Friendship experiences of young adults who use Augmentative and Alternative Communication

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Abstract

Background: Friendship is a crucial relationship for young adults with disabilities as it offers practical support and enjoyment, and it is essential to well-being and health. The present study examined the friendships of young adults with physical disabilities whose challenges with natural speech necessitate the use augmentative and alternative communication.

Methods: Ten adults aged 19-32 were interviewed about their friendships. The semi-structured interviews were often co-constructed conversations between the participant, the carer and the interviewer. A process of largely inductive thematic analysis was followed, although this was guided by the existing literature on friendship experiences of persons using AAC.

Results: Four themes were identified, namely companionship, quality of friendship, desire for independence, and the role of technology in mediating friendships.

Conclusion: The participants in this study experienced positive relationships with friends. The importance of being understood by their friends and the role of social media in maintaining these friendships were highlighted.

***Key words*:** Augmentative and alternative communication, co-construction, communication disabilities, friendship, social media.

1. Introduction

Social relationships and friendships make an important contribution to the quality of life of all people (Amichai-Hamburger, Kingsbury, & Schneider, 2013), including those with disabilities (Batorowicz, Campbell, von Tetzchner, King, & Missiuna, 2014; Chappell, 1994;

Friedman & Rizzolo, 2018). Friendship is described as one of the most important human relationships (Brent, Chang, Gariépy, & Platt, 2014; Salmon, 2013) as it provides companionship, assistance, guidance and support. The importance of friendships increases with the advent of adolescence and adulthood (Noller, Feeney, & Peterson, 2001), since an increasingly higher priority is given to the influence of peers when personal identity issues develop and need to be resolved (Ponti, Guarnier, Smorti, & Tani, 2010). Friends are perceived as the primary source of guidance, opinion formation and social support (Collins & Laursen, 2000). Friends may also be a refuge from conflict within family relations during adolescence and early adulthood when there is a need for greater independence (Laursen & Pursell, 2009). Good friends seem to be closely associated with experiencing a high quality of life and improved health outcomes, and they contribute to psychological well-being and happiness (Demir & Davidson, 2013;World Health Organisation, 2015).

The centrality of communication in developing friendships cannot be denied. For persons without disabilities, the ability to express who they are build relationships, friendships and achieve emotional resonance with others seems to rely heavily of the use of spoken language (Wickenden, 2011b). For persons who lack functional speech and use augmentative and alternative communication (AAC), any decrease in either communicative effectiveness or emotional responsiveness may be expected to have a negative influence on the patterns of friendship acquisition and maintenance between themselves and persons who use speech to communicate (Anderson, Balandin, & Clendon, 2011; Therrien, 2019) This may be particularly true for persons who, in addition to relying on AAC, with its implications for reduced rate of communication, also have limited linguistic competence and are constrained by an AAC system with limited expressive capacity (Light, Arnold, & Clark, 2003). Persons with physical disabilities can experience additional barriers to friendship formation, including difficulties with transport and physical accessibility of community venues or the homes of friends, while also facing stigma related to disability that is possibly exacerbated by the visibility of their disability (Antle, 2004; Stevens et al., 1996)

At the same time, there is evidence that persons using AAC (including those with physical disabilities) are able to develop and maintain friendships in spite of limited communication skills. Although these friendships may differ in some respects from those amongst persons using speech, researchers and clinicians should guard against a normative definition of and framework for friendship. It has been questioned, for example, whether the construct ‘friendship’ can be objectified and measured from observations and reports by outsiders (Ladd, 2009; Therrien, 2019), and definitions of friendships have been shown to engender a degree of cultural and contextual bias (Crossley, 2015). Obtaining the view of persons who use AAC themselves on how they experience and perceive friendships may be the most valid way of understanding the phenomenon, and also of identifying possible barriers and support needs.

A few studies have investigated the perspectives of adolescents and adults who use AAC on social relationships and friendships (Cooper, Balandin, & Trembath, 2015; Therrien, 2019; Wickenden, 2011a; b). Cooper et al. (2015) interviewed six young adults with CP using AAC about their experiences of loneliness. Participants all indicated the importance of friendships as a source of support, but also noted that their communication limitations (being unable to speak) restricted their friendships, particularly with others with communication disabilities or other disabilities. Although AAC played an important role in mitigating communication challenges, its effectiveness relied, amongst others, on competent partners as well as the skills of the person using it. Wickenden (2011a; b) conducted a qualitative anthropological investigation into the life worlds of nine teenagers who used AAC. She found that teenagers emphasized their social-relational identity when defining themselves, and reported a small number of reciprocal friendships. At the same time, they also reported a desire for more friendships and increased social inclusion outside of the family. Therrien (2019) investigated the perspectives of eight literate adults who used AAC on their friendships via online interviews and a focus group. Although friendships sometimes developed from relationships that could be described a business or professional relationships (e.g., with paid carers), and although persons using AAC benefitted from the help of their friends, reciprocity and contribution from both partners in the friendship dyad were emphasised. Mutual enjoyment of each others' company was mentioned as a defining characteristic of friendships. Shared characteristics, interests, and activities were factors underlying friendships, even when the experience of using AAC or having a disability was not shared.

