Integrating Community Participation with Interpretative Phenomenological Analysis: Reflections on Engaging the Autism Community

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Integrating Community Participation with Interpretative Phenomenological Analysis: Reflections on Engaging the Autism Community

Short Title: Community Participation & IPA in Autism Research

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The Author(s) declare that there is no conflict of interest.

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Abstract

Members of the autistic community have long advocated for more input into and participation with autism-related research. Currently, the power to determine the direction of autism-related research and knowledge production related to autism lies with non-autistic researchers, while the wishes and perspectives of the
autistic community are largely ignored. There is a growing trend toward ethical autism-related research, however, in which the perspectives of all stakeholders, particularly those of autistic individuals, are sought and their expertise on autism is foregrounded. In a study exploring the experiences of childhood adversity and resilience among autistic adults, we strove to conduct our research in an inclusive and ethical way, by integrating participatory methods, such as community engagement to inform research design, and credibility checking with participants to validate analysis. Five stakeholders, representing parents of children on the autism spectrum, professionals, and autistic community members were recruited to provide input into the research design and provide insight into autistic ways of communicating, interacting, and being. The recommendations generated through this community engagement were then integrated into an interpretative phenomenological analysis (IPA) framework and implemented with four adult autistic participants. Through reflection on the process of community engagement, development of research design, implementation of the study, and credibility checking, it is clear that incorporating participatory methods into IPA increases rigour and ensures that autistic perspectives are represented through research.

Keywords: autism, interpretative phenomenological analysis, participatory methods, ethical autism research, community engagement, credibility checking

Introduction

Historically, researchers studying autism have excluded the input of autistic individuals into research priorities, aims, and design. As a result, knowledge about autism has been produced by non-autistic stakeholders, leading to misunderstandings and misinterpretations of what it means to be autistic. Furthermore, this has exacerbated power imbalances between non-autistic researchers and autistic participants, where non-autistic researchers are positioned as the experts in autistic experiences, rather than autistic individuals themselves (Milton, 2014; Milton & Bracher, 2013; Milton et al., 2012). Advocates for ethical autism-related research have suggested that including autistic perspectives in the prioritization of research objectives, study design, and implementation of autism-related research are key practices for researchers (Chown et al., 2017; Milton & Bracher, 2013; Pellicano et al., 2014; Pellicano & Stears, 2011).

In a recent study [reference withheld for blind review], an exploration of the influence of childhood adversity and resilience in the lives of autistic adults, we, as non-autistic researchers, strove to conduct ethical autism-related research and honour the perspectives of the autistic community. To do this, we employed interpretative phenomenological analysis (IPA) and integrated participatory methods, including community engagement to inform the research design, and credibility checking with participants, post-analysis. While limited, there is evidence in the literature for incorporation of participatory methods with IPA (Bush et al., 2019; MacLeod et al., 2019). Bush et al (2019) argued that IPA blends well with community-based participatory research (CBPR) given that both methodologies facilitate a joint construction of knowledge by researchers and participants. While we did not engage fully with a participatory methodology like CBPR, we conducted a community engagement phase, prior to designing and implementing the research. This practice is common in IPA research within the health field (Larkin & Thompson, 2012). In this phase, we sought the input of the autism and autistic communities on the value of the research question, appropriate methods for data collection, insight into autistic ways of communicating and interacting, and how best to approach autism-related research in an inclusive, ethical way that honours the autistic community. The community advisors provided rich and detailed feedback that informed all aspects of the study. The objective of the subsequent IPA analysis was to understand, directly from autistic participants, how their experiences of childhood adversity influenced their well-being and the meaning of resilience in their lives. The purpose of this paper is to outline the advisors’ recommendations and how we integrated them into an IPA methodological framework, and to demonstrate how the integration of participatory methods into IPA improved rigour.
Process of Engaging Community Advisors

