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In this paper, the insights and experiences of a research team involved in conducting qualitative research with families living with autism spectrum disorder are drawn upon to provide reflections and recommendations across all stages of the qualitative research process. Particular attention is given to the steps involved in semistructured interviews, specifically, interview guide preparation, participant recruitment, obtaining informed and voluntary consent/assent, conducting effective interviews, accurate analysis and interpretation of data, ways to involve participants in data analysis, effective communication of research findings, and providing feedback to participants. In addition, reflections and recommendations are provided for maintaining researcher health throughout the qualitative research process.

CONCEPTUAL PAPER

# Qualitative research with families living with autism spectrum disorder: Recommendations for conducting semistructured interviews

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**Abstract**

In this paper, the insights and experiences of a research team involved in conducting qualitative research with families living with autism spectrum disorder are drawn upon to provide reflections and recommendations across all stages of the qualitative research process. Particular attention is given to the steps involved in semistructured interviews, specifically, interview guide preparation, participant recruitment, obtaining informed and voluntary consent/assent, conducting effective interviews, accurate analysis and interpretation of data, ways to involve participants in data analysis, effective communication of research findings, and providing feedback to participants. In addition, reflections and recommendations are provided for maintaining researcher health throughout the qualitative research process.

**Introduction**

Research focusing on the experiences of individuals with autism spectrum disorder (ASD) and their families is on the rise (Bayat, 2007; Bradford, 2010; Hastings & Taunt, 2002). Reasons for this growing research attention include the increase in individuals being diagnosed with ASD (Boelte & Poustka, 2000; Duchan & Patel, 2012; Fombonne, 2002, 2003), and a growing recognition of the importance of understanding the complex impact ASD has on families (Cridland, Jones, Magee, & Caputi, 2014; Morgan, 1988; Seligman & Darling, 2007). Many of the studies in this area have used qualitative methodologies (Cocks, 2008; Mascha & Boucher, 2006). The benefits of using qualitative approaches when investigating families living with ASD include their capacity to measure complex issues (such as family dynamics and mixed or ambiguous attitudes; Cridland, Jones, et al., 2014; Dew, Balandin, & Llewellyn, 2008; King et al., 2006; Meadan, Stoner, & Angell, 2010) and emphasis on presenting rich descriptions rather than on testing a priori hypotheses (Krogh & Lindsay, 1999). In addition, qualitative approaches are considered an appropriate method when involving children (Dockett, Einarsdottir, & Perry, 2009; Mishna, Antle, & Regehr, 2004) and individuals with disability (Barnes, 1992; Cocks, 2008) in research.

Of the range of qualitative methods (e.g., unstructured interviews, focus groups, observations, diaries, etc.), semistructured interviews are one of the most commonly used in this research area (Krogh, & Lindsay, 1999). Semistructured interviews involve in-depth conversations between the researcher and interviewee, which have an overall purpose prompted by the research aims, but are strongly guided by the interviewee's perceptions, opinions, and experiences (Carrington & Graham, 2001; Minichiello, Aroni, Timewell, & Alexander, 1995). The benefits of using semistructured interviews with families living with ASD include flexibility to focus on issues that are meaningful to participants (Barbour, 2000), permitting diversity of perceptions rather than being inhibited by "standard" or

"expected" response categories (Mascha & Boucher, 2006; Petalas, Hastings, Nash, Dowey, & Reilly, 2009), and minimisation of researcher control over participants' expression of their experiences (Brewin, Renwick, & Fudge Schormans, 2008).

Literature exists for conducting qualitative research with children (Docket et al., 2009; Mishna et al., 2004) and individuals with learning disability (Cocks, 2008; Krogh & Lindsay, 1999). However, despite the increase in qualitative research conducted with families living with ASD, we were unable to identify guidelines specifically for conducting research with this population. Identification of specific considerations for conducting qualitative research with individuals with ASD and their families is needed, as literature based on either neurotypically developing (NTD) children or individuals with other disabilities cannot be directly applied to individuals with ASD. Central to this are the various social and communication impairments, behavioural difficulties, and cognitive processing differences inherent in ASD (Attwood, 2007; Deruelle, Rondan, Gepner, & Fagot, 2006; Sachse et al., 2013). There are also various unique experiences for family members of individuals with ASD that are worthy of consideration when conducting qualitative research with this population. Such unique experiences include positive and rewarding aspects of having a family member with ASD (Bayat, 2007; Pakenham et al., 2005, ongoing grief responses (O'Brien, 2007), and management of a range of unique intolerances, social misunderstandings, and sudden mood changes exhibited by their family member with ASD (Attwood, 2007; Heiman & Berger, 2008; Macks & Reeve, 2007). These and other experiences warrant specific considerations for conducting research with this population.

