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A letter to editor regarding Bambara et al. (2021) "Using Peer Supports to Encourage Adolescents with Autism Spectrum Disorder to Show Interest in Their Conversation Partners"

--Manuscript Draft--

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Abstract:

Purpose The purpose of this letter is to address interpretations regarding Bambara et al. (2021) study and help resolve potential for further missteps within this line of research.

Conclusion There is clear value in teaching skills that are wanted by autistic people. The primary issue within the paper is that it does not acknowledge the double empathy problem and is constructed based on only a neurotypical system of interpretation or communication style. What is being promoted is to address skills autistic participants request.

Response to Reviewers:

Dear Prof Stephen M. Camarata,

Thank you for offering the opportunity to submit a revised draft of my manuscript titled: 'A letter to editor regarding Bambara et al. (2021) "Using Peer Supports to Encourage Adolescents with Autism Spectrum Disorder to Show Interest in Their Conversation Partners"' to Journal of Speech, Language, and Hearing Research. I appreciate the time and effort that you have dedicated to providing valuable and insightful feedback on the manuscript. We are grateful to the review for the insightful comments on the paper and have highlighted the changes in the manuscript in yellow.

Here is a point-by-point response to the reviewers’ comments and concerns.

Comments from Reviewer 1

We have addressed reviewer one’s comments point-by-point, and will respond to each comment.

The letter raises important issues. However, the frame seems to be primarily on high functioning autistic people. Because of this, the letter should include a short, but more detailed description of how autistic people broadly, who have very diverse communication ability, can be included in the key points you make. Specifically, how autistic people who are nonverbal or minimally verbal can be included in this rubric should be acknowledged and/or addressed. Also, the people in Bambara et al were adolescents, so it is unclear how this is balanced with parent rights and responsibilities.

-This is an important point. Thank you for bringing this to my attention. I have addressed this in the manuscript parallel to the rest of the letter. Further detail is available to what has been written – however, I sought to be concise to avoid obscuring the points being made.

On the manuscript title page:
- Please include the author’s full name and affiliations
Yours Sincerely,

Nathan Keates

19.1.2022
A letter to editor regarding Bambara et al. (2021) “Using Peer Supports to Encourage Adolescents with Autism Spectrum Disorder to Show Interest in Their Conversation Partners”

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The authors have no conflicts of interest to declare.

This study was unfunded.

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Abstract

Purpose The purpose of this letter is to address interpretations regarding Bambara et al. (2021) study and help resolve potential for further missteps within this line of research.

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Key words: double empathy problem, communication, autism, skill development, system of interpretation, neuronormativity.
Introduction

Bambara et al.’s (2021) study investigated three autistic participants to help their development of peer-focused conversation with a cue sheet to assist in self-reflection. The paper addresses the development of capabilities the three autistic participants did not have previously well. Enabling the skill development of abilities frequently required in life (such as language and flexibility) can be beneficial (Kapp, 2020). Nonetheless, due to potential literature missed, some key factors have not been considered. For example, as McCracken (2021) argues, the practice of altering autistic communication is essentially asking them to pass as neurotypical (of which it is known causes harm, Cage & Troxell-Whitman, 2019; Halsall et al., 2021; Libsack et al., 2021).

Considering the Double Empathy Problem: Autistic Sociality

Autistic people tend to have to change to suit other people’s communication styles (Williams et al., 2021). Ensuring the social engagement of communication is put upon the autistic person, terming them as ‘socially disabled’. This creates social pressure upon them to accommodate the neurotypical communicative need. However, as per Morrison et al. (2020), the perception of atypical autistic sociality is unfounded and there is a need to acknowledge the real-world relational dynamics. Recent studies including those by Crompton et al. (2020) and Morrison et al. (2019) found there are benefits for autistic people to socialising with those with an insider identity, e.g., being autistic. The neurotypical difficulties experienced by the mismatch in neurotype with autistic peers are an important part of the social difficulties (Davis & Crompton, 2021) upon which Bambara et al. (2021) is based. Furthermore, Bambara et al. (2021) indicate how the goal of demonstrating interest in their conversation partners was through verbal means, but other forms such as non-verbal methods exist (e.g., nods, smiles and eye gaze). Jack (2013) discusses that autistic communication does not seem to be constructed as neurotypical human communication. Instead, autistic people may engage in communication through their system of interpretation (contrary to the wider cultural norms, e.g., eye contact in many western cultures) (Williams et al., 2021). Similarly, such systems of interpretation (i.e., backchanneling, the verbal sounds made to signify the interlocutor is listening)
are found to not be used in the homogenous autistic neurotypes interlocutors (Rifai et al., 2021).

Albeit that it is commendable that the autistic participants in Bambara et al. (2021) were not forced to adhere to neurotypical backchannelling, the peer focus within the study means the skills are still comparable to the neurotypical peers. Thus, the peers were assigned more power in regard to their position within the research, i.e., improving the autistic participants’ conversation skills.

DeBrabander et al. (2021) reports that autistic people have rapport with other autistic people due to the lack of impediment that any one social encounter has upon a desire for another social exchange. In fact, Crompton et al. (2020) found that neurotypical people self-rate themselves higher than observers and autistic people are more accurately self-rate their rapport. Therefore, this reifies that autistic people do not need to learn peer-focused communication when their communication may be accepted elsewhere.

Likewise, non-speaking autistic people have a non-normative communication style (Ashby & Causton-Theoharis, 2009; Baggs, 2012; Lebenhagen, 2019). For examples of autistic accounts of being non-speaking, see Higashida et al. (2016) and Baggs (2012). As for autistic people in moments of greater support needs (to avoid the misnomer of high/low binary of ‘functioning’; Alvares et al., 2019), a hypothetical triggering event may leave someone to be selectively mute (e.g., Peña, 2019); if those around them empathise and are supportive, there is scope to engage in the communication style necessary in that moment. For an example of positive engagement with non-speaking autistic children, Jaswal et al. (2020) found parents could form an emotionally reciprocal relationship with their child(ren) by considering the forms of connection the child offers (assuming competence and through acceptance).

Milton’s (2012) double empathy problem relates to these issues through a mismatch of salience. The autistic participants were not understood when using their own communication style and as such were required to comply with and emulate their neurotypical peers.
The autistic voice matters

As social validity centres on the social importance and acceptability of goals (Foster & Marsh, 1999), in this case, network peers’ agreement about whether autistic people succeeded may not hold true social validity for the autistic participants. With ten neurotypical peers and three autistic people, the study reported asking the neurotypical peers whether the autistic participants achieved their target skills. This places the perceived social validity onto the neurotypical participants, rather than the autistic participants. This echoes the concern regarding social validity as given above, and further amplifies a mismatch of salience. Crucially, this is a case of ‘oughtism’ (Evans, 2019), whereby autistic people ought to be other than themselves. The weight of whose opinion matters is at disparity. Therefore, their opinions are diminished unless they match the views of their network. It remains unclear whether the autistic participants were asked if these skills were desired. There are autistic people that do want to learn ‘relevant’ social skills to fit in with society or maintain friendships, yet everyone must adapt their communication (to some extent) dependent on who they are talking to (i.e., in relation to Milton’s Double Empathy Problem).

It is vital to engage autistic people in their needs. An ever-increasing amount of work is being conducted acknowledging the need of the autistic voice in research (e.g., Ashworth et al., 2021; Botha, 2021; Pellicano & den Houting, 2021; Waldock, 2019). Therefore, this should be the same within research that is attempting to support and form development opportunities. It is only too common that the autistic experience is devalued (Baggs, 2010). Akin to Arnstein’s ladder of citizen control (Arnstein, 1969), autistic people should have a level of power equivalent to citizen’s control (Arnstein, 1969) regarding their own autonomy (including desired skills taught), and more broadly, research about autistic people (or preferentially with autistic people).

The power imbalance noticeable in Bambara et al. (2021) begs the question about reporting what was wanted by the autistic participants (and not just ‘enjoyed’). We need to acknowledge the impact of compliance (see Sandoval-Norton & Shkedy, 2019), the need to change the widely accepted
normative idea about what being social means (neuroqueering interpersonal communication theory; Cole, 2021), and autistic people being valid in and of themselves (Yergeau, 2017). There is a growing body of knowledge which demonstrates the importance of gaining a positive identity (which would include autistic system of interpretation) and being accepted by others improves quality of life (Cage et al., 2018; Cooper et al., 2017).

Lastly, language used to describe autistic people in the field of autism research has been found to vary across different groups of people (Kenny et al., 2016). Although some autistic people will use or want person-first language, it is important to acknowledge the role of stigma (Bottema-Beutel et al., 2021) and how many autistic people understand being autistic as part of their identity (Sinclair, 2013). This is vital to consider, especially when considering power imbalances and the autistic voice within research.

Conclusion

There may be some scope to run skills training that matter to autistic participants. However, social and communication skills must address the double empathy problem and not require autistic people to adhere to a neurotypical system of interpretation. Furthermore, being critical of who is defining what is relevant in regard to power imbalances is a necessary consideration. Lastly, social validity must be both important and acceptable for the primary, key stakeholder(s), i.e., the autistic individuals.

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References