After receiving institutional ethics approval for the community engagement phase of this research, we recruited community advisors directly through the first author’s professional network and through snowball sampling. Five advisors were recruited. Several advisors had multiple roles and of the five, two were mental health professionals who work closely with autistic individuals, three were autistic self-advocates, and two were parents of children on the autism spectrum. Parents, professionals, and autistic self-advocates are all stakeholders in the outcomes of autism-related research and have unique and valuable perspectives on conducting research for the autism community (Pellicano & Stears, 2011). Community advisors were considered study participants, and therefore gave written or verbal informed consent, depending on their preferences, and were provided with the interview guide (see supplementary materials). Advisor participants were given the option to be interviewed by phone or via videoconference. They were not offered in-person interviews due to COVID-19 safety concerns and local restrictions. Recorded interviews lasted between 60 and 155 minutes and were conducted by the first author. One advisor also provided answers to interview questions via email post-interview. Advisors gave concrete suggestions for engaging and communicating with autistic research participants, as well as insight into autistic ways of thinking, knowing, and communicating. Advisors gave feedback on the research question, its value to the autistic and autism communities, and provided insight into the power imbalances that exist between non-autistic researchers and autistic participants. They identified potential pitfalls and potential sources of disconnect between participants and researchers and how to avoid them.

Following the interviews, the first author reviewed the recordings and identified the recommendations from each advisor, combined them into a master list, and categorized them according to research methods, engagement strategies, and overall considerations (see Table 1). We then integrated the recommendations into the research design prior to recruitment of participants for the main study.

Community Advisor Recommendations and Researcher Reflections

Research Design

Research Question

Advocates for ethical autism-related research have noted that excluding the autistic community from research has meant that non-autistic researchers have determined the priorities of autism-related research without consultation (Milton, 2014; Pellicano & Stears, 2011) and that ethical autism-related research needs to focus on making the lives of autistic people better (Chown et al., 2017). As such, it was important to us that the research topic and question had value for all stakeholders in the autism community, but especially for those who are autistic. We asked community advisors to give their feedback on the research question and to offer insight into how this research might be valuable to the groups they represented (i.e., parents, professionals, autistic self-advocates). The community advisors validated that the research had the potential to inform positive change in the lives of autistic individuals, including improved awareness of mental health issues faced by autistic individuals and potential interventions to ameliorate those challenges.

Recruitment

Community advisors were not asked specifically to comment on participant recruitment; however, the topic came up in several interviews. There was some disagreement among advisors about appropriate inclusion criteria to ensure participants had the capacity to give informed consent and provide insight into their childhood experiences. One advisor suggested that limited executive functioning skills could make participation in the study challenging for some participants; thus, executive functioning ability could be a more appropriate exclusion criteria than intellectual disability. However, another advisor proposed that recruiting and then excluding participants based on a test of executive functioning could negatively affect their well-being. Given this disagreement, combined with the input of the institutional research ethics board, we determined that
executive functioning would not be an appropriate exclusion criterion for this study. Instead, participants were asked to self-report that they did not have a co-occurring intellectual disability.

Our experiences recruiting community advisors influenced our subsequent recruitment procedure for participants. Recruitment of community advisors was done via email and included a significant amount of text-based information. We discovered that some advisors preferred not to read information, opting instead to review the informed consent form with the first author and give verbal consent. This experience prompted us to consider the best way to engage potential participants, as we were concerned that a recruitment poster with too much information might not be accessible to all members of the autistic community, thus limiting the inclusion of participants who communicate differently. As such, we prepared a recruitment poster with minimal text (see supplementary materials) and a short video introducing the first author, explaining the aim of the study, and outlining the eligibility criteria for participation. A link to the video and the poster were shared together to engage participants through multiple modes of communication.