The reflections and recommendations throughout this paper cover all stages of the qualitative research process. Figure 1 depicts these stages, which include research preparation, data collection, data analysis, and dissemination of research findings.

Consideration is also given to the health and wellbeing of researchers in this area across all stages of the research process.

**<<PLEASE INSERT FIGURE 1 ABOUT HERE>>**

*Preparation*

*Interview guide development*. Preparation is an important aspect of all research (Dickson-Swift, James, Kippen, & Liamputtong, 2007, 2008; Sandelowski, 1995). A critical component of preparation in qualitative research using semistructured interviews is the development of the interview guide (Minichiello et al., 1995). The interview guide underpins the interview process and therefore influences subsequent research stages (Minichiello et al., 1995). Given the range of considerations related to interviewing an individual with ASD (such as discomfort discussing certain topics, preferring to discuss topics of interest to them), a strong interview guide is likely to help researchers focus on these aspects rather than on practical components of the interviews (e.g., appropriate wording of interview questions).

*Participant recruitment*. Effective recruitment strategies are another critical component of all research studies, as recruitment of an appropriate sample is a founding element to valid research data (Minichiello et al., 1995). Traditionally, recruitment of participants has relied on flyers, posters, and information in community newsletters (Minichiello et al., 1995). However, there may be various barriers to using traditional approaches when recruiting individuals with ASD given that responding to such material requires a willingness to engage socially (usually by phone contact) with the researchers. Social discomfort inherent in such engagement may present as a barrier to some individuals with ASD signing up for the study.

There may also be barriers to using such approaches when recruiting families of individuals with ASD. First, families living with ASD may frequently receive invitations to participate in research and, given the impersonal nature of traditional recruitment approaches,

they may be less likely to read and respond to them (Krogh & Lindsay, 1999). Additionally, responding to a study flier is unlikely to be a priority for families living with ASD, given they are busy with the pressures of having a family member with ASD in addition to the usual stressors of family life (Heiman & Berger, 2008; Macks & Reeve, 2007; Pakenham, Samios, & Sofronoff, 2005). Further, there is the possibility of recruiting a skewed sample when relying on these approaches as "high-functioning" families may be more likely to respond (Kirkland, 2012).

*Obtaining informed and voluntary assent/consent*. Obtaining informed and voluntary consent is a necessary component of all research (Agre & Rapkin, 2003). It ensures that individuals understand the study aims, the commitment of being involved in the study, any potential risks and benefits of being involved, and the expected outcomes of the research (Agre & Rapkin, 2003; van den Hoonaard, 2002). Further, informed consent is an ongoing process, rather than a time-limited event, and is best sought at all stages of research (van den Hoonaard, 2002).

Although parents/carers of individuals with ASD are likely to be the family members who initially show interest in the study, it is important to ensure they do not provide consent on behalf of other members of their family. Individuals with ASD (Cocks, 2008) and children (e.g., NTD siblings; Mishna, et al., 2004; Potter & Hepburn, 2005) may be particularly vulnerable to having their consent provided for them (Cocks, 2008). Similarly, although parental/carer consent is generally the primary requirement needed for children to be involved in research, this should not replace obtaining assent from the individuals with ASD and children themselves (Dockett et al., 2009).

Data collection

*Appropriate interview settings*. In this field of research, semistructured interviews are often conducted within the family home (Mascha & Boucher, 2006). Benefits of this

approach include avoiding connotations of a clinical assessment, promoting familiarity for participants, and gaining a unique understanding of family dynamics (Mascha & Boucher, 2006).

The main challenge of conducting interviews within the family home is ensuring interviews are completed in an appropriate private space to maintain participant confidentiality (Mascha & Boucher, 2006). Participants may not recognise the importance of conducting the interviews in a private space, particularly if they indicate that their family is "open" with discussing all issues in front of each other (Dockett et al., 2009). If this is the case, it is important to discuss the need for participant confidentiality. Other possible drawbacks of conducting interviews within the family home include safety issues and practicalities of travel for researchers (Minichiello et al., 1995).