Factors that facilitated friendships were also noted in this study (Therrien, 2019). Participants noted that their competence in using what can be described as a generative form of AAC helped them to develop friendships. For example, they pre-programd messages into their AAC systems to speed up conversations. Shared activities were highlighted. Such shared experiences over time can foster a sense of belonging and provide topics for conversation (Østvik, Ytterhus, & Balandin, 2018). Positive attitudes towards persons using AAC, patience in communication interactions, and competence in understanding the communication of the person using AAC characterised the friends of persons who use AAC, as found in studies on the friendships between children using AAC and their peers (Anderson, Balandin, & Clendon, 2011; Østvik, Balandin, & Ytterhus, 2018). Online asynchronous communication methods were sometimes found helpful to reduce the challenges of communication rate posed by face-to-face interactions. Social media and technology can enrich friendship experiences of persons with disabilities and particularly those using AAC (Asbjørnslett, Engelsrud, & Helseth, 2011; Caron & Light, 2015; Cooper et al., 2015; Hynan, Murray, & Goldbart, 2014; Raghavendra, Newman, Grace, & Woods, 2013; Raghavendra, Wood, Newman, Lawry, & Sellwood, 2012). Social media can allow persons with disabilities more opportunities for self-representation, partly because they are able to compose messages in their own time without the communication rate requirements of face-to-face interactions (Hynan et al., 2014; Raghavendra et al., 2012). They may also be able to control what they reveal about themselves to others more than in face-to-face encounters (Hynan et al., 2014). Environmental factors that could hinder or support friendships included transport, accessibility of shared spaces, and the role of family members and professionals. Similar contextual factors were also found in a systematic synthesis of the perspectives of adults with intellectual disabilities on friendships and intimate relationships (Fulford & Cobigo, 2018)

From the research, it is clear that adolescents and adults with who use AAC value friendships, and strive to build and maintain them. It is also clear that they experience barriers to friendships, related to their communication and the physical and social environment. On the other hand, environmental facilitators (e.g., accessible physical and virtual spaces, accepting communication partners, and supportive networks) as well as competence in employing communication-enhancing techniques can foster friendship formation and maintenance. Since contextual factors can influence friendships in unique ways, the current study sought to understand the friendship experiences of young South African adults who use AAC from their perspective. In doing so, we aimed to gain a situated view of friendships for this group. The overarching research question was: How do young adults who use AAC describe their friendship with their best friend? The sub-questions posed were (1) How did these friendships come about? (2) What activities do they do with their friend? (3) What methods do they use to engage and communicate with their friends? and (4) How do they characterise their friendships (i.e. key factors that are central to the friendship)?

2. Method

2.1 Research Approach

This study aimed to understand the phenomenon of the experience of friendship in young adults who use AAC from their perspective. It was intended that the data would contribute to an understanding of the way in which persons using AAC view and experience friendship, as well as potentially supporting clinical practice. The focus is therefore primarily on the participants and their thoughts, experiences and circumstances, as reported by them in response to a semi-structured interview. In order to understand the friendship experiences of persons who use AAC, we adopted a qualitative research design.

2.2 Participants

Convenience sampling was used to recruit participants who were part of a Communication Empowerment Program run at a university. The program focuses specifically on empowering young adults with severe communication difficulties to communicate using AAC. It is run annually at a university-based institution, and participants take part in communication and empowerment training activities for the duration of 1 week. In order to participate in the project, the young adults have to be able to convey their own thoughts and meanings. They therefore typically use a form of AAC. They also have to have a basic understanding of English, and have the stamina to participate in daily workshop activities for a few hours at a time. Recruitment into the study was not contingent upon any additional selection criteria. All seven participants taking part in a particular year were approached in person during the program week. Additionally, three alumni of the program were contacted via sms or email. Information letters and consent forms were provided in easy English to both the participants and their carers who accompanied them to the empowerment project or a family member. The information letters were read out to the participants and their carers/family members. Participants were made aware that their participation was voluntary, and that they could withdraw at any time. They were also assured that their future involvement in the empowerment program would not be influened by non-participation in the research project. All participants and carers/family members gave consent to participate in the study and for video recordings to be made of the interviews. The study included 10 participants aged 19 to 34 years. One of the participants lived independently with a paid carer, whilst eight lived with their parents at home. One lived with his family most of the time but with a partner some of the time. De-identified participant details are presented in Table 1.

2.3 Interviews

The semi-structured interviews comprised five open-ended questions that pertained to the friendship experiences of young adults who use AAC. The structure of the interview was based on recommendations from the literature (Kvale, 1996) and commenced with a briefing, followed by introductory questions, follow-up questions, probing, specific questions and direct questions. The interview concluded with a debriefing. Participants were asked about their best friend, and to describe how and when the friendship began, how it is maintained, and the qualities of their friend. Follow-up questions such as “Can you tell me more about why s/he’s your best friend?” were also used. The interview guide is provided in the appendix.