At the time of community engagement, some elements of the research design had been tentatively planned to meet the requirements of the first author’s graduate program. In the proposed design, participants would be included if they were over the age of 18 but had been diagnosed prior to turning 18. This methodological decision was rooted in the principles of IPA, in which it is desirable to have a small, homogeneous sample (Larkin & Thompson, 2012; Pietkiewicz & Smith, 2014; Smith, 2004; Smith et al., 2009). Furthermore, one of the aims of this study was to understand how a child’s autistic identity interacted with experiences of adversity and resilience factors to shape their ongoing well-being. As such, we pre-supposed that an autistic identity would be developed in childhood and adolescence following a diagnosis of autism. When they became aware of this eligibility criteria, some community advisors advised against excluding individuals diagnosed with autism later in life, as the experiences of this demographic hold equal value and their experiences of childhood adversity could stem from being undiagnosed. After significant consideration, we decided to continue with the original eligibility criteria, to maintain the rigour gained by having a homogenous sample, especially considering the necessary small sample size for manageable thesis research.

Interestingly, this decision prompted feedback from the autistic community related to the call for participants. A link to the study recruitment video was shared, without our knowledge, to a social media group populated by members of the autistic community. Several individuals contacted the first author to express their concerns with the exclusion criteria, suggesting that it implied their experiences were not valuable or important. They also expressed concern about the implications of a non-autistic researcher making decisions about whose experiences should contribute to the generation of knowledge about autistic experiences. The first author engaged in dialogue with each of these individuals, explaining the aims of the study and the research design. The conflict was resolved with each individual, however, this experience prompted us to reflect further on the role of non-autistic researchers and methodological decision-making in autism-related research. While our methodological reasoning was sound, it was contrary to the advice we received from community advisors. This is one of the tensions that exist between non-autistic researchers and the autistic community (Pellicano & Stears, 2011) and requires careful consideration by non-autistic researchers, to honor the needs and wishes of the autistic and autism communities, while prioritizing rigorous research design. In this case, given the small sample size and the first author’s need for guidance as a novice researcher, it was logical and justified to adhere to the IPA practice of maintaining a small, homogenous sample. However, it is possible that our adherence to IPA methodology disproportionately influenced our decision, and thus caused distress and distrust for some members of the autistic community. Further consultation with community advisors about the eligibility criteria may have led to a different methodological decision or altered our approach to recruitment, while maintaining the original exclusion criteria. By communicating the intent and the aims of the study more clearly, we may have mitigated the potential for harm.

Notably, the age of diagnosis was seemingly irrelevant to understanding the experiences of the participants in this study. They were diagnosed as early as three years old and as late as 17 years old. This broad range did not seem to influence the homogeneity of their experiences of either childhood adversity or resilience. While being autistic did influence their experiences, having a formal diagnosis did not seem to change the effects
that being different had on their lives. Furthermore, there were similarities in their experiences, specific to being autistic, regardless of the age of diagnosis that were consistent across participants.

Data Collection

Community advisors were asked for ideas about how to collect data in ways that would create space for participants with communication differences or other neurodivergent traits, to engage in the process more easily and comfortably. The first author was keenly aware that, as non-autistic researchers, we were ignorant to the ways in which some participants may interact, communicate, or think; and that most of the time, the onus falls on the autistic individual to adjust to non-autistic ways of communicating and interacting, which deepens the power imbalance that exists between autistic participants and non-autistic researchers (Milton, 2014). It was important to us not to expect autistic participants to adjust to our non-autistic ways of conducting research; instead, we made it a priority to adjust the research design to their unique ways of being. One advisor noted that communicating in a non-autistic way can be overwhelming to some autistic people and by adapting the process to their ways of communicating, it would make participation more manageable. One advisor noted that language is contextual for many people on the spectrum. Other advisors suggested that traditional interviews might overburden participants and suggested that participants have the opportunity to choose how they would communicate their data. Some advisors also suggested that interviews be structured differently, possibly conducting multiple, shorter interviews or building in breaks for longer interviews.