*Practicalities of conducting interviews*. Numerous practical issues need to be considered when conducting qualitative research with families living with ASD. Such issues include organising interviews at an appropriate time of day for participants, allowing ample time to travel to scheduled interviews, conducting interviews at an appropriate pace, and considering the most appropriate method of recording the interview (e.g., scribing, voice-recording, or video-recording). Consideration of such issues during the planning stages of research will help facilitate effective interviews. Additionally, it may be necessary to reflect on the processes in place during the data collection stages and make appropriate changes if warranted.

The skill base of interviewers is an important consideration in all qualitative research (Brinkmann, 2007). Generally it is recommended that, at a minimum, interviewers are well acquainted with the interview guide and familiar with the interview process (Brinkmann, 2007; Minichiello et al., 1995). Additionally, personality characteristics such as patience, an open and empathetic attitude, and an ability to listen are highly valued (Brinkmann, 2007). In

the context of ASD research, it is also important that researchers have a clear understanding of the characteristics of ASD and how these may present in participants (Cocks, 2008; Krogh, & Lindsay, 1999).

*Data analysis*

*Accurate analysis and interpretation of data*. In qualitative research, data analysis and interpretation are overlapping, yet conceptually different, processes. More specifically, qualitative analysis involves the breaking down of data, whereas qualitative interpretation illuminates a new way of understanding the data while remaining faithful to the original data (van den Hoonaard, 2002). It is important to note that the analysis and interpretation stages of qualitative research are influenced by all other stages of research, including preparation, data collection, transcribing, and reading of transcripts (van den Hoonaard, 2002).

Issues to be considered during data analysis and interpretation include considering transcribing as an integral component to the data analysis process, reflecting on what participants discuss as well as issues they do not discuss in interviews, and having multiple researchers involved in the analysis and interpretation of data.

*Involving participants in data analysis*. Involving participants in data analysis is a relatively recent concept (Dockett et al., 2009). The rationale behind involving participants in data analysis is to ensure data are accurate (Dockett et al., 2009) and in line with the process of ongoing informed consent (van den Hoonaard, 2002). There are benefits of including participants in data analysis, such as giving participants the opportunity to reflect on their interviews and brainstorm "themes" emerging from their interviews, and developing an appreciation of the research process (Dockett et al., 2009). Further, some participants may find such involvement to be rewarding and/or therapeutic (Dockett et al., 2009).

One challenge of involving participants in data analysis processes is the possibility that participants may reflect on certain things they had said (particularly discussion of

negative aspects of living with ASD) and express a desire for such aspects of the interview to not be included in analysis (Barbour, 2000). Another challenge may be participants asking to read other family members' transcripts, particularly parents asking to read their children's transcripts. Strategies to manage these challenges include normalising experiences of discomfort when reading transcripts, discussing the use of deidentified data when reporting results, discussing the rights of participants to withdraw consent from the study, and discussing the rationale regarding not allowing participants to read other family members transcripts (i.e., participant confidentiality).

*Dissemination of findings*

*Effective communication of research findings.* The communication of qualitative research studies is traditionally confined to academic journal articles and/or conference proceedings (Keen & Todres, 2007). This can often limit the application of research findings in facilitating positive change for the lives of those affected by the research—in this case families living with ASD. Put another way, the dissemination of research findings to practice is often seen as a task beyond the research process (Keen & Todres, 2007). However, we recommend considering the dissemination of research findings as an integral component of the research process (see Figure 1).

The intended target audience of the research is the criteria on which dissemination strategies should be based. Target audiences for research focusing on individuals with ASD include families, clinicians, health practitioners, teachers, policymakers, and so on. Therefore, dissemination strategies may include a range of approaches from presenting to local ASD community groups to presenting to key stakeholders such as governments and other policymakers.

*Providing feedback to participants.* Communicating feedback to participants about the results of the study is not considered a necessary component of the research process.

However, there may be a range of benefits of doing so. First, feedback provides participants with findings of the study and overall outcomes of the research (e.g., policy changes, publications, funding, etc.) that they may not otherwise have learned. Additionally, families living with ASD who participate in ASD research are likely to have a genuine interest in the research outcomes and therefore appreciate feedback. Feedback also acknowledges the significant commitment of participating in research and may facilitate participants having positive experiences of being involved in qualitative research. Further, providing feedback to participants may help consolidate research findings for the researcher and highlight the issues of importance for families living with ASD (Keen & Todres, 2007). Feedback about research findings and outcomes may occur periodically or at the conclusion of the research, depending on the nature of the project.

