

Commentary on Jaswal & Akhtar

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The loneliness of me: The assumption of social disinterest and its worrying consequences in autism

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Abstract

We share Jaswal & Akhtar's concerns about the unintended repercussions of assumed social disinterest in autism. We expand consideration of these consequences with discussion of the literature and our own work on loneliness, mental ill-health, and self-representation, which is a cornerstone to social and emotional health. Further study is needed with expansive, mixed methodologies and involvement of the autistic community.

Jaswal & Akhtar (J&A) raise the spectre of the unintended consequences that could arise from traditional assumptions of social disinterest in autism. The authors both centre on autistic voices and widen the scope of our view to observe the non-autistic participant in a dyad, whose beliefs may markedly affect, or worse reduce, interaction. As clearly shown in the qualitative data presented by these and other authors (Causton-Theoharis et al. 2009; Hickey et al. 2018), loneliness is an immense problem in the autistic population, and one that might be exacerbated by just this assumption.

Some accounts, in autistic children and adolescents, present different subjective experiences and understanding of friendships and loneliness (Bauminger & Kasari 2000). Social interaction may not actually reduce loneliness, and likewise loneliness can coexist with decreased desire for social interaction (Deckers et al. 2017), which may reflect that social interaction, when it occurs, is not always a pleasant experience. However, other accounts have emphasised the similarity in the way that autistic and non-autistic people experience loneliness, with feelings of “disconnect” and “longing” for understanding and companionship, at the heart of this concept, which is clearly differentiated from the need for time alone (Causton-Theoharis et al. 2009; Hickey et al. 2018). In strong accordance with J&A, these accounts emphasise that it is “not disinterest that separates people with autism from others” but rather their “difficulty navigating the world of people” and their unconventional approach to the same (Causton-Theoharis et al. 2009, p. 92).

As in non-autistic people, loneliness in autism is associated with poor mental health and, by increasing the likelihood of depression, predicts self-injury and suicide ideation (Hedley et al. 2018). Autistic people are at substantially greater risk of suicidality (Cusack et al. 2016), making this a crucial focus for research and intervention. Our group recently

investigated self-injury and suicidality in 134 autistic adults who took part in an online survey. The unpublished (thus far) data corroborate the link between loneliness and suicidality ($r = .339, p < .001$) with another measure of suicidality.

Qualitative data collected in the same study highlighted difficulties in communication between autistic people and healthcare professionals. One participant wrote: “You are speaking a different understanding and it is so hard to find a moment where understanding touches.” Of course, professionals are subject to the same assumptions as the lay public. In 2005, many primary and specialist healthcare providers endorsed the belief that autistic children are unlikely to form emotional bonds with others (Heidgerken et al. 2005). Ten years later, less than 10% of physicians expected autistic people to show an interest in others (Zerbo et al. 2015). Assumptions of social disinterest may thus mean that autistic individuals who do attempt to connect, however idiosyncratically, are less likely to be diagnosed, which in turn may reduce attempts from professionals to connect with autistic people. Our survey reiterated how much autistic adults value caring relationships and emotional connections with others (“People need relationships, love and appreciation”) and how much they appreciated such a connection (“being heard,” “having regular time”) with their healthcare professionals. Sadly, and perhaps partially pertaining to attitudes about autism, many autistic people are dissatisfied with the care they receive and their relationships with healthcare professionals (Nicolaidis et al. 2015).

Our recent work indicates that these differences in autism may be related to differences in self-related cognition and emotional processing (Sui & Gu 2017). For example, people normally tend to make faster and more accurate responses to information about themselves than others, and a reduction in this trend predicts negative mood state (Sui & Gu

2017). Other researchers have demonstrated that self-referential processing is atypical in autism (Lombardo & Baron-Cohen 2011), and that these differences may be associated with social problems in autism (Gillespie-Smith et al. 2018). We argue that altered self-representation impacts on the way one perceives and reacts to others, because the self–other interaction represents a basic point for our construal of the world through the life span (Sui & Humphreys 2015). Self-representation in autism is related to the development of social competence, relationships, and emotional health (Bauminger et al. 2010), such that understanding changes in self-representation and how they contribute to social interaction in autistic individuals may be important to develop full accounts of the autistic experience.

Further study is needed, and we would reiterate, alongside J&A, the importance of using expansive, mixed methodologies. The way autistic people talk about loneliness, for example, is influenced by the methods used to explore it (Lasgaard et al. 2010). The combination of quantitative and qualitative methods provides a more complete picture of a phenomenon, especially when findings complement each other. We would suggest that qualitative methods allow autistic people a more prominent role in the research process and greater buy-in with the end-product that contains their voices. J&A’s target article challenges scientists to move beyond a purely empirical tradition to a more humane, respectful approach that should maintain scientific rigor while being open to methods from other disciplines. This is evinced, for example, in the combined epidemiological and anthropological approach adopted by Barg et al. (2006) to study loneliness in non-autistic adults. Another way of centring autistic participation in our research is to use instruments specifically designed through collaboration with autistic people, as is emerging in mental health research (Cassidy et al. 2018)).

Given the suicide crisis in autism, it is more important than ever to check our normative interpretations of autistic behaviours, lest they impact on everyday well-being and the provision of vital services. As emphasised by the J&A, autistic voices should be embedded in more imaginative approaches to addressing scientific questions of value, such as investigations of mental health and the psychological factors that influence it. In potentially impeding communication between the autistic, the scientific, and the clinical communities, assumptions of social disinterest may ultimately leave us all the poorer, most notably those who can least afford it.

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