“Happy and excited”: perceptions of using digital technology and online social media by young people who use augmentative and alternative communication

Abstract

Young people are using digital technology and online social media within their everyday lives to enrich their social relationships. The UK government believes using digital technology can improve social inclusion. One well-recognised outcome measure for establishing social inclusion is to examine opportunities for self-determination. Individuals with physical disabilities and complex communication needs who use forms of augmentative and alternative communication (AAC) have lower social participation opportunities. The integration of mainstream digital technology into high-tech forms of AAC (voice output communication aids), and the recent appearance of voice output ‘Apps’ on Apple and Android products, has provided increased opportunities for people who use AAC to engage with digital technology. Research exploring this area, especially in regard to online social media, with people who use AAC is extremely limited and a specific gap for self-reported experiences exists within the UK.

This paper describes qualitative, interview-based grounded theory research with twenty-five adolescents and young adults who use AAC about their use of digital technology and online social media. The data presented here are part of a larger study and the findings within this paper suggest participants have a desire to use the internet and online social media as it is perceived to increase opportunities for self-determination and self-representation whilst enriching friendships. The wide diversity of literacy and language skills amongst participants, as well as accessibility challenges, mean collaborating with others and receiving technical support from educational settings, families and friends are vital.

Keywords

Augmentative and alternative communication (AAC), voice output communication aid (VOCA), complex communication needs, literacy, adolescents, young adults, physical disabilities, grounded theory, digital technology, online social media, social inclusion

Introduction

This paper describes a qualitative grounded theory research project exploring the everyday use of digital technology and online social media (DT & OSM) by adolescents and young adults with physical disabilities and complex communication needs who use augmentative and alternative

communication (AAC) to support or replace their natural speech. DT & OSM are becoming indispensable to adolescents and young adults as they share intimate information online that reinforces and enriches offline social relationships (Mesch and Talmud, 2010; Ofcom, 2011). The potential benefits of DT are well documented and the UK government believes it can increase social inclusion opportunities (Champion for Digital Inclusion, 2009). Milner and Kelly (2009) and Mahar et al., (2013) investigated outcome measures for social inclusion and both established that exercising self-determination was a key component.

Complex communication needs and AAC

Severe motor impairment and complex communication needs have implications for social participation opportunities (Fauconnier et al., 2009; Imms, 2008; Parkes et al., 2010). AAC can support natural speech and writing, and total communication strategies focus on integrating natural speech with forms of AAC (Clarke et al., 2012; Marshall and Goldbart, 2008). AAC is either 'unaided' (using gesture or sign language) or 'aided' (using a computerised device known as a Voice Output Communication Aid (VOCA) in the UK) and primarily supports face-to-face communication. Using total communication can be 'intricate and nuanced' (Clarke et al., 2012:45) and AAC-mediated conversations will be significantly slower than a typical exchange (Higginbotham et al., 2007). Repairing misunderstandings and changing or initiating topics are different when one partner uses AAC (Murray and Goldbart, 2009) and can challenge conversational conventions in areas such as turn-taking (Sacks et al., 1974). This can lower perceptions of social competence causing negative attitudes to form about people who use AAC (McCarthy and Light, 2005). Interactional discourse to share narratives and experiences can be difficult affecting social communication and self-representation (Black et al., 2012; Todman et al., 2008; Waller, 2006).

Opportunities and challenges for VOCA and DT use

Using DT & OSM may change the dynamics of interpersonal communication for people who use AAC by alleviating turn-taking challenges and reducing the time pressures of face-to-face conversations (Sundqvist and Ronnberg, 2010). VOCAs have progressed since 2007 to become multi-purpose computers facilitating access to mainstream DT & OSM (Chapple, 2011) and voice output 'Apps' (on Apple and Android devices) has created a two-tier market and

increased opportunities for online engagement by people who use AAC. However, access to DT is challenging for people who use AAC on a physical and cognitive level.

People who use AAC either have ‘direct access’ (can use physical contact or point to a resource, including via eye gaze) or ‘indirect access’ (using a form of scanning to identify a desired item before activating a switch to select it). VOCA manufacturers have expertise in the switch control area and historically the mainstream arena has been weak but the latest iOS7 operating system from Apple has incorporated ‘switch control’ as standard (Ablenet, 2013). Literate individuals can create and store text messages on their VOCAs whilst non-literate individuals can use symbol-based vocabularies. People with complex communication needs often face challenges in areas such as literacy (Browning 2002; Smith, 1992) and language domains (Sturm and Clendon, 2004) so it may be difficult to engage in online text-based environments. VOCA devices and voice output ‘Apps’ have developed ways of using symbolised vocabulary software to post onto social media sites in a text-based form.