*Researcher health*

   *Importance of self-care*. Self-care involves a range of activities aimed at ensuring the physical, emotional, and psychological wellbeing of the researcher, such as exercise, social activities, hobbies, and travelling. The importance of self-care for qualitative researchers investigating emotionally laden topics is recognised but often overlooked (Rager, 2005a, 2005b; Stamm, 1999). Researcher self-care is imperative across all aspects of the research process.

   In discussing the potential for emotional effects of conducting qualitative research with families living with ASD, it is not our intention to recommend that researchers guard against all emotional reactions to research. On the contrary, we recognise the important role of emotion in qualitative research (Brinkmann, 2007; Rager, 2005a, 2005b), such as the ability to empathetically consider the psychological world of participants. Rather, we recommend that researchers use strategies to manage the possible negative emotional effects of conducting qualitative research. Such strategies include being involved in debriefing

sessions, maintaining a journal, and organising interviews with adequate spacing to reduce the intensity of interviewing commitments and allow ample time for reflection between interviews.

*Developing and maintaining healthy boundaries*. In qualitative research, it is common for researchers to negotiate multiple roles (such as data collector and empathetic listener; Lavis, 2010). In fact, these multiple roles are often considered necessary for effective qualitative research whereby the researcher must conduct ethical practices while also developing authentic relationships with participants (Lavis, 2010). Developing and maintaining healthy boundaries around researcher roles is critical for conducting research in this field, given the potential for role confusion that may result when involving children and/or individuals with disability in research (Brinkmann, 2007). Boundary confusion is a bidirectional process whereby misunderstandings from either the researchers or participants can result in inappropriate roles (Brinkmann, 2007). Strategies to help maintain healthy boundaries include a clear understanding for both researchers and participants about the role of the researcher and limitations to this role, and using various monitoring strategies such as other researchers attending the interviews or reading the transcripts.

Table 1 provides detailed recommendations based on the issues discussed. The recommendations are based on the literature and experiences from the authors' involvement in qualitative research focusing on families living with ASD.

**Conclusion**

Conducting qualitative research with individuals with ASD and their families is not easy, as highlighted by the range of challenges and considerations discussed throughout this manuscript. However, with these challenges also comes a multitude of rewards; predominantly, the opportunity to meet a range of different people and hear their stories. Just as we attempt to do justice to the significance of participants' experiences during the write-up

of empirical papers, we aim to honour the significance of our research practices by sharing our experiences with other researchers with this paper. The issues discussed contribute to existing knowledge regarding conducting qualitative research with individuals with ASD and their families and promotes our understanding of ASD in general.

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**Table 1. Recommendations**

| | Research stage | Recommendation | General rationale | Rationale for ASD research |
|---|---|---|---|---|
| 1a. | *Preparation:* Interview guide development | Include an introductory statement. | An introductory statement before commencing the interview can be helpful in reminding participants about the general content of the interview and the expected length of the interview. It may also facilitate a clear and concise introduction to the interview process. | An introductory statement may be particularly relevant for individuals with ASD given their general preference for preparedness (Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). |
| 1b. | *Preparation:* Interview guide development | Begin interviews with a "warm-up" question. | A warm-up question will "set the scene" for the interview while also allowing participants to experience mastery and relax into the interview. Example warm-up questions may be "Tell me who is in your family" or "What activities do you like doing with your family?" | Initial nervousness may be of particular relevance when interviewing individuals with ASD due to the social and communicative impairments associated with their condition (Cridland, Caputi, Jones, & Magee, 2014; Solomon et al., 2012). |
| 1c. | *Preparation:* Interview guide development | Provide a prelude to challenging questions. | A prelude prepares participants for the upcoming question and normalises any feelings of confusion or discomfort they may have. An example of a prelude is, "Some people find the next few questions difficult …". | There are topics that individuals with ASD are likely to find challenging to talk about, such as discussing abstract concepts, social difficulties, emotions, perspective talking, etc. A prelude to challenging questions may help prepare participants with ASD and their families for questions they may find difficult. |
| 1d. | *Preparation:* Interview guide development | Structure interview guide to have challenging questions followed by easier topics. | Oscillating between challenging and less challenging topics can help reduce the emotional and psychological demands of the interview on participants. | Efficacious "easy" questions should either aim to foster mastery without beginning a lengthy conversation or relate in some way to the research topic (Minichiello et al., 1995). Easy questions for individuals with ASD about hobbies or special interests are best avoided as they may lead to lengthy conversations of little relevance to the focus of the study. It may also be difficult to redirect participants back to the interview. |