Based on the advisors’ recommendations about data collection, the first author developed a pre-interview survey (see supplementary materials) for participants to identify the best way to engage in the data collection phase of the study. All participants contacted the first author by email to volunteer, therefore we provided them the survey via a Microsoft Forms link, with the offer to conduct the survey verbally, by phone, if they preferred. All participants opted to complete the survey online. Participants were asked what their preferred mode of communication was for answering questions related to the study, including via a video conference interview, phone interview, written narrative, online text-based chat platform, pre-recorded audio files, or through visual images with supplemental narratives or audio recordings. They were also given a space to identify another unlisted mode of communication. As with advisor interviews, in-person interviews were not offered to participants due to COVID-19 safety considerations. Two participants opted for phone interviews, one for a video conference, and one for the text-based chat platform.

Other options on the survey included the best time of day for the interview and the opportunity for breaks, multiple, shorter interviews, the chance to review interview questions ahead of time, either written or audio recorded, inclusion of a support person in the room, inclusion of a pet or other comfort items, and a pre-interview “getting to know you” visit to build rapport, comfort, and trust between the interviewer and participant. While the broad range of options required more flexibility and accommodation from us in terms of scheduling and interview preparation, they were based on specific recommendations by advisors to make the interview experience as accessible and comfortable as possible for participants. For example, the option to choose what time of day the participant would prefer to complete the interview was based on the suggestion of one of the mental health clinicians, who noted that for some autistic individuals, the time of day may affect their ability to access technology in shared living circumstances or lessen the potential for overwhelming sensory stimuli in their environment.

The pre-interview survey also covered two other important preferences. We asked participants to provide their preferred language related to autism. There is debate in the autism community about the use of person-first and identity-first language to describe a person’s autism diagnosis (Kenny et al., 2016). In an attempt to reduce the power imbalance between the interviewer and participants, we wanted to respect their language preferences and not assume that we knew the best way to characterize their diagnosis. Additionally, on the recommendation of one advisor, the survey included a question regarding assistive technology and whether participants required research materials (e.g., interview guide) in another, more accessible, format.

Of the options provided, all participants opted for an interview of some type (phone, video, or text-based),
three participants chose a time during the day on a weekday and one on a weekend. All requested that they have access to the interview guide ahead of time. One participant requested a “getting to know you” visit prior to the interview and one opted to take several breaks during the text-based chat interview. Participants chose times of day that worked well for them and all provided their preferred way of identifying in relation to autism.

One advisor recommendation related to data collection created some tension for the research team and required significant discussion and reflection to determine if it could be integrated into the research design. One advisor noted that some autistic people do not speak, or communicate more effectively using visual images, however most research studies are designed to engage participants in verbal interviews or questionnaires. IPA has received criticism as a methodology for conducting autism-related research, given that autistic participants may use language quite differently than a non-autistic researcher. Howard et al. (2019) argued, “[i]f IPA is so intrinsically bound to the elicitation of voice, questions may well be raised as to whether it can be a legitimately useful tool for autistic individuals with language difficulties” (p. 1874). They also suggested giving participants the opportunity to share data via another mode of communication in IPA studies. To prevent exclusion of potential participants who are non-speaking or who express themselves more effectively through images, the advisor recommended that participants have the option to express themselves through art or photographs, with a trusted person serving as translator between the participant and researcher. While it was important to us not to inadvertently exclude participants, who do not communicate using spoken language, the suggestion posed a logistical, methodological, and ethical quandary. Adding translators to the research design would require additional informed consent considerations, would potentially reduce confidentiality for participants, as there was no guarantee translators would keep the sensitive information shared by participants private, and it could be difficult to schedule the amount of time necessary to conduct an interview in this way.

From a methodological perspective, using a translator to interpret potentially abstract images, seemed to jeopardize the ideographic nature of IPA. The focus on the particular by IPA researchers allows them to develop a detailed, in-depth appreciation for a participant’s experience, as it occurred in a particular context at a particular time. Researchers give much attention to each case before moving to an examination of the whole data set, comparing and contrasting the interpretations of each case (Pietkiewicz & Smith, 2014; Smith, 2004; Smith et al., 2009). We were concerned that the details and context would be lost in the translation process. Furthermore, the suggestion posed a problem related to the interpretive nature of IPA. There is a double hermeneutic in IPA, that is, multiple levels of interpretation of the participants’ experiences (Smith, 2004; Smith et al., 2009; Smith & Osborn, 2015). Firstly, the participant is making sense of their own experiences and sharing that interpretation with the researcher. From there, the researcher interprets the participant’s interpretation, therefore interpretation of the experience happens twice, creating a double hermeneutic. Furthermore, interpretation does not end with the researcher and participant, rather it continues to a third level as a reader interprets the research findings through their own lens (Smith, 2004; Smith et al., 2009). Including a translator to the data collection would add another layer of interpretation, potentially changing the meaning intended by the participant or understood by the researchers. By adding translators, we were concerned that we would lose the ability to closely examine and analyze a participant’s interpretation of their experience.