Existing self-report research by people who use AAC of using DT & OSM

Self-report data from people who use AAC about the use of DT & OSM is extremely limited and existing research is patchy and scattered across different countries. In Australia, Raghavendra et al., (2012) conducted qualitative interviews with a cohort of 15 children with physical disabilities (of whom 5 had complex communication needs) and found the internet was used for a variety of purposes but the extent and frequency of use was lower than peers. The digital skills of parents, siblings and friends were significant influences on levels of use.

Garcia et al., (2011) looked at the use of computers and AAC devices by 30 young people with cerebral palsy and associated communication challenges in a Spanish special educational centre. Questionnaire data revealed a strong interest in computers but using DT required a high level of support from professionals and little assistive technology was available within home settings. In the USA, 4 small studies found people who used AAC thought email facilitated support with other people who use AAC (Cohen and Light, 2000; Rackensperger et al., 2005; Sundqvist and Ronnberg, 2010) and was ‘the most effective way of being understood by others’ (Atanasoff et al., 1998:32).

Cooper at al., (2009) found using computers mitigated feelings of loneliness and Dattilo et al., (2008) found computers increased leisure opportunities for people who use AAC. Individuals who use AAC have reported the benefits of using DT; for example, '*Lesley'* felt using a computer supported meeting new people online (Krogh and Lindsay, 1999), Stevens (2011) said using a hybrid VOCA and an iPad had 'revolutionised my mobile telephony' (p.7) and Hyatt (2011) felt accessing the internet on an iPad deepened her social communication in ways not possible on her single-function VOCA.

These studies show DT & OSM may have social inclusion implications for people who use AAC but historically this is a marginalised research population (Morris, 2003; Rabiee et al. 2005; Wickenden, 2009). This current study is unique as the views of people who use AAC are specifically under-represented within the UK literature base on the topic of DT, especially in relation to the use of OSM.

Research Aims

The literature review has guided the development of four research aims:

1. To investigate the self-reported experiences of the accessibility of the internet and online social media by people who use AAC
2. To investigate the self-reported use of the internet and online social media by people who use AAC
3. To explore the perceived role and importance of the internet and online social media for self-determination and self-representation
4. To establish how online social media is perceived in terms of social ties for people who use AAC

Study design

Constructivist grounded theory

Grounded theory takes an inductive approach to theory formation which is suitable for looking at 'the underlying processes of human action and interaction' (Skeat and Perry, 2008:107) and is good when little is known on a topic. A constructivist grounded theory approach recognises knowledge is socially produced from multiple viewpoints (Charmaz, 2006).

Pilot Investigation

A pilot investigation was carried out with a literate man (aged 30+) who used a VOCA, home computer and mobile phone. The two-hour semi-structured interview followed a topic guide (Appendix A) and data was coded through a six-step thematic network analysis approach developed by Attride-Stirling (2001). Initial coding highlighted meaningful text segments that were checked, amended or re-labelled to create Basic Themes. These were grouped under more abstract Organising Themes and refined into Global themes. The resulting thematic networks were shared with the participant who confirmed their representation of the interview and felt the themes developed were relevant to people who used AAC. The pilot investigation findings were presented at the 2011 Communication Matters AAC conference [**Ref 1st author**] and published within the Communication Matters journal [**Ref 1st author**] to further establish the credibility of the analysis by people external to the study (Creswell and Miller, 2000). Feedback indicated issues identified, especially for self-representation and social friendships, were important and should be taken forward.

Main study

Recruitment and participants

Purposeful sampling targeted the small UK AAC population through AAC-focused educational settings and organisations. Inclusion criteria required participants to be over 14, use a VOCA and the internet and OSM (this assumed literacy). Following an enquiry from a speech and language therapist, students with low cognitive and literacy skills who were using OSM with support were also included. Valuable data would have remained hidden if inclusion had been limited to independent, literate internet users.

Twenty-five young people (aged 14-24) who used VOCAs, qualified as level V on the Gross Motor Function Classification System (GMFCS), (Palisano et al., 2007), and had a wide diversity of language/ literacy skills and access requirements took part in the study. Four participants used Makaton signing[1], a communication book, an alphabet board, and an eye-transfer frame[2]

1 Makaton is a type of sign language http://www.makaton.org/

2 An eye-transfer (E-tran) frame is a Perspex board containing visual information. This is held between a communication partner and an AAC user and the AAC user points to

during their interview (from choice or technical breakdown) and in fifteen of the interviews a communication support partner was present.