| 1e. | *Preparation:* Interview guide development | Develop single-faceted questions. | Single-faceted questions are easier for participants to understand and accurately interpret. Examples of single faceted questions are, "What are your favourite subjects at school?" and "How do you find homework?" This is opposed to a multifaceted format: "What are your favourite subjects at school and how do you find homework?" | Single-faceted questions suit the processing style of participants with ASD and facilitate accurate interpretation of the question (Cridland, Caputi, et al., 2014; Solomon et al., 2012). |
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| 1f. | *Preparation:* Interview guide development | Use both positively and negatively framed questions. | Using positively and negatively framed questions facilitates discussion of both rewarding and challenging experiences, attitudes, and feelings, which contributes to a balanced understanding of issues. | It is recognised that living in a family with ASD involves both rewarding and challenging experiences, attitudes, and feelings (Cridland, Jones, et al., 2014; Davis & Gavidia-Payne, 2009; Pakenham et al., 2005) and these issues need investigation. In doing so, it may be important to acknowledge that not all participants will share the range of experiences. A prelude such as "Some people find positive aspects of living with ASD. Have you experienced this?" may help normalise discussion of challenging aspects of living with ASD and encourage open discussion. |
| 1g. | *Preparation:* Interview guide development | Avoid using leading questions. | All research studies have aims and hypotheses; however, it is important that interview questions do not elicit responses solely in support of these hypotheses. An example of a leading question in a study focusing on the challenges of transitioning to high school would be, "What have been the hardest parts of transitioning to high school?" An example of a "neutral" question for investigation of this issue would be, "What has been your experience of transitioning to high school?" | When responding to questions, individuals with ASD may be more likely to provide answers that are specific to the question posed rather than using that question as a platform on which to elaborate, as NTD participants may. Therefore, continuing with the current example, if participants with ASD are asked about the challenges of high school they are likely to only discuss challenges even if they think there are also positive aspects (Cridland, Caputi, et al., 2014). |
| 1h. | *Preparation:* Interview guide development | Pilot test the interview guide. | Pilot testing the interview guide is helpful in estimating the time needed to conduct the interview and promote researcher familiarity with the interview guide. | Pilot testing with an individual with ASD may be useful in identifying questions that may be confusing or open to misinterpretation. |

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| 1i. | *Preparation:* Participant recruitment | Provide multiple methods of contact when advertising the study. | Providing multiple methods of contacting the research team gives participants flexibility in response options. Methods of contact may include text message services, email, or social media such as Facebook. | Some methods of contact (such as emails) may be less socially demanding on individuals with ASD, which may encourage better response rates to the study. Additionally, options such as text messages may be less time demanding for family members. |
| 1j. | *Preparation:* Participant recruitment | Provide clear and detailed information about the study in recruitment information. | Providing participants with transparent and detailed information about the study during recruitment may encourage potential participants to respond to the study advertisement. Such information may include study aims, participant requirements, study timeframe (e.g., recruitment cut-off, data collection phases, etc.), and expected benefits to participants. | Providing detailed study information when recruiting individuals with ASD may improve response rates. This is likely to be associated with the social and communicative impairments inherent with ASD. |
| 1k. | *Preparation:* Participant recruitment | Employ some nontraditional recruitment approaches. | Employing some nontraditional recruitment approaches will increase the number of potential participants that the study is advertised to. | Approaches that may be effective when recruiting families living with ASD include attending community ASD support groups, outlining the study to school teachers so that they can personally provide information to families of students with ASD enrolled in their school, and snowballing from recruited participants. |
| 1l. | *Preparation:* Participant recruitment | Include information about the expected positive outcomes of being involved in the study. | Being involved in qualitative research has been found to be a rewarding and enriching experience for participants (Dickson-Swift et al., 2007, 2008; Dockett et al., 2009; Rager, 2005a, 2005b). Sharing this information with potential participants may increase their interest in being involved in the study. | The positive outcomes of being involved in qualitative research for families living with ASD may include having an opportunity to discuss issues important to them, developing greater awareness and understanding of family member's perspectives, and having an opportunity to "give back" to the ASD community. |
| 1m | *Preparation:* Obtaining informed and voluntary assent/consent | Organise a "preliminary meeting" with potential families to outline the study. | A preliminary meeting is useful for providing potential participants with written and verbal information about the study and requirements of participants (e.g., time commitment). It is also useful for answering participant questions and ensuring that research eligibility criteria are satisfied. | During this meeting it may be useful to ask what terminology a family uses to refer to the ASD diagnosis (e.g., autism, Asperger's, Aspie, etc.) and ensure that all relevant family members have knowledge of the ASD diagnosis. |
| 1n. | *Preparation:* | Obtain informed | While written assent from child participants is | Child participants in this research area include |