In grappling with this dilemma, we considered the insight of another advisor, who explained the concept of an autistic language and the misunderstandings that often occur between autistic and non-autistic individuals. They suggested that autistic people spend time and energy translating the things they want to communicate into the language of a non-autistic communication partner. This can lead to miscommunication and misunderstanding, not unlike those that occur between speakers of English and French. We conceptualized this internal translation as a fourth level of interpretation of a participant’s experience; however, it is different in that it is still the interpretation of the participant, not an external person removed from the experience. This advisor posed a similar suggestion to help combat misunderstandings between autistic participants and non-autistic researchers. They recommended employing an autistic individual to read and translate the transcribed participant interviews prior to analysis. This recommendation prompted the same
methodological concerns.

Interpretative phenomenological analysis has been used in autism-related research previously, and MacLeod (2019) suggested that the double hermeneutic in IPA could mitigate the potential for misunderstandings by addressing the double empathy problem, wherein the lack of understanding of another’s perspective occurs in both the autistic and non-autistic communication partner (Milton, 2012). The dominant, non-autistic view of the communication challenges that occur between non-autistic and autistic individuals is that autistic people lack the ability to empathize with others; whereas the autistic perspective is that non-autistic individuals are unable to empathize with those on the autism spectrum, which leads to non-autistic communication partners making assumptions about what an autistic person is saying, feeling, or thinking. This lack of empathy by both communication partners is the double empathy problem. The double hermeneutic in IPA, therefore, addresses this problem as researchers strive to understand and make meaning of a participant’s understanding of their experiences (MacLeod, 2019). Additionally, by engaging in the double hermeneutic, the researcher acknowledges that their interpretation of the participant’s experience is filtered through their own, non-autistic lens, and thus, does not claim that their interpretation is a purely autistic perspective (Howard, 2019; MacLeod, 2019). Furthermore, by exploring participants’ experiences ideographically, researchers describe the particulars of individual experiences and convey their commonalities, rather than deriving a general theory through analysis of a population (Pietkiewicz & Smith, 2014; Smith & Osborn, 2015). It is the shared creation of understanding between the researchers and participants, within a particular context, that makes IPA congruent with the aims of participatory research, in which the meaning of experiences is also co-created (Bush et al., 2019).

Ultimately, we decided that given the ethical and logistical barriers to incorporating these recommendations, as well as the interpretative and ideographic nature of IPA, that we would forego those recommendations for this study. However, these suggestions are not without merit and could be valuable to researchers employing methodologies that are not interpretative or participatory.

**Interviews.** Community advisors had specific suggestions for conducting interviews with autistic participants. They suggested that participants be provided with the interview guide ahead of time, and that we provide a rationale for each question, to give participants the context of what information we hoped to glean from the question (see supplementary materials). Advisors disagreed on the best types of questions to ask. Some suggested that shorter, concrete questions would be best, while others suggested broader, more abstract questions. One advisor pointed out that many people on the autism spectrum enjoy language and have large vocabularies, and that using rudimentary language would be an insult to some. To meet the needs and preferences of participants who might require different types of questions, we created an interview guide that included broad questions with specific, concrete sub-questions for drawing out detailed recounts of childhood experiences, if needed (see supplementary materials). The interview guide included a rationale for each question, with an explanation of the objective of each. Participants had the opportunity to review the interview guide prior to participating in the interview.