Interviews with the seven project participants took place in a quiet room at the university facility. The three alumni of the project were interviewed in their homes in a quiet area. The interviews were conducted by the first and second authors, who are both speech language pathologists. The first author conducted six of the interviews, and the second author the other four. Both have extensive experience as communication partners with people who

Table 1

Participant Description

Participant Number	Pseudonym	Gender	Age	Diagnosis, GMFS[a] and MACS[b]	AAC device	Other mobile technology	Technology functions used for connecting with friends	Speech	Mobility	Carer present at interview	Basic Literacy
1	Nsizwa	Male	26	Cerebral palsy GMFCS: 4 MACS: 3	Laptop with orthography-based AAC software	Smartphone	Facebook SMS[c] Blackberry Messenger Voice calls	Mostly intelligible to familiar partners	Wheelchair	None	Yes
2	Dumisani	Male	32	Cerebral palsy GMFS: 4 MACS: 4	Laptop with orthography-based AAC software	Android Tablet Smartphone	Facebook WhatsApp SMS Voice calls	Mostly intelligible to familiar partners	Wheelchair	None	Yes
3	Fanyana	Male	29	Cerebral palsy GMFS: 4 MACS: 5	Laptop with orthography-based AAC software	Smartphone	Facebook WhatsApp SMS Voice calls	Mostly intelligible to familiar partners	Wheelchair	None	Yes
4	Noxolo	Female	19	Cerebral palsy GMFS: 2 MACS: 3	Laptop with orthography-based AAC software, alphabet board	Smartphone	WhatsApp SMS Voice calls	Sometimes intelligible to familiar partners	Ambulatory	Mother	Yes
5	Sanele	Female	21	Cerebral palsy GMFS: 5 MACS: 5	Laptop with orthography-based AAC software, alphabet board	Smartphone	Facebook WhatsApp SMS Twitter Instagram	Minimally intelligible, even to familiar partners	Wheelchair	Mother	Yes
6	Charmaine	Female	24	Cerebral palsy GMFS: 5 MACS: 5	Laptop with orthography-based AAC software, alphabet board	Smartphone iPad	Facebook WhatsApp SMS Twitter Instagram Voice calls	Minimally intelligible, even to familiar partners	Custom-made wheelchair	Paid carer	Yes

Participant Number	**Pseudonym**	**Gender**	**Age**	**Diagnosis, GMFS[a] and MACS[b]**	**AAC device**	**Other mobile technology**	**Technology functions used for connecting with friends**	**Speech**	**Mobility**	**Carer present at interview**	**Basic Literacy**
7	Thembe	Male	22	Traumatic brain injury	iPad with graphic symbol-based AAC application	Laptop Smartphone	Voice calls	Minimally intelligible, even to familiar partners	Ambulatory	Mother	No
8	Kabelo	Male	20	Cerebral palsy GMFS: 2 MACS: 2	iPad with graphic symbol-based AAC application	Smartphone	Facebook WhatsApp SMS Voice calls	Sometimes intelligible to familiar partners	Ambulatory	Mother	No
9	Rebecca	Female	20	Cerebral palsy GMFS: 4 MACS: 3	Laptop with orthography-based AAC software, alphabet board	Smartphone	Facebook WhatsApp Instagram Voice calls	Sometimes intelligible to familiar partners	Wheelchair	Mother	Yes
10	Lee	Male	34	Cerebral palsy GMFS: 4 MACS: 4	Laptop with orthography-based AAC software, alphabet board	Smartphone	WhatsApp SMS Voice calls	Mostly intelligible to familiar partners	Wheelchair	None	Yes

Note. The GMFS and MACS scores are given for individuals with CP.

[a] Gross Motor Functioning Classification System; [b] Manual Ability Classification System; [c] Short Message Service

use AAC, and were familiar with all the participants through the communication empowerment program.

2.4 Data collection

Ethics approval for the study was obtained in South AFrica. Six participants were accompanied by their carer to the interview, four elected not to have a carer present. Seven interviews took place in the researchers' office, and three interviews took place at the participants' homes. Each interview lasted approximately 60 minutes and participants were asked all questions. Interviews were video recorded to capture the non-verbal responses of the participants, particularly as many of their AAC methods were not speech generating. Confidentiality was maintained through assigning pseudonyms and removing any identifying information.

The carers that were present in six interviews were mostly biological mothers (n = 5). One was a paid carer who had been employed as the participant's primary carer for 4 years. The carers ranged in age from 40 – 54 years. Four of these carers spent extensive time with the participants every day. Thembe's mother worked full time, and Sanele lived in a school residence during term time. They therefore spent less time with the participants than the other carers. All carers assisted participants with activities of daily living, the extent of which was determined by the participant's physical disabilities. The role of the carers present during the interviews was to assist the participants to convey their responses to the interviewer. Familiar communication partners are often in a position to best understand not only the speech, but also other (often idiosyncratic) methods of communication (e.g., eye gaze and body movements) used by persons in need of AAC (Dowden, 1997). A knowledge of the participant's context and his/her friendships also enabled carers to clarify their messages to the interviewer.

Conversations with persons using AAC are often co-constructed with the communication partner(s) (Brekke & von Tetzchner, 2003; Solomon-Rice & Soto, 2011), and this was also the case for the interviews conducted for this study. Meaning was co-constructed between the person using AAC, the interviewer, and also the carer, when a carer was present. Strategies such as eli, questioning, prompting, offering interpretations, and repeating (primarily used by interviewers) were evident, and functioned to elicit information from the person using AAC, to request and suggest elaborations on the information provided, and to check understanding. Carers would also volunteer information and elaboration at times, and interviewers then attempted to establish if the person using AAC agreed with these contributions. The following is an example of a co-constructed message. In this case, the interviewer, carer and participant sat in close proximity to each other. The interviewer had a clipboard with paper on her lap, and a pen. She was positioned in such a way that both the carer and the participant could see her clipboard. Thembe had an alphabet board in front of him.