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| | Obtaining informed and voluntary assent/consent | assent from child participants. | not always necessary to fulfil ethical requirements of research (Agre & Rapkin, 2003; van den Hoonard, 2002), its inclusion is important to ensure all participants are voluntarily participating in the study. | children with ASD and NTD siblings. If using assent forms for children with ASD a "checklist" format may be appropriate as participant requirements can be clearly outlined. |
| 1o. | *Preparation:* Obtaining informed and voluntary assent/consent | Remind participants of the research aims and participant commitments at each contact. | Discussing research aims and participant commitments regularly facilitates informed and voluntary assent/consent. These discussions may involve providing participants with a study information sheet and/or consent form and asking if they would like to continue their involvement in the study. | Ongoing consent is of particular relevance when involving individuals with ASD in research, as they may have additional queries about the study which they may not raise unless overtly given the opportunity. |
| 1p. | *Preparation:* Obtaining informed and voluntary assent/consent | When conducting research with families, ensure consent is obtained from individual family members. | Although parents/carers may be the family members who initially show interest in the study, it is important that they do not provide consent on behalf of other members of their family. Additionally, we advise against requiring all family members to be involved in the study in order for a family to be eligible for study participation. This flexibility will reduce the possibility of some family members feeling pressured to provide consent and also reduce the number of families deemed ineligible for the study. | Individualised consent procedures are equally important in families living with ASD. Further, the literature highlights that individuals with ASD (Cocks, 2008) and children (e.g., NTD siblings) (Mishna et al., 2004; Potter & Hepburn, 2005) are particularly vulnerable subgroups in having their consent provided for them. |
| 1q. | *Preparation:* Obtaining informed and voluntary assent/consent | When conducting research with families, clearly outline confidentiality procedures. | Clearly outlining confidentiality issues ensures participants are aware that information provided during interviews will not be shared with other family members (unless the study has an open nature). This awareness may encourage openness during the interviews and prevent participants asking about other family members' responses. | Participants may feel reluctant to speak openly about the challenging aspects of living with ASD if they are uncertain whether their interviews will be shared with other family members. This may result in denial or minimisation of such topics. |

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| 2a. | *Data collection:* Appropriate interview settings | Ensure home interviews are conducted in an appropriate private space. | Conducting home interviews in an appropriate private space, such as a quiet living area or study, ensures confidentiality of information shared. Additionally, there will be fewer distractions for participants and a quiet environment for clear recording (if used). | Conducting home interviews in a private space may facilitate discussion of challenging issues, such as the difficulties of living in a family with ASD, which participants may otherwise feel hindered to discuss openly if they felt family members could overhear. |
| 2b. | *Data collection:* Appropriate interview settings | Consider using an alternative venue if home interviews are not appropriate. | Alternative venues should be considered if there is no appropriate space within the family home (e.g., open-plan living, strained family relationships, etc.), or if participants and/or the researcher do not feel comfortable or safe conducting the interview within the home. Suitable venues include a quiet room in the researchers' workplace or a bookable room in a community building, such as a library. | Alternative venues may need to be considered if interviews involve discussion of difficult topics associated with living with ASD, and the researcher or participant feel it is more appropriate to discuss these outside the family home. Safety issues of particular relevance when conducting interviews with individuals with ASD involve unexpected responses or behavioural reactions. For example, a participant may become highly aroused if feeling confused about a question or feeling uncomfortable about discussing a particular topic. Strategies to promote a safe environment include conducting the interviews with two researchers (a primary researcher conducting the interview and a second to observe or scribe), and/or ensuring a parent/carer is available but not present. |
| 2c. | *Data collection:* Practicalities of conducting interviews | Schedule interviews at a preferred time for participants. | Participants are more likely to be engaged in the interview process if it is conducted at a time suitable for them. In order to conduct interviews at appropriate timeslots, researchers may need to be flexible, which may include conducting interviews outside of business hours (such as on weekends). | The engagement of participants with ASD may be particularly influenced by the timing. For example, mornings may be identified as a "good" time for an interview rather than shortly after school or work when the participant may be stressed or tired. Additionally, contacting participants with ASD before the interview to check the arranged time is still appropriate is recommended. Rescheduling if needed is important, as conducting an interview with an individual with ASD who is not in an appropriate frame of mind may result in tainted |

