The results of this study and previous studies related to social media use by other populations who require AAC, suggest that current technologies may create barriers to effective social media use (e.g. Caron & Light, 2015; Hynan et al., 2014; Raghavendra et al., 2012). In order to benefit from social media to enhance communication, individuals who use AAC need access to: (a) social media tools that are easy to learn and use; (b) AAC systems that are integrated seamlessly with mainstream technologies (supporting full access to all the communication options that individuals without disabilities have); (c) alternative access techniques that allow efficient control of AAC devices and social media sites; and (d) AAC and social media platforms that have consistent designs to reduce operational demands.

Previously, individuals who used AAC were often expected to rely on one technique that may have been effective in a single environment (Williams et al., 2008). Yet today, there are increased expectations for participation; including demonstration of communicative competence across a range of communication environments and partners, including social media (Light & McNaughton, 2014). The increased demands pose new challenges to individuals with complex communication needs (and the partners who support these individuals), yet, through collaborations between mainstream technology and AAC developers, researchers and individuals who use AAC, advancements in technology can support, not impede, communicative competence. Specifically, it is paramount to focus on human-computer interface design that responds to the needs of individuals with a wide range of skills in order to maximise performance (Light & McNaughton, 2014).

Limitations

This paper is based upon the findings of only one focus group with seven individuals; consequently, the outcomes must be considered with caution. The results of this pilot study would be strengthened with additional focus groups and different

questions, as recommended by Morgan and Kruger (1998). As in any self-report, the contributions of the participants in this study may have been influenced by their memory of particular events. Their reports may or may not reflect their actual use of social media. Furthermore, due to the method used, the study does not offer information about how the perspectives of adolescents and young adults with cerebral palsy may alter over time due to changes in their needs, physical capabilities and changes in the environment (e.g. technologies and service delivery).

The participants all had access to the Internet and independently used social media at least three times per week. Due to purposeful sampling, individuals who were not successfully using social media were excluded from this study. The views and experiences of individuals who differ in diagnosis, literacy skills and/or frequency of social media use (or lack of use) could potentially deviate from those of the participants in the current focus group. Although five of the seven participations used more than one social media site, all of the participants in this study expressed a preference for Facebook. Further insights might have been obtained (or the findings of this study verified or expanded upon) had the participants included people who meet the inclusion criteria but preferred a variety of social media platforms (not just Facebook).

The pilot study reflected traditional qualitative research designs, presenting individual experiences of social media through data triangulation (Balandin & Goldbart, 2011). Unique to previous research with individuals with complex communication needs who use AAC and social media, this study uses focus group methodology instead of interviews and observations. Despite this contribution, the study did not explore the size, makeup or structural layers of the social networks as seen by Hemsley et al. (2015). Further research using these techniques are required to extend our understanding of the experiences of adolescents and young adults who use AAC and social media.

Future research directions

Based on the results of the current investigation, there are several potential directions for future research. Further research is required to extend our understanding of the experiences of adolescents and young adults who use AAC. Future studies should include replications of this study with other adolescents and young adults with cerebral palsy with various social media site preferences, as well as individuals with other diagnoses that require AAC, especially those who are not successfully accessing social media. A variety of qualitative research studies (e.g. interviews, focus groups) could continue to

contribute to the growing understanding of social media use by individuals who use AAC.

More sophisticated and technical examination of social media data by young people who use AAC is needed. Observational, case studies, social network analysis and hashtag research could potentially delve further into how individuals with and without disabilities actually communicate via social media (e.g. preferences for media such as text, photos or videos; common communication topics), who they communicate with and what type of communication on social media sites increase participation and communication partners' responsiveness. Intervention research is also needed to investigate the skills required to be successful communicators through social media and the progression in acquisition of skills related to independent social media use. Emerging research indicates that individuals with disabilities can learn to use the Internet and social media, yet future research should examine appropriate starting points, methods of learning and the required supports.

Conclusion

The ultimate goal of intervention for individuals with complex communication needs is to support the development of communicative competence so that these individuals have access to the power of communication through a full range of communication supports (Light & McNaughton, 2014). As social media use, texting, instant messaging and emailing have pervaded society, these outlets have become accepted and necessary forms of communication, yet recognition of the value of social media (and other electronic modalities) for individuals with complex communication needs has not been fully translated into practise (Caron & Light, 2015).

Individuals with complex communication needs face increased requirements for linguistic, operational, social and strategic competencies in order to maximally participate in on and offline environments (Light & McNaughton, 2014). Despite the exciting technological advancements, some individuals still face barriers related to literacy, technology and policy, preventing them from access to communication through social media. As clinicians, technology developers and policy-makers move forward, it is of utmost importance that they consider access to on and offline communication, collaborate to mitigate barriers and provide support to develop and maximise communication competence for adolescents and young adults school students who require the supports of AAC so that all adolescents and young adults who use AAC have the opportunity (if they choose), to say, "I use [social media site] to talk with my friends and family!"

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