> Interviewer: What do you do with your friend Mash when you visit him?
> Thembe: (smiles) (looks down at sheet for a while and indicates on board M)
> Interviewer: (writes M on clipboard)
> Thembe: (indicates on sheet U)
> Interviewer: (writes U on clipboard)
> Thembe: (looks at clipboard then back at sheet, looks for a while then indicates C on sheet).
> Interviewer: (writes on clipboard C)
> Carer: Does he wanna say music?
> Thembe: (nods while looking at clipboards)
> Interviewer: Ok, he wanted to say music.

It is evident that Thembe provided information during each turn he took. The interviewer repeated this information by recording it in writing on her clipboard (within view of Thembe) in a way that Thembe could either agree or refute her recording. The carer suggested an interpretation (in the form of a question) once she believed she was able to predict what Thembe wanted to say (very possibly based on the fact that she is knowledgeable about the activities Thembe and Mash enjoy together). Thembe confirmed it, and the interviewer repeated the interpretation to confirm her understanding. It is clear that Thembe's alphabet board, the writing strategy of the interviewer, as well as the carer's guessing strategy all contribute towards the construction of meaning. While it is clear that the participant is not communicating independently in the sense that he is reliant upon partners to assist in the co-construction of meaning, the process should still preserve his communicative autonomy (i.e., his ability to bring across their own intentions of meaning in communication without being imbued by others' incorrect or partially correct interpretations of these (von Tetzchner & Grove, 2003).

2.5 Data Transcription

The interviews were transcribed verbatim, and notes were made of the non-verbal communication of the participants (McLellan, MacQueen, & Neidig, 2003). Approximately 40% of the transcripts were independently checked for transcription accuracy and minor modifications to transcripts were made. A form of member checking was performed during the course of the interview, as the understanding of the information provided by the interviewee was confirmed repeatedly by the interviewers.

2.6 Data Analysis

The researchers employed the technique referred to as 'conventional qualitative content analysis', where categories are drawn directly and inductively from the collected data (Hsieh & Shannon, 2005). This method of analysis, which consists of an inductive, reflexive analysis, focuses on the emergence of ideas, codes and thematic structures rather than the frequency with which particular words or objective content occur (Soffer & Chew, 2015). The stages of the data analysis followed those outlined in the Framework Analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013), where texts were assigned codes inductively. The first author initially read the transcriptions in their entirety, including verbal and non-verbal elements, and the meaning or significance of the text as a whole was determined. She then read the transcripts several times and underlined messages (often co-constructed) that were essential to the friendship experience of the participants. She inductively assigned codes to the identified text units. As this process unfolded, she adapted and refined the codes in an iterative manner, to refine and accommodate the new codes (Fereday & Muir-Cochrane, 2006; Gale et al., 2013). Once all the transcripts were coded, the two authors coded and analysed transcripts independently, and thereafter worked together inductively to classify the codes by similarity into themes. Disagreements were discussed until consensus was reached. This peer review of coding enhanced the interpretive rigour of the analysis (Ryan & Bernard, 2003). Although the analysis was largely inductive, the researchers were guided by the themes around friendship experiences of persons using AAC previously identified in the literature (e.g., Anderson et al., 2011; Cooper et al., 2015; Østvik et al., 2018). Member checking was only conducted during the interview to ensure that the interviewer had correctly understood the message the participant was intending to convey. Further member checking of the coded transcripts, although desirable, was not done due to challenges with email access and literacy.

3. Results

Four themes were identified from the data, namely i) Companionship: being together and doing things together; ii) the quality of friendship; iii) barriers to independence; and iv) technology-mediated friendship. Each theme will be described and illustrated by representative quotes.

3.1 Companionship: Being Together and Doing Things Together

All the participants' accounts of friendship spoke to the need for companionship. In this study, companionship entailed spending time together in the same space while engaged in joint activities, including conversations. Often, companionship would entail spending time at each other's homes (mentioned by seven participants). Some participants spent time together at school or at the school's residence (mentioned by two participants still attending school), at church meetings (mentioned by four participants) or at support group meetings (mentioned by two participants).

Dumisano expressed his desire to spend time with his friend, and stated he enjoyed "visiting and staying with his friend once a month". He described his friend as "fun to be with". Noxolo, using her speech-generating device, described some of the activities shared with her friend, which included "sitting, talking, and listening to music together, swimming, and playing sports together". She further stated: "I like to be with them because, sometimes I don't want to be alone – I need someone to talk to. I don't want to be bored." She explicitly states that being alone is something she does not want, and that she enjoys her friends' company. Companionship for her involves actual communication with her friends. Friendship serves to thwart boredom.

While some participants were able to engage with their friends in activities outside of the home or school, others seemed to mainly realise their friendships by communicating and being together, as illustrated in the two contrasting quotes below:

> Dumisano: We go to the movies.
> Interviewer: You go to the movies? …Ok. So you enjoy going to the movies together?
> Dumisano: (nods) Mm.
> Interviewer: That's lovely. Ja, can you tell me a little bit about that?
> Dumisano: Ja, we, go see, movies.
> Interviewer: Any movies?
> Dumisano: (nods) Mm.
> Interviewer: Ok. You enjoy a whole range of movies.

Dumisano: Mm. Yes. Especially comedy.
Interviewer: And you talk?
Fanyana: (nods) Talk.
Interviewer: Ok that's nice. Do you go and do things together, like …?
Fanyana: (looks at Interviewer)
Interviewer: You know (shrugs) I don't know - go to the movies? Or -
Fanyana: (looks down, shakes head) No.
Interviewer: Nothing like that.
Fanyana: (shakes head slightly) Hmm.

