

Ethical considerations when conducting research with people with nonverbal autism: A reflective commentary

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Abstract

People with severe (nonverbal) autism are significantly under researched. Physical, communication and social limitations have created misconceptions concerning their ability to engage in meaningful communication and to participate in inclusive research. Those who are nonspeaking often communicate by use of a specialised device that requires the assistance of a personal facilitator. This process, while representing the preferred and frequently only method of communication for people who do not speak, is subject to significant criticism by some scholars. Therefore, ethical and practical considerations concerning authenticity, capacity and consent require careful attention when conducting research with such populations. These factors however, must be held within a methodological design that provides space for the inclusion, respect and empowerment of research participants to ensure their voices are authentically represented. This commentary reflects on these considerations as they were addressed within a research study that used interview as a method of data collection for people with nonverbal autism.

Keywords: Ethical Considerations, Nonverbal Autism, Facilitated Communication, Capacity, Consent

Introduction

The rapidly growing numbers of children being diagnosed with autism represent a global health concern (Blumberg et al., 2013). However, despite efforts in the community to reclaim the identity of autism, a scoping literature review conducted by the authors exposed a lack of information about the lived reality of those with severe autism (nonverbal autism), especially from their own perspective. This means that this population remains excluded from research opportunities. The lack of academic literature prompted the exploration of grey literature authored or co-authored by people with nonverbal autism. Authors communicate by use of a

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process called facilitated communication. These works, collectively titled the 'nonverbal narrative literature' by the researcher, provided a valuable contribution to the available knowledge (Hills, Clapton, & Dorsett, 2016). This commentary reflects on some unexpected ethical considerations that arose during the planning phase of a research study intentionally designed to work collaboratively with people with severe autism. The study, titled 'Spirituality in the Context of Nonverbal Autism', sought to explore the spirituality of people with nonverbal autism.

Autism is considered a spectrum disorder with a long variance of expressions and abilities. Those with the most severe form generally exhibit pronounced physical, social and communication limitations, with little or no verbal speech (American Psychiatric Association, 2013). The inability to use verbal speech has led to the assumption that these people are severely cognitively impaired, although recent findings are debunking this belief (Nader, Courchesne, Dawson, & Soulieres, 2016; Hills, Clapton, & Dorsett, & Andersen, 2019). People with nonverbal autism are further marginalised by the belief that they are incapable of other forms of communication such as gestures and body movement to compensate for a lack of verbal speech (Howlin, 1999; Vosseller, 2018). This misconception is addressed in the nonverbal narrative literature. Authors of this genre claim the issue doesn't lie with the inability for expression by someone with nonverbal autism, but rather in the inability of others to recognise and translate certain behaviours (Fleischmann & Fleischmann, 2012; Goddard & Goddard, 2012; Hills et al., 2016). This misunderstanding has grave implications for people with nonverbal autism regarding their ability to access strategies for meaningful communication.

When working with people who are nonverbal, careful attention to ethical and practical issues is paramount. These considerations underpin the development of a workable methodology for inclusive research with this population (United Nations, 2006). Two specific issues that must be addressed when designing collaborative research with these people lie in the ability of participants to meaningfully communicate with the researcher, along with their capacity to understand and consent to their involvement in the research process.

How people with nonverbal autism communicate

People with nonverbal autism often communicate by use of a communication device specifically designed to meet individual needs. Physical and sensory issues common to people with autism mean that users of these devices frequently require the support of a trained communication facilitator. These facilitators provide dexterity assistance along with psychological support as the person with autism points or types on a letterboard or electronic device similar to an iPad. The relationship between the facilitator and the communicator is paramount to the success of this process, commonly referred to as Facilitated Communication (FC) or Facilitated Communication Training (FCT). Participants of this study had been proficient in FC for several years. Seven participants worked with six different facilitators, requiring various degrees of assistance ranging from total support of the typing hand, to a light touch on the corresponding shoulder for stability.