Community advisors provided recommendations for conducting the interviews, with a particular focus on ensuring that participants could be as comfortable as possible when engaging with the interviewer. For example, they suggested that the interviewer provide silent moments so that the participants would have adequate time to cognitively process questions and formulate answers. They also suggested avoiding yes/no questions, as these may not encourage participants to share details beyond the expected yes or no response. Given that participants on the autism spectrum may experience challenges related to sensory overstimulation, advisors suggested that video conference interviews be done with a plain, non-distracting background, and that the interviewer wear solid, non-descript clothing to ease sensory stimulation. Additionally, it was suggested that participants be encouraged to take breaks if needed and to be reminded that their comfort throughout the process is a priority. Lastly, several advisors noted that sometimes autistic people need time to process an experience and will have more to say on a topic after some time has passed. It was recommended that the interviewer follow-up with participants a few days after the initial interview to give another opportunity to add additional thoughts and comments. It was also suggested that this follow-up
contact would be an opportunity to check in on the well-being of participants after the potential emotional toll of discussing childhood adversity, a consideration supported in the IPA literature. Exploring one’s lived experiences may create distress for participants and researchers are responsible for ensuring that participants’ emotional well-being is supported (Smith et al., 2009; Pietkiewicz & Smith, 2014). Besides following-up with participants post-interview, we provided participants with a list of mental health resources available in their communities and offered them two free counselling sessions with a counsellor of their choice. One participant took advantage of this benefit.

While integrating the many strategies suggested by the community advisors required more time and effort than traditional semi-structured interviews might have, the benefit of providing options for participants was clear. All the participants expressed that participating in this study was a positive experience and that they felt comfortable in engaging with the first author, who conducted all the interviews. Interestingly, the four participants who volunteered for this study were individuals who had significant insight into their experiences, used language in ways that matched the first author’s way of communicating, and did not require intensive support from the interviewer to participate fully in the interviews. As such, the participants did not choose many of the interview options provided to them. For example, none of the participants requested to do multiple, shorter interviews, to provide data via written narratives or visual images, or to have research materials provided to them in an accessible format. For this particular group of participants, the most useful options were to have the opportunity to review the interview questions ahead of time and to have alternatives to the video conference interview. However, based on the variability of expression of autistic characteristics in people on the autism spectrum, evidenced in the multifarious recommendations from community advisors, the broad range of options was appropriate and necessary.

Researcher Positionality

In addition to the specific research design recommendations and strategies for implementing the study, the community advisors provided insight into how autistic people may experience the world and considerations for us, as non-autistic researchers, for engaging with participants and completing data analysis. These considerations were mainly related to the power imbalance between non-autistic researchers and autistic research participants, a phenomenon that is documented in the research literature (Milton, 2014; Pellicano et al., 2014). The community advisors for this study provided examples of how the first author’s positionality may inherently perpetuate this power imbalance and influence participants, which could subsequently affect the quality and richness of the data and data analysis. One advisor noted that the power imbalance will be greater than the researcher perceives it to be. To ensure rigour, therefore, it was important that the first author strive to create an interview space where participants would feel comfortable and safe to share openly about their experiences and even disagree with the researcher. For example, one advisor noted that the first author’s previous career as a teacher meant that she may represent an authority figure to some participants, particularly if they had experienced negative interactions with teachers in their childhoods. Participants may have had experiences in school where they were discouraged from sharing their opinions, disagreeing with teachers, or avoided negative interactions by acquiescing or deferring to teachers. If participants believed that they could not disagree with her, present a contrary point of view, or felt pressured to respond with answers that would be desirable to her, the rigour of the study and strength of the findings could decrease. The first author was also concerned that she may slip into this role of authority figure and expert, thus amplifying the position of power and influencing interactions with participants.