Fanyana's answers suggest that, whereas communicating with each other is a part of his friendship, other joint activities (particularly those based in public domains) may be limited.

Eight of the 10 participants reported having had friendships over long periods of time. Some made friends at the age of three or seven when they started school. Most friendships started at school and continued over the years. Charmaine and Fanyana had both known their friends from childhood; they grew up with their friend and both spent time remembering and reminiscing about their friendships over time.

Interviewer: Were you in the same class?
Fanyana: (shakes head) No.
Interviewer: Ok
Fanyana: (looks up) Boarding school!
Interviewer: You would stay in the boarding school…?
Fanyana: Ja
Interviewer: So tell me a bit about him?
Fanyana: He is a good guy, we used to play marbles.

Five participants reported friendships with other young adults in the community. In four cases, these were also friends they had known for a long time and regularly spent time with engaging in mutual activities. Only one participant reported a more recent friendship, facilitated by the participant joining a church a year before the interview.

3.2 Quality of friendship

All participants mentioned that talking and communication were central to their friendships. The need for the friend to understand their speech or means of communication was highlighted. The quality of the friendships was described in terms of the friend's ability to understand not only their speech, but also their moods and feelings. The need for the friend to understand the participant was common to all the friendships. It was considered an important part of the friendship as the participants had various modes of communication. Participants spoke about being able to 'talk about everything', about being understood and being known by their friend, as illustrated in the quotes below.

> Interviewer: Anything else about her?
> Dumisano: She - Ja, we always talk.
> Interviewer: (nods)
> Dumisano: About anything and everything. And, I think, we have (the) same dreams.
> Dumisano: Uh, and, she understands me a lot.
> Interviewer: She understands you a lot.
> Dumisano: Mm.
> Interviewer: Ok. Does that mean, she understands, uh, …?
> Dumisano: My mood.
> Interviewer: Your mood?
> Dumisano: Hmm. (nods)

In the next example, Nziswa also refers to the importance of being understood and how this determines the quality of friendships.

> Nziswa: … She was, the one, that… (unclear).
> Interviwer: She was the one that?
> Nziswa: I could, talk to.
> Intreviewer: You could talk to.
> Nziswa: Yes.
> Interviewer: Ok -?
> Nziswa: But I talk, to everyone.
> Interviewer: (nods)
> Nzuiswa: Except… she was the one, who, knew, me.
> Interviewer: Ok.
> Nziswa: (nods) Mm.
> Interviewer: So you were saying that you talk at - to everyone at church?
> Nziswa: (nods) Hmm.
> Interviewer: …but she's the one who knew you.

Nziswa: Yes.
Interviewer: Ok. She could understand you?
Nziswa: (nods) Yes.

Noxolo, on the other hand, complains that her mom "does not understand" her when compared to a friend. Her carer agrees in this co-formulated message:

Carer: I am her mother, but sometimes, if she (Noxolo) talks, I can't understand her, but Mary will.
Noxolo: (looks at carer and interviewer and smiles)
Carer: But if I call Mary to…
Noxolo: (laughs and nods)
Carer: … tell me what she is saying. Even if Noxolo is talking and she cannot finish the words Mary finish it for her.
Noxolo: (laughs)

The co-formulation of the response indicates how Noxolo confirms what her carer is saying on her behalf, through eye contact, nodding and laughing. Noxolo utilises non-verbal communication in place of spoken or symbolised language to participate in the conversation.

Similarly, Thembe, who has limited functional speech, agrees on the importance of friends being able to understand him. Thembe would only use laughing and some vocalisations to maintain 'spoken' (maybe better described as 'vocal') conversations via mobile phone. Such 'vocal' phone conversations appeared to be the trend for at least seven of the participants to remain connected with friends.

The mutuality of friendship is also evident in the conversation with Sanele. Her friend pushes her around in her wheelchair at the hostel while Sanele shares her music and the movies on her laptop with her friend.

Carer: What are you saying?
Sanele: (groans and nods)
Carer: Mm. Lerato is, uh, is… (turns to Sanele's laptop)
Sanele: (spells out push on laptop)
Carer: Pushing. Pushing, around the…
Interviewer: Residence.
Sanele: (looks at Interviewer)

> Carer: Hostel?
> Sanele (nods)
> Carer: Sanele also shares her music with her friends and they watch movies on her laptop (which is her communication device).
> Carer: She has got movies in the computer. Music. They will play music.
> Interviewer: Ok
> Sanele: (nods)

3.3 Barriers and Facilitators to independence

Six of the ten participants mentioned barriers to independence experienced within their friendships. These barriers related mostly to transport and mobility challenges, and were experienced by five participants using a wheelchair (including the two who had a GMFCS) score of 5) as well as one ambulatory participant who was unable to use public transport due to his communication difficulties. For both Charmaine and Rebecca, the severity of their disability makes going out alone (without a carer) difficult and puts different demands on the friendship. Charmaine expressed a desire to go to a club with her new friend alone and have a cocktail. However, the logistics of having a car that can transport her wheelchair is difficult to arrange:

> Interviewer: So you would like to go to a club?
> Charmaine: (moves in chair, smiles)
> Interviewer: Like a dancing club?
> Charmaine: (nods)
> Interviewer: With Renee?
> Charmaine: (smiles, laughs)
> Interviewer: Does Renee go out?
> Charmaine: (nods)
> Interviewer: Yes, so would you like to go with Renee to a club?
> Charmaine: (nods, laughs)
> Interviewer: And dance.
> Charmaine: (laughs)
> Interviewer: And I don't suppose you can take a cocktail?
> Charmaine: (moves in chair)
> Carer: She can.
> Interviewer: You can take a cocktail?
> Charmaine: (nods) Ja!