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| | | | | responses (e.g., negatively framed responses or lack of responses). |
| 2d. | *Data collection:* Practicalities of conducting interviews | Allow ample time when travelling to interviews to ensure punctuality. | Apart from a general sign of courtesy, punctuality portrays a professional attitude toward the research. Arriving on time is also a sign of respect for the participant's time commitment of being involved in the study. | Punctuality may be of particular relevance for interviews with individuals with ASD, as they may become agitated or upset if the researcher is late. |
| 2e. | *Data collection:* Practicalities of conducting interviews | Take time to build rapport with participants. | The importance of rapport building in qualitative research is well established (Brinkmann, 2007; Lavis, 2010; van den Hoonaard, 2002). However, in building rapport it is important to not just "do" rapport, where the researcher engages in "faking friendship" to obtain knowledge from the participant (Brinkmann, 2007). | Rapport building is essential in this research area given the highly personal nature of research topics. Rapport with families living with ASD is likely to be established by showing a genuine interest in their experiences, having an open attitude throughout the interview, and regarding the participant as the expert on the interview topic. |
| 2f. | *Data collection:* Practicalities of conducting interviews | Be aware of your rate of speech when asking interview questions. | Asking interview questions in a measured, slow pace facilitates accurate interpretation. | A slower pace of information presentation has been shown to suit the processing style of individuals with ASD (Deruelle, Rondan, Gepner, & Fagot, 2006; Myles & Simpson, 1998; Sachse et al., 2013). Related to this, individuals with ASD may require a longer length of time to provide an answer to interview questions (Deruelle et al., 2006) and researchers should allow ample time for a participant to respond before checking in that they understood the question. |
| 2g. | *Data collection:* Practicalities of conducting interviews | Consider video-recording interviews. | The benefit of using video recordings over voice recordings is the ability to analyse both verbal and visual information (e.g., facial expression, hand gestures, body movements, etc.). | Video-recording interviews is an emerging methodological approach in this field (Meirsschaut, Roeyers, & Warreyn, 2011; Mossman Steiner, 2011; Naber et al., 2008). The benefits of this approach when interviewing participants with ASD includes ability to analyse inconsistencies between verbal responses and body language, individualised uses of hand |

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| 2h. | *Data collection:* Practicalities of conducting interviews | Leave recording device going until the interview has come to an absolute conclusion. | Participants may continue to speak after the last interview question and useful information may be missed if not recorded. | Participants often continue to share their experiences of living in a family with ASD after the interview. |
| 3a. | *Data analysis:* Accurate analysis and interpretation of data | Transcribe interviews rather than use scribes. | Transcribing has been considered an integral component of preliminary data analysis (van den Hoonaard, 2002). Transcribing is also an important way to improve interview techniques, such as the wording of questions, smooth transitioning between topics, and beginning and concluding the interview. | Improving interview techniques as a result of transcribing may be particularly important when interviewing individuals with ASD, given the heightened importance of appropriate wording of questions and suitable beginnings and conclusions of interviews with these individuals. |
| 3b. | *Data analysis:* Accurate analysis and interpretation of data | Attend to issues that participants do not discuss. | There is a focus on what a participant says in qualitative research. However, it is also important to reflect on issues participants do not discuss. Participants may not discuss issues due to legitimate irrelevance of a topic, minimal rapport with the researcher, or a desire to portray a certain image during the interview. | Participants may find it difficult or even taboo to discuss the challenges of living in a family with ASD. Similarly, participants may wish to portray an image of resilience or positivity by focusing on the rewarding aspects of living in a family with ASD. |
| 3c. | *Data analysis:* Accurate analysis and interpretation of data | Have multiple researchers code the data. | The credibility of qualitative data analysis is improved with multiple researchers coding the data (Barnes, 1992; Braun & Clarke, 2006). The process of coding with multiple researchers includes a primary researcher conducting, transcribing, and analysing the data, while other members of the research team read, and independently code the data for comparison (Braun & Clarke, 2006). | Multiple coders are important when conducting research with families living with ASD because it is common for researchers in this field to have strong connections and investment with the research topic (Potter & Hepburn, 2005) and this background may interfere with objective data analysis. It is important that researchers are aware of their potential for bias (Brinkmann, 2007; van den Hoonaard, 2002). |
| 3d. | *Data analysis:* Accurate analysis and interpretation of data | Use analytical techniques that model the characteristics of family data. | In using analytical techniques that model the characteristics of family data researchers are able to gain insights into interpersonal relationships within the family, in addition to the perceptions from individual family members. | In researching families living with ASD there may be discrepant perceptions across family members (e.g., a sibling reporting that they take on significant caregiving responsibilities, whereas parental reports indicate they do not contribute |