IPA researchers can increase rigour by maintaining sensitivity to context, which is partially achieved during the interview when the researcher articulates an “appreciation of the interactional nature of data collection within an interview situation” (Smith et al., 2009, p. 180). Smith et al. (2009) indicated that “obtaining good data require close awareness of the interview process—showing empathy, putting the participant at ease, recognizing interactional difficulties, and negotiating the intricate power-play where research expert may meet experiential expert” (p. 180). This is congruent with the recommendations of advisors, who suggested that the interviewer openly acknowledge the power imbalance with participants, encourage participants to ask clarifying questions, reinforce that their data will be included even if a participant disagrees with
the interviewer, and take steps to ensure participants feel comfortable throughout the interview. The first author, therefore, opened each interview with transparency about her positionality, the motivation for the study, and the objectives in conducting this research. This included acknowledging the power imbalance inherent between the first author as a non-autistic researcher and the autistic participant. Participants were encouraged to ask questions, disagree, and request breaks or other support as needed. To maintain this openness and equality throughout the interview, the first author frequently checked in with participants about their well-being and comfort level and asked permission before moving to a new question or topic, to give participants the time necessary to answer questions in detail.

During data analysis, the first author addressed the potential influence of her positionality and biases through reflexivity. For example, when reviewing the interviews, the first author noticed instances where it seemed participants were verbally agreeing but their body language or tone of voice did not match that agreement. We wondered if these were occurrences of participants acquiescing to avoid conflict or were deferring to the interviewer’s expertise. We were careful to consider that the data generated in those instances was potentially inaccurate or irrelevant, comparing it to the data set as a whole to determine whether it could be used to contribute to the overall analysis and generation of themes.

Credibility Checking

Credibility checking is used to ensure that researcher interpretations in IPA are of a high quality and ensures rigour (Larkin & Thompson, 2012). While there are a variety of methods for engaging in credibility checking, including audit by an external expert or peer sample (Larkin & Thompson, 2012), the most common means of credibility checking in autism-related IPA studies is to invite study participants to validate researcher interpretations (MacLeod, 2019). By engaging in credibility checking non-autistic researchers can minimize the risk that they have inaccurately interpreted the experiences of autistic participants through a non-autistic lens, which reduces power imbalances (MacLeod, 2019). As one community advisor in the present study pointed out, if the findings of an autism-related research study are not validated by autistic people, they are simply hypotheses about autistic people, made by a non-autistic researcher. Credibility checking reduces the power imbalance when researchers give up the role of expert and seek validation from participants with humility. Community advisors in the present study provided feedback on how best to engage participants in this process. Similar to data collection, the recommendations of the community advisors were to ensure that the task of credibility checking would be manageable for participants. They suggested presenting information in small chunks; for example, organizing interpretations for participants to review in smaller pieces, such as by themes.

The participants in this study were eager to engage in credibility checking and the first author scheduled a meeting with each of them to discuss the themes resulting from the data analysis, with supporting data from their individual transcripts. This fits with the development of themes in IPA data analysis as findings reflect the comparison of themes across cases, although themes may or may not be evident in every participant’s experience (Smith et al., 2009). Accordingly, it is appropriate to provide participants the opportunity to comment on the validity of themes generated across cases, as they relate to their own experiences. Three participants opted to meet over the phone and one via videoconference. These credibility-checking interactions with all participants were audio recorded. Participants were provided with a document outlining each theme, sub-theme, and associated supporting quotes from their individual interviews. Credibility checking discussions did not follow a formal structure, however, all participants opted to systematically review the document with the first author and for each theme or sub-theme, validated the interpretation, provided supplemental data to support the theme, and/or clarified details that we had misunderstood. Interestingly, some participants offered new data to support sub-themes that we had not previously interpreted as part of their experiences. During credibility checking it became evident that the sub-themes derived from other participants’ experiences were also relevant to their lives even though they had not been apparent in their original data. Some participants provided additional data with this realization.