Charmaine, here, shows interest in partaking in social activities in the same way that her friend does. The co-formulation of the interviewer-participant-carer triad is also evident here, with questions posed to the participant, who responds using mainly gestures, while the carer provides additional detail. It is important to note that throughout the whole communication process, the participant is afforded the opportunity to confirm or refute the statements made by the interviewer or the carer. The triad enables communication without completely silencing the participant. This is also evident in Rebecca's response:

> Interviewer: What would be a fun thing to do with your friends?
> Rebecca: (looks down at sheet, begins to indicate)
> Carer: (adjusts sheet on desk) "H.A." Having?
> Rebecca: (Hmm)
> Carer: D? Drink.
> Interviewer: Drinks?
> Rebecca: Hmm!
> Interviewer: Having drinks?
> Rebecca: (nods)
> Interviewer: Where?
> Carer: (wipes mouth)
> Rebecca: Hmm. (indicates on sheet, hums)
> Interviewer: S?
> Carer: A U?
> Interviewer: And a P. Spur?
> Rebecca: (nods)
> Interviewer: You'd like to go to the Spur with your friends?
> Rebecca: (smiles)
> Interviewer: Ok. And order a, milkshake? Or a, drink? What kind of drink?
> Rebecca: (nods)
> Carer: (looks at Rebecca)
> Rebecca: (unclear)
> Interviewer: Just going out, like that and having a meal.
> Rebecca: (nods, smiles)
> Interviewer: Ok. That would be nice for you. Have you ever done that?
> Rebecca: (shakes head)
> Carer: (shakes head)

Again, participants express a desire to participate in different activities with their friends. Barriers due to a lack of safe and accessible transport also came to the fore in other interviews. Many of the participants made friends while at school and did not easily manage to meet up with these friends once they had left school – unless the friends were able to travel, as revealed in Kabelo's case:

> Interviewer: So did he (best friend) come to your house, Kabelo?
> Kabelo: (nods)
> Carer: Yes. He will -
> Interviewer: Did you also go to his house?
> Kabelo: (shakes head)
> Interviewer: No.
> Carer: No.
> Interviewer: He comes to your house.
> Kabelo: (nods)
> Carer: Because uh - Kabelo is not go too far…Kabelo is not know to go to the taxi.
> Interviewer: Ja. It's difficult.
> Carer: Because he'd not - It's difficult to, to talk.

Kabelo's communication challenges made it difficult for him to use public transport (minibus taxi) to visit his friend. However, his friend was able to visit him.

Four participants who did not mention transport barriers indicated that they were able to participate in activities with their friends without the presence of a carer. In all cases, their friends were living in the same geographic community, and these participants were independently mobile and could access the houses or community places (e.g. a church hall) where they could meet up with their friends. In all cases, these places were within a reasonable distance from their residence, and were accessible to them by walking/using a wheelchair. One carer mentioned that her safety concerns were allayed by the presence of the friend.

> Interviewer: Ok. So when she goes out in the community you let her go on her own
> Carer: With Mary because I trust Mary.

3.5 Technology-mediated friendships

Digital technology and online social media were also used to enrich friendships and social relationships. All participants used technology to remain connected with friends. The use of social media platforms such as Facebook or Instagram was common (see also Table 1). They did not always know people prior to becoming friends with them on the social networking site. All the participants stated that technology enabled initiating and maintaining a friendship. Dumisano described how he and his friend "met on Facebook". It was only after meeting on Facebook that they realised they had attended the same school during their childhood. All the participants used some form of social medium to maintain friendships. They also used mobile phones to send text messages, and to vocalise on the phone.

Technology also offered a degree of selectivity in what to reveal about oneself, as Sanele explained that her profile pictures do not include her wheelchair. She reported that this enables her to make friends with people without disabilities. Fanyana was able to use social media to keep in touch with friends who did not live in close proximity, and who were without disabilities.

> Interviewer: Are those friends from school?
> Fanyana: No
> Interviewer: How did you meet those friends?
> Fanyana: We were talking on the street…..
> Interviewer: How do you stay in touch?
> Fanyana: Facebook
> Interviewer: So social media makes it possible
> Fanyana: Hey its quite good ja, quite good

Mobile phones also fulfil the role of a communication board when technology is not available – as is illustrated by Rebecca.

> Interviewer: So… - Does she come and see you at the house?
> Rebecca: (nods)
> Carer: Ja, she comes. She comes.
> Interviewer: Ok. And then you all just chat.
> Carer: Mm.
> Rebecca: (nods)
> Carer: Just chat.
> Interviewer: Just chat.
> Rebecca: (nods)

> Carer: They sometimes exchange phones if uhm, if (points to Rebecca) Rebecca's phone is, is not with her. Outside. And then she will, exchange phone - her phone, for Rebecca to write whatever. Like there in uhm, the text…
> Interviewer: Oh, the text. And then you communicate.
> Carer: Then, ja. They communicate.
> Rebecca: (nods and looks up at Interviewer)

Mobile technologies also provided a platform for activities to enjoy with friends, as Thembe indicates.