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| 3e. | *Data analysis:* Involving participants in data analysis | Include participants in data analysis. | Including participants in data analysis may involve giving participants the opportunity to read their own transcripts (member checks), and encouraging participants to brainstorm "themes" emerging from their interviews. In addition, participants may be invited to read drafts of reports and provide feedback to researchers. | Including individuals with ASD and their families in data analysis is in line with recommendations in the literature (Cocks, 2008; Dockett et al., 2009; Mishna et al., 2004). The benefits of including these participants in data analysis include giving participants the opportunity to reflect on their interviews, develop ownership of their data, and an appreciation of the research process. Further, some participants may find this process rewarding and therapeutic. |
| 4a. | *Dissemination of findings:* Effective communication of research findings | Provide feedback about the study's findings to relevant individuals and community groups. | The benefits of providing feedback to relevant individuals and community groups include sharing of research information and fostering networks, which may be used in future research endeavours. | Relevant individuals and community groups for research focusing on individuals with ASD may include local ASD community groups, ASD research centres, as well as mainstream and ASD-specific schools. |
| 4b. | *Dissemination of findings:* Effective communication of research findings | Consider target audience when choosing journals to publish research findings. | To facilitate effective communication of research findings, it is important to consider the intended target audience of the research when choosing journals to publish in rather than focusing on other research criteria such as the prestige of the journal. Additionally, be prepared that the target audience may change over the course of the research. | Target audiences for research focusing on individuals with ASD may include families, clinicians, health practitioners, teachers, policymakers, etc. |
| 4c. | *Dissemination of findings:* Effective communication of research findings | Consider presenting findings to community members. | Academic journals and conferences have their place in disseminating research findings; however, it may be efficacious to also pursue other avenues when disseminating findings to the broader community. Such avenues may include community forums, radio stations, and newspapers and/or television news programs. | When disseminating research findings to community members interested in ASD research it may be efficacious to present findings to local ASD community groups, forums, etc. Additionally, when using mainstream media avenues, it may be useful to advertise upcoming programs through local ASD community groups. |
| 4d. | *Dissemination of findings:* Providing | Provide participants with written feedback | Information sheets are an appropriate method for providing feedback to participants because they provide a succinct outline of information, they | When developing information sheets for individuals with ASD, a structured format (i.e., use of headings, bullet points, etc.) may facilitate |

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| | feedback to participants | about the study's findings. | are a tangible resource for participants to refer to, and they are economical and practical.<br>The main drawback of information sheets is that they may be considered impersonal. | their understanding of the information.<br>Additionally, it may be useful to provide information about local ASD community groups for participants who do not access support services. |
| 4e. | *Dissemination of findings:* Providing feedback to participants | Provide participants with the opportunity to come to a group feedback session. | Group feedback sessions are useful for conveying in-depth findings and provide participants with an opportunity ask questions and provide comments.<br>Considerations when conducting feedback sessions for families include running sessions at various times/dates to cater for commitments such as work and after-school activities, providing a venue with suitable child minding facilities, and providing written information for participants who are unable to attend. | A secondary benefit of group feedback sessions is an opportunity for participants to interact with other families living with ASD. The social support provided by such feedback sessions may be equally as important to participants as receiving information about the outcomes of the study. |
| 4f. | *Dissemination of findings:* Providing feedback to participants | Reflect on the impact of being involved in the study with participants. | Reflections from the research team may include professional and/or personal insights, and challenges and rewards of conducting the research. Additionally, reflections from the research team acknowledge the significance of participants sharing their experiences for the research. | Qualitative research investigating the experiences of individuals with ASD and their families is likely to involve participants sharing a range of highly personal experiences, meaning that the reflections from the research team about their experiences of being involved in the research may be particularly warranted. |
| 5a. | *Researcher health:* Importance of self-care | Be involved in debriefing sessions to manage the emotional impact of conducting qualitative research. | Debriefing sessions allow researchers to reflect on challenging experiences