As researchers, the credibility checking process was valuable, both in terms of producing rigorous findings
but also as validating that the research is important and helpful to autistic individuals and the overall community. This was especially important to the first author, who frequently questioned whether she was the best person to be conducting this research and whether the implementation and findings of the study would be helpful or harmful to the autistic community. Participants expressed pleasure and gratitude for the opportunity to participate in the study and expressed how participation in the study provided them with the opportunity to explore their experiences, gain further understanding of themselves, and continue to heal from adversity. The first author felt honoured to be a witness to the recounted experiences of these participants and is indebted to them for their candid and insightful participation in this study.

Dissemination

Community advisors had minimal recommendations regarding dissemination but validated that the research question was important and that the findings should be disseminated broadly to the autistic and autism communities. Advisors suggested multiple modes of dissemination to reach multiple audiences. For example, dissemination to academic journals to reach researchers and professionals working with individuals on the autism spectrum, and social media to reach the autistic community. Additionally, some advisors requested that they receive acknowledgement through co-authorship on publications and presentations. For this study, advisors will be named in the acknowledgements of academic publications and named as co-authors on lay publications and presentations, as appropriate.

Conclusion

Increasing involvement of the autistic community in autism-related research is a priority for autistic self-advocates and researcher allies who wish to make autism-related research more ethical, inclusive, and valid (Chown et al., 2017; Pellicano et al., 2014). One aim of the present study was to engage the autistic and autism communities to inform the research design of and, ultimately, the knowledge generated by this study. Three autistic and two non-autistic mental health professionals provided insight and feedback into the research methods used for this study, which led to successful engagement of autistic participants and rigorous findings. The recommendations of community advisors outlined in this article will be helpful to other non-autistic researchers in ensuring that their qualitative research designs include the perspectives and wishes of the autistic community.

Table 1

Community Advisor Recommendations

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<tr>
<th>Category</th>
<th>Recommendations</th>
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<tbody>
<tr>
<td>Recruitment</td>
<td>Executive functioning instead of IQ for exclusion criteria; excluding participants based on executive functioning could be damaging Include participants who were not diagnosed in childhood</td>
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<tr>
<td>Data Collection</td>
<td>Have clear goals and motivations for interview questions Multiple, shorter interviews Use concrete questions and use broad open-ended questions Give participants a chance to review interview questions in advance Let people choose their own mode of communicating their data; interviews might be overwhelming to some people Avoid rudimentary language – often people on the spectrum have big vocabularies and do not like to be talked down to</td>
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<td>Category</td>
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<tr>
<td>Category Recommendations</td>
<td>Follow up with participants after a couple of days so that they can add additional details Follow up with participants after a couple of days to check on their well-being Invite participants who communicate differently to include a support person who can serve as a translator. Follow up with people who work closely with the participant to get further understanding about the participant’s meaning</td>
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<tr>
<td>Researcher Positionality</td>
<td>Researcher as a former teacher might trigger a perceived power imbalance because sometimes autistic individuals generalize bad experiences to others Explicitly tell people they can ask clarification questions Participants may see the interviewer as a person with power, causing anxiety, thus may be deferential as a result Acknowledge the role of non-autistic researchers Validate that participants’ perspectives are valued and important Researcher can acknowledge and name power imbalances, inviting equality Power imbalance will be greater than the researcher realizes Give participants choice of time of day for interviews</td>
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<tr>
<td>Interviewing Strategies</td>
<td>Use visuals due to challenges with working memory Provide processing time when waiting for answers Ask participants what would make the process comfortable for them Plain background and plain clothes for video interviews Participants may use assistive technology and require alternate format materials Ensure people know they have permission to take a break Avoid yes/no questions Be curious and ask clarifying questions of participants</td>
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<tr>
<td>Credibility Checking</td>
<td>Conduct credibility checking in manageable chunks over time Credibility checking could be broken down by theme or idea Provide manageable chunks of data in separate documents Interpretations must be validated by an autistic person or it is just another hypothesis by a non-autistic researcher Credibility checking needs to be accessible</td>
</tr>
<tr>
<td>Dissemination</td>
<td>Disseminate to social media to reach the autistic community Disseminate to academic journals to reach researchers and professionals</td>
</tr>
</tbody>
</table>

References


Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L.,