Informed consent was obtained by sending differentiated information in advance to allow information to be disseminated. Before the interviews, secondary checks were made, especially for video recording. Non-verbal communication is often used by people who use AAC so video recording removes the need to verbally describe messages, which can disrupt the interview rapport. Two participants decided to withdraw completely at this secondary stage and three declined video recording. Appropriate university ethical approval and criminal record clearance were obtained before recruitment began.

Main data collection and analysis

Semi-structured interviews (30 mins – 2 hours), using the topic guide (Appendix A), took place within eight mainstream and special educational settings (three of which were residential). Time challenges limited the number of questions covered and some were summarised to target key emergent ideas e.g. ‘How does using Facebook make you feel?’ Twenty-four face-to-face interviews were conducted and one participant contributed via a blog. Three participants asked for questions in advance so the topic guide (Appendix A) was sent by email.

In line with the concurrent data collection and analysis procedure of grounded theory, the interviews were immediately transcribed verbatim and initially coded on a line-by-line basis to identify actions within the data (Charmaz 2006). Memos then sought to analyse emerging concepts which were taken into subsequent interviews. Theoretical sampling was used to identify participants who could provide information on emerging theory and the final interviews were conducted with literate participants who used social media independently. At the end of data collection, 25 transcripts (average length: 3,000 words) were imported into Nvivo 9.0, a software programme that manages narrative data. The lead author then continued coding to select and draw together the initial codes that made most analytical sense of the data and created focused codes. The focused codes were then carried forward into the theoretical coding phase where relationships between the focused codes were explored and raised to analytical categories which tell the story of the data (Charmaz, 2006).

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desired items using eye gaze.

Findings

The data presented here are part of a larger study and a detailed description of results, data analysis and discussion of the interpretation will be published elsewhere. The current findings represent the six analytical categories that emerged from the theoretical coding stage: (i) desire to be online, (ii) self-determination, (iii) self-representation, (iv) enriched friendships, (v) access technology and (vi) describing support. For ease of reading, participant's pseudonyms are used and the quotes do not use AAC transcription conventions, but were created on VOCAs, blog and email, or (in Harriet's case) spelt letter by letter on an alphabet board.

The six analytical categories

Category 1 - Desire to be online: Participants were asked how they felt about using the internet, Peter said 'now I'm starting to use it more, very excited', Jack said 'happy and excited' and Caroline (blog) explained 'the internet and social media are an important part of my life. I cannot imagine life without that'. Georgie used her eye-transfer frame to say Facebook makes her feel happy. When asked what they liked about the internet, Nancy said 'I like use Facebook Skype', and Olivia replied 'with Facebook I want to use more'. Asked how it would feel if online access was unavailable Caroline said in her blog 'I am fed up if I do not have access somewhere'.

Category 2 - Self-determination: Self-determination was perceived to increase through using the internet. Xavier was asked how he felt when he first used the internet and said 'It made me very happy. It gave me more independence. I can organise things like meetings myself'. Asked what the internet was used for, Peter said 'planning trips with my P.A.' and added if he lost access he 'would have to rely on others to find things out for me'. Harriet said she uses 'Facebook, shopping and I build websites, just started my business. I do advertising on my status'. Nicholas follows his basketball team and posts information on Facebook to show they are 'special'. Moira follows the Paralympic sport of 'Boccia' and Becky shares news about 'rebound' (a form of trampoline exercise). When asked if there was anything she would like to add that she had not been asked about, Harriet said, 'main thing about Facebook is I can send a message to either my brother or my dad if I have a problem … because I can't always tell the person with me'.

Category 3 - Self-representation: The participants indicated Facebook increased their opportunities for self-representation. When asked what kind of things they put on Facebook, Will said ‘what I think’ and ‘a lot’ about himself. Harriet showed her sense of humour and ‘put silly stuff on my Facebook’ joking new friends ‘would probably run’ when viewing her page. Keith answered, ‘I like seeing me holding Pikachu’ and Carol (using Makaton signs) answered the question by pointing animatedly at herself. Asked if this meant telling people about herself, she nodded ‘yes’ vigorously. Nancy felt ‘it good show pictures’ and Harriet said the timeline feature was good for sharing ‘really old’ events. When asked what the main benefit of being online was, Nancy replied, ‘people understand me better in writing’.

Category 4 - Enriched friendships: When asked to explain the value of the internet and OSM, typical responses were: ‘for talk to people’; ‘it me in contact with everybody’; ‘it helps to talk everyone’; ‘talk a moment and take a nosy’; ‘I can talk to people on it’ and ‘talk friends’. People who use AAC can have difficulty keeping in touch with others but there was evidence that OSM supported relationships over distance. Xavier explained he found email useful ‘especially when I am here” (in residential college), Olivia valued Facebook to keep in touch with ‘my old teachers’ and Nicholas and Keith both used it to keep in touch with people from ‘old school’. Keith explained he would ‘send them a text. I find them’ and Harriet said she could ‘get in touch with friends I know in New Zealand’ whilst Caroline said ‘I love Facebook! … I stay in touch with people I do not see often’.

Category 5 - Access technology: Asked about how they used a computer, Nicholas said he used ‘special switches eight at home’ and Nancy used her VOCA to drive an independent computer explaining ‘need my cable to computer’. Not knowing about access equipment was an issue; Peter and his family only found out through visiting a further education college that Switch XS™ software would allow Peter to independently access a computer. Olivia was waiting for a 3G dongle to be installed on her VOCA so she could start to use Facebook and texting on her own. Will (indirect access) likes playing online ‘golf’ but explained ‘it’s hard’ and asked if he played other types of games, he said ‘I cannot play’ due to intricate controls. Moira (direct access) likes to play ‘anything’ but finds the integrated computer on her VOCA limiting because, ‘I can’t play a game’. Gaining independent access was valued; Caroline said ‘for ages I wanted to access the internet independently, but … I did not know how … Now I can write a

message on the [VOCA] then post it on Facebook. I was really, really excited the first time I did that independently'.

Category 6 - Describing support: Parental knowledge of technology was sometimes lower than that of the participants. Will's parents were not interested in social media but technology was a 'big thing' for him. Many participants were reliant on parents or personal staff to produce and share online content and reasons for this were: insufficient literacy skills, lack of relevant equipment and the slow speed of access technology. As explained by Mary, Researcher: 'do you ever do Facebook when you are on your own', Mary: 'no' but she used MSN because it was 'easy than Facebook' which was difficult to 'read'. Before Peter received Switch XS™ he and his dad (Paul) did Facebook together, Paul: 'we'll go on and see what's come through ... I read them out ... you get the opportunity to comment', Peter: (laughs). Caroline, who can independently post says sometimes that 'My mum helps me, I talk with my voice and she types what I say [because] my switch is really slow. The problem is that#s (sic) not private'. Sibling support was described, Keith explained the person who helped him with Facebook was 'my sister'. Mary used MSN to communicate with her younger sister from their respective bedroom computers and her sister said not to use Twitter because of 'rude people'.

Discussion

The data presented here considers the research aims to: (i) investigate the accessibility of the internet and OSM, (ii) investigate the self-reported use of the internet and OSM, (iii) explore the role of the internet for self-determination and self-representation and (iv) establish how OSM impacts on social ties. The following discussion will address how the research aims have been answered by the six analytical categories: (i) desire to be online, (ii) self-determination, (iii) self-representation, (iv) enriched friendships, (v) access technology and (vi) describing support.

The first aim of investigating accessibility was shown to be challenging on many levels. Difficult controls prevented participants from using entertainment activities, which are known to be popular among young people (Livingstone and Helsper, 2007; Soderstrom, 2009). A lack of knowledge about specialised equipment prevented independent use and certain participants did not have the right equipment to overcome their mobility limitations. These difficulties can socially construct disability by denying access to cultural material (Goggin and Newell, 2003) and create forms of digital exclusion (Macdonald and Clayton, 2012).

The other main barrier to independent access was literacy. As illustrated, this is known to be difficult for people who use AAC (Smith, 1992) and literacy teaching has been identified as vital for those who use AAC (Light and McNaughton, 2012; McNaughton and Bryen 2007). Collaborating and sitting beside a literate companion to: co-create content, watch content being constructed, observe written responses and hear them read aloud, is a motivational form of exposure that may support the development of literacy skills (Smith, 2006). Websites also have a duty to ensure access and Hollier (2012) reported that Web Content Accessibility Guidelines (WCAG) 2.0 are not always applied and sites such as Facebook and Twitter fall short of expected standards for consumers with disabilities. Accessibility challenges have implications in terms of the UN Convention on the Rights of Persons with Disabilities which places an obligation on member states to ensure people have access to cultural materials (United Nations, 2006).

The second aim sought to investigate the self-reported use of the internet and online social media. The participants described using a range of entertainment and social media sites reflecting the typical interests of young people (Livingstone and Helsper, 2007). The participants in this study demonstrated how frustrated they feel if they cannot go online and there was evidence they would like to use DT & OSM more frequently. This supports the findings of Raghavendra et al., (2012) that the extent of use for young people with physical disabilities was lower than peer groups.

Exploring the implications of using the internet and online social media for self-representation was the focus of the third aim. The limitations for self-representation within face-to-face conversations appear to be alleviated by the use of OSM sites. A Facebook identity offered the participants an opportunity to show their humour, create personal narratives and use the timeline to create an historical framework, all of which can be limited on traditional AAC technology (Black et al., 2012). Bowker and Tuffin (2002) say being online offers opportunities for people with disabilities to exercise choice over self-representation. Zhao et al. (2008) suggested Facebook users liked to control what they show others to promote their ‘hoped for’ self which enhances a person’s self-image and has concrete consequences within the offline world. This study confirms previous research that using OSM helps people who use AAC to be understood by others (Atanasoff et al. 1998).

The fourth aim was to look at online social ties and the participants demonstrated a strong interest in using OSM to keep in touch over distance. This is consistent with existing literature within other youth populations with and without disabilities (Cohen and Light, 2000; Lenhart et al., 2010; Ofcom, 2011; Soderstrom, 2009). New knowledge is generated by this research in terms of how OSM is perceived by the people who use AAC to increase opportunities to 'talk' to others which reflects the documented communication challenges associated with face-to-face conversations (Black et al.,2012; Clarke et al., 2012; Higginbotham et al., 2007; Murray and Goldbart, 2009; Todman et al., 2008; Waller, 2006;).

The implications of this research suggest that family and sibling support are important components of DT use (Raghavendra et al., 2012) and high levels of collaboration may be needed. Also, the support and commitment from educational settings must not be under-estimated. Young people who use AAC are at a heightened risk of digital exclusion if these levels of support are not in place.

The current study suggests that future research may explore the implications of virtual participation within the framework of the International Classification of Function, Disability and Health, Children and Youth version (ICF-CY) (WHO, 2007). It also suggests the importance of exploring the use of DT and OSM with older age groups who do not benefit from educational setting support.

Limitations and alternative research methods

Using narrative techniques to explore the experiences of people with complex communication needs may seem counterintuitive (Booth and Booth, 1996) and other methods were considered. Creative activities (art, photography, dance) have been used successfully to support abstract discussions within concrete contexts (Greenstein, 2013) but the existing physical challenges for operating VOCAs raised concerns that using creative methods may have introduced novel disabling factors. Observation could not have captured the meaning that participants may attribute to their experiences. Some participants demonstrated how they used OSM and this data was useful for understanding process issues. Collecting data through engagement with participants on OSM sites such as Facebook was discounted as: it raised ethical concerns around consent and privacy for family and friends, potentially transgressed agreed professional boundaries with educational settings and made the position of the main

author unclear (friend/researcher?) especially for exit strategies. Using email with participants was acceptable as it does not have the associated social boundary ambiguities.

Despite the challenges posed by technical equipment, available vocabulary, communication breakdown, participant fatigue and time pressure, interviews were believed to ‘best-fit’ the research objectives to gather self-report data within the context of this study.

Appendix A – Interview topic guide

1. Can you tell me about how you access your computer?
2. Can you tell me about what you use the internet for?
3. Could you describe things that help you to access the internet?
4. Could you describe things you find challenging when using the internet?
5. How did you first learn to use the internet?
6. How does using the internet and online social media make you feel?
7. How do you manage your safety and privacy online?
8. Do you need help from someone else to use the internet or online social media?
9. How would you describe your use of the internet for social purposes?
10. Do you use the internet for other purposes, for example, business or study?
11. Can you tell me about how you represent yourself online?
12. Do you share different information with different people?
13. What advice would you give to someone who uses AAC who may be just starting to use the internet and online social media?
14. Do you feel using the internet is an important part of your life?
15. How do you perceive the internet changes your life?
16. Do many of your friends use the internet and online social media?
17. How would losing access to the internet affect your life?
18. How do you feel using the internet might support or hinder your communication with others?
19. Can you explain the role of technology in a typical day for you?
20. Has using the internet changed the way you socialise?
21. What are your feelings about offline and online friendships?
22. Do you have any friendships that only exist online?
23. Have you met anyone you first made contact with online?
24. Do you use the internet or online social media sites to stay in touch with old acquaintances?

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