> Interviewer: Ok. So Mashudu would get some music on a CD and give to you?
> Thembe: (looks down at sheet)
> Carer: Mm. On the cellphone. On his cellphone.
> Interviewer: Ok - oh on the cellphone. Ok. (turns page over on clipboard) That's fantastic.
> Thembe: (looks at page on clipboard)
> Interviewer: That's wonderful so - so that's what you do together. You share music.
> Thembe: (nods)

Social media and mobile technologies provide their friendships with a platform for interaction that does not rely predominantly on verbal communication. Activities are shared, as in the case of Thembe and his friend sharing their music, allowing both individuals in the relationship to experience something they mutually enjoy.

4. Discussion

4.1 Descriptions of friendship

The themes emerging from the data highlighted some of the factors that are central to friendship experiences of young adults using AAC. As in previous research, companionship (defined as the ability to cooperate while spending time together in shared activities) (Bukowski, Hoza, & Boivin, 1994) characterised all the friendships. Communicating with each other as well as engaging in joint activities have been described as key elements of friendships regardless of age (Bagwell & Schmidt, 2011; Hartup & Stevens, 1999), and for young adults with severe communication disabilities, these elements come to the fore in their descriptions. Joint activities in a shared time and space create contexts for socialising, and enable the building of shared memories that can strengthen friendships (Mesch & Talmud, 2006). Long-standing friendships as those described by the participants offer the opportunity to build such a shared history over time (Knox & Hickson, 2001). Even for participants who relied on AAC systems with limited generative capacity, communication played a central role – being understood by their friends was foregrounded by all the participants. Participants and carers commented that the friends understood the participants' communication methods very well – often better than even close family members. Good listening skills, patience, and a willingness to learn alternative forms of communication have been noted as characteristics of the friends of persons using AAC (Therrien, 2019).

Friendships were not only about doing things together or communicating with each other. On a deeper level, they were also about developing intimacy – participants commented that they could 'talk about everything' and that friends were the ones who truly 'knew' them. Intimacy in friendships develops through through mutual openness, as friends were able to reveal degrees of themselves, their motivations, experiences, and personal traits (Noller et al., 2001). The findings in this study reveal that 'typical' communication skills were not a prerequisite for such intimacy developing in friendships.

Mutuality and interdependency as further characteristics of friendships of people with an without disabilities (Knox & Hickson, 2001; Hartup & Stevens, 1999) were also noted in the participants' friendships. The findings were similar to those recorded by Therrien (2019), where adults using AAC described their friendships as characterised by mutuality, commitment and depth. In this study interdependency in the friendship extended to the communication process, where friends assisted others to understand the person with AAC. Interdependency was also shown in the study by Anderson et al. (2011) where typically developing children functioned as translators for their friends who used AAC.

4.2 Barriers

While face-to-face joint activities were mentioned by all participants, barriers to such activities were also commonly highlighted. Participants mentioned that they wished they could ‘go out’ with their friends, for example, to a club, or to have a meal or a drink. Lack of transport options and in accessibility of public spaces, however, are barriers. The fact that such activities, if possible, usually had to be mediated by a carer were further challenges. The presence of a carer can impede on building intimacy in friendships, as the privacy to open up to the friend may not be afforded (Fulford & Cobigo, 2018).

A lack of public recreational activities offered in peri-urban and rural low SES areas, limited affordable private and public transport options – exacerbated for those with communication and physical disability ability, and a wheelchair-inaccessible environment have been reported as barriers to participation (Booyens, van Pletzen, & Lorenzo, 2015; Dada, Kathard, Tönsing, & Harty, 2017; Lindström, Hanson, & Östergren, 2001). As a result, many of the young adults seemed spent time with friends primarily in private rather than public domains. Interestingly, Emerson and McVilly (2004) found that adults with intellectual disability living in supported accommodation in England realised their friendship activities primarily in public settings, highlighting the influence of context on friendships.

Watermeyer (2006) posits that many opportunities are unreachable for South Africans with disabilities because of the lack of safe and accessible transport and not as a result of the characteristics of an individuals’ disability alone. Previous studies in high income countries have focused on the general population, on the elderly, and on people with visual and physical impairments (Jensen, Iwarsson & Staehl, 2002). A lack of accommodations for those with communication disabilities has also been noted in other studies (e.g., Ashton et al. 2008). In a study investigating the provision of accessible public transportation in South

Africa, Mashiri, Bogapane-Zulu, and Chakwizira (2010) found that taxi drivers have difficulty communicating with ‘passengers with hearing impairments and those who cannot speak’ (p. 7), while Green, Mophosho, and Khoza-Shangase (2015) reported that taxi drivers at times lacked awareness of communication methods other than verbal communication.