Investigation of the current literature concerning alternative communication processes, along with an exploration of contemporary practices for this technique were considered a necessary precursor for this study. This search however, revealed a long standing debate about the authenticity of FC. The increasing popularity of facilitated methods of communication appears to have raised significant ethical challenges in terms of the authenticity and quality of the data generated from participants (Nind, 2008). This literature asserts that there is no scientific evidence that supports the authenticity of these communication methods; that the messages

are authored by the facilitator; that they cause harm to the users; and that facilitators lack training and qualifications (e.g., Travers, Tincani, Thompson, & Simpson, 2016). The risk of abuse by facilitators has been sensationalised by cases such as that of Anna Stubblefield (Mintz, 2017) and some cases of alleged sexual abuse (Margolin, 1994; Shane, 1994) that were reported via a communication device. Small research studies involving specific participants have claimed to demonstrate the inauthenticity of current practices and have highlighted the need for further research in this area. This is despite convincing evidence pointing to the authenticity and validity of FCT from industry specialists and nonverbal users. Those in support of such communication processes provide lengthy and expert evidence as to the scientific underpinning of these methods and their success in supporting people who are nonverbal to participate in meaningful communication (Ashby, Jung, Woodfield, Vroman, & Orsati, 2015; Cardinal & Falvey, 2014). Physiology and neuroanatomy research provides detailed explanations concerning the complex processes of speech and language (Demir-Lira et al., 2018; Hardy et al., 2017), thus demonstrating that an inability to speak does not necessarily equate to a language impairment. This literature indicates that the ability to formulate language is not necessarily the issue for people with nonverbal autism, it is the process of expressing these words that creates difficulties for them. Furthermore, sensory movement differences necessitate certain assistance for dexterity and accuracy (Donnellan & Leary, 1995). This is why the support of a communication facilitator, and the quality of this support relationship, is fundamental to the success of the communication process (Ashby & Causton-Theoharis, 2009; Woodfield & Ashby, 2016). It can be argued however, that issues of familiarity and trust are fundamental to the quality and success of any interpersonal communication. Therefore, this ingredient of the communication process should not be viewed as suspicious for this population, simply because of a variation to communication style.

The passion expressed by both sides of this discourse shows an important commonality. Each are calling for further research in the quest for best practice and improved societal participation for people who are nonverbal. It is clear that the priority of both opinions is focused towards the best interests of people who do not use speech. Therefore, perhaps both sides of this argument capture a common spirit – a type of ‘hermeneutics of suspicion’ that is facilitating a mutual contribution to the betterment of the daily lived experiences of these people. It seems impossible to argue against the numerous personal narratives from people who assert that their lives have been transformed by FC. Practitioners from many different geographical areas (e.g., Australia, America and Great Britain) consistently report successes when clients are introduced to a personalised communication device. This is also validated in the nonverbal narrative literature, where almost without exception these authors expressed life changing benefits from finally finding a method of communication after years of having no means for expression (Hills et al., 2016). In a relatively new and emerging discipline, these narratives appear compelling. As Vosseller (2018) observed

Once you see a nonspeaking student spell out their thoughts, you can't unsee it. You have two choices, believe or do not believe what you are seeing. Choosing to believe means that there is more to learn about autism and that we don't yet have all the answers. (para. 16)

On the other hand, no one should argue against solid empirical evidence for best practices and client protection, or against the utmost importance of evidence-based practice. In emerging disciplines however, it can transpire that research is led by practice innovation, and in this case, it would seem that *practice-based evidence* is propelling the results. In light of limited suggestions of alternative evidence-based interventions (e.g., Picture Exchange Communication System) to FC (Travers et al., 2016), it would seem prudent to continue to explore current methods of communication that from all accounts are providing life changing opportunities for a group of formerly voiceless people.

Both sides of this debate should be called to reflect upon their standpoint in light of

accumulating evidence. Those in opposition to the use of FC are surely working to protect people who are nonverbal. Therefore, they must also ensure that their advocacy in no way further excludes these people by preventing them from taking an equal and valued role in society. Furthermore, it is imperative to ensure that this discussion does not allow a controversy about their chosen style of communication to further silence this population. The authors ponder if future research will identify that neurological differences seen in these people may *require* the support of a sympathetic facilitator for successful communication, which arguably is a necessary component of any form of communication – verbal or otherwise.

Capacity

As identified, the intelligence of people with nonverbal autism is often inappropriately assessed (e.g., Blackman, 1999; Goddard & Goddard, 2012; McKinley, 2011). Therefore, the researcher chose to assume the intelligence of potential participants, rather than to assume unintelligence as would *appear* congruent with their countenance. Even so, as building trust was a priority, recruitment of participants became a lengthy exercise. Six of the seven participants were recruited from a local literacy group for nonverbal poets, and the other from a personal encounter with the researcher at an international conference. The recruitment process involving email and personal communication outlining the expected involvement and commitment of respondents, provided opportunity for the researcher to interact with potential participants, and whilst doing so gauge their intellectual capacity. Competency to participate collaboratively in the research soon became evidenced by the content and quality of these encounters. Further confirmation of their level of cognition is demonstrated by the calibre of public performances and disseminations produced by the literary group from which most participants were recruited. Even so, during the formal ethics process, the committee identified the *societal perception* that people with severe autism may be unable to understand and independently consent to participation. It should be noted that this is an issue commonly confronted in any research involving people with a cognitive ‘impairment’ or communication issues and is not limited to people with nonverbal autism (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007). Therefore, the research team needed to hold a tension between the ethical underpinning of the project that sought to ensure the inclusion, respect and empowerment of this population, while also meeting standard ethical requirements. As such, the consent process became an important ethical consideration.

Consent

Initially it was envisioned that the close and trusting relationship between the participant and their facilitator would prove an advantageous resource for this study. The research team assumed that the facilitators could intercede for participants by ascertaining their ability to fully understand provided information, along with their capacity to give consent. This strategy proved to be a humbling misconception, and another rich discovery that emerged from the consent process as participants proved that they were more than able to advocate for themselves. Therefore, proxy consent was not provided by the participant’s facilitator. Each participant enthusiastically provided their consent to participate via their communication device in view of the student researcher and research assistant.

The benefits afforded people when their basic rights to communication are respected and embraced cannot be underestimated, and for people who do not speak, is representative of a justice issue at the very core of human rights. The need for greater transparency and inclusiveness in research with individuals with nonverbal autism, by validating their “frequently overlooked, under-valued and ignored” (Ridout, 2017, p. 53) voices is highlighted. This research study has provided a platform for future research with people who do not use speech to communicate. A balanced approach regarding their chosen method of communication is imperative to ensure that their lives and voices are authentically represented. Now that a

methodological approach to conducting such research has been tested, it is evident that working inclusively with people who use Facilitated Communication as direct respondents is not only possible, but necessary to understanding their lived reality. Following the groundbreaking work of Douglas Biklen (2005), future opportunities for inclusive research that partners with people with nonverbal autism as co-designers and collaborators is an exciting opportunity that can only expand the body of knowledge concerning this currently under researched population.

Conclusion

Communication is one of the fundamental elements of humanness. Conducting research with people with barriers to communication presents specific ethical considerations concerning agency and inclusion. Designing a methodology that considers responsible ethical practice alongside respectful participant involvement in the research process is paramount. Furthermore, such research must ensure that the voice of the participant is authentically represented. As such, working with participants' chosen communication style is vital to the success of the project. Future research must deflate the common misconception that "not being able to speak means not having anything to say" (Grandin, 2011, p.110).

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Biographical notes

Dr Karenne Hills completed her Ph.D. at Griffith University in 2019. Her thesis explored the spirituality of people with non-verbal autism. She has a special interest in theological and spiritual considerations for people with disability, an interest born largely out of her personal journey with her two sons, each of whom live with significant disabilities. Karenne has published in high quality peer review journals and presented her work at national and international conferences.

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