4.3 Role of technology

As in the case of studies from Australia (Cooper et al., 2015; Raghavendra, et al., 2013; Raghavendra et al., 2012) and the United Kingdom (Hynan et al, 2014), mobile technology and social media were found both to enrich friendship experiences and to provide opportunities for self-determination. Technology-mediated friendships (Asbjørnslett et al., 2011) were also evident in the interviews; all participants used social media such as Facebook and Instagram to remain connected with friends. A previous study conducted in South Africa found that text messaging and using social media were amongst the most frequent activities that adults using AAC engaged in on their mobile technology (Bornman, Bryen, Moolman, & Morris, 2016). Mobile technology with its portability, interconnectivity, and social acceptability can offer persons in need of AAC undeniable benefits (McNaughton & Light, 2013) and can support many valued adult roles (McNaughton & Bryen, 2007), including the initiation and maintenance of friendships. Where lack of transport options limited face-to-face contact with friends for some of the participants, social media and technology often became the shared space where participants could meet up with their friends.

Most participants knew their best friends before making contact with them via technology, and technology was more often used to maintain than form friendships. Friendships between persons who are able to meet face-to-face and engage in common activities are often stronger than friendships that started and remained in a virtual space (Mesch & Talmud, 2006). Some participants mentioned that they had met friends via social networking sites, which may create the risk of online harassment, though this was not mentioned in this study (Mishna, Cook, Saini, Wu, & MacFadden, 2010). Meeting friends online enabled participants to choose the timing of disclosing their disability. For persons with visible (e.g., physical) disabilities, this control is absent in face-to-face encounters. Disclosing disability can result in stigmatisation and the withdrawal of potential friends (Salmon, 2013), and timing can have an effect. Social media allows persons with disability a form of self-representation that foregrounds their abilities and strengths before a disability is disclosed (Hynan et al., 2014).

Technology also functioned as a platform for shared activities such as listening to music or watching movies. These findings emphasise that mobile technology is multifunctional, and may fulfil various roles for persons with disabilities (McNaughton & Light, 2013). Regarding friendships, this study found that technology not only facilitates communication with friends, but also enables joint engagement in mutually enjoyable activities.

5. Conclusion

This study provided a multi-voiced account of friendship by a group of South African young adults who use AAC. The results indicated that young adults who use AAC were more likely to enjoy friendship activities that take place in the home or school setting, rather than in the public domain, and also highlights the influence of context and access barriers as a possible reason. This study also illuminates the pronounced impact that digital media have on modern friendships. Connecting with friends on Facebook makes forming a new relationship easier. Long-distance relationships with friends can be maintained through the use of mobile technologies.

The findings offer further insights into the experiences of friendship for people who use AAC. The narratives revealed that young adults using AAC experienced companionship and support in their friendships. Being understood by their friends emerged as an important factor in their friendships. At the same time, young adults also expressed their desire to engage in more activities with their friends – activities that they cannot access at the moment.

These results must however be treated with a degree of caution. As a qualitative study, it makes no claims to represent all youth who use AAC. Findings describe the specific individual experiences of this group. The category of “friend” was self-defined by the individual participants, and the perspectives of their friend were not obtained.

The study does, however, extend and often confirm the findings of previous studies, and extend our insights about friendships to an under-researched context. Future research should explore in more detail factors such as the role of technology in friendship (Hartup & Stevens, 1999), and the roles that friends play within these networks. The voice of the friends identified by the young adults should also be given a platform in future research.

5. Clinical Implications and Future Directions

In view of the important role that friendships can play in promoting health, well-being and quality of life (Amichai-Hamburger et al., 2013; World Health Organization, 2015), clinicians might be encouraged to consider and explore the friendships that their clients using AAC already have in order to understand how these are formed and maintained. In the current study, all participants reported having a friendship, and friendships were maintained in spite of severe communication challenges, even by those who did not have access to a generative language system. Both these participants and their carers emphasised that these friends were the ones who understood the participants’ speech and other unaided communication forms very well, and often better than even close family members. Learning how this meaning is negotiated between the person who uses AAC and his/her friends (which may or may not be mediated by formal AAC strategies) may provide the clinician with important insights about the way communication is already realised. This could provide a platform that would enable a more systemic and nuanced approach to further supports, that are not focussed on ‘remediating’ the person with a communication disability. It may also expand clinicians’ views of meaningful intervention targets beyond a focus on the formal AAC system. The important role that friends play in mediating communication between the person using AAC and other partners (including family members) clearly emerged from this study, and ways in which such mediation can be leveraged without detracting from communicative autonomy (von Tetzchner & Grove, 2003) should be explored.

Insights from such explorations may also reveal areas that require support in order for clients to develop and maintain friendships. A tool like ‘Social Networks” (Blackstone & Hunt Berg, 2012) can assist in identifying persons with whom friendships could be developed and/or strengthened. In collaboration with clinicians, clients may be encouraged to consider and explore communication supports such as appropriate preprogramd vocabulary and rate enhancement techniques that could facilitate communication with existing and potential new friends. Capturing activities jointly engaged in with the friend (e.g. using the camera function on a mobile device) for later retrieval and sharing could be another strategy to relive and strengthen shared experiences. Importantly, communication partners may benefit from training as well as exposure to the way good friends already interact with the person using AAC, in order to gain skills that could facilitate communication and friendship building. On a more systemic level, clinicians should also be encouraged to assist their clients in overcoming access barriers (e.g. transport problems) to forming and maintaining friendships. Effective communication strategies to use public transport, for example, could be considered. The importance of sharing activities with friends was highlighted in this study, and assisting clients in identifying and gaining access to enjoyable activities where they can engage with friends or form new friendships can be an important task in supporting friendships. Finally, clinicians can also assist clients to leverage social media and mobile technologies as platforms for and facilitators of friendships.

Disclosure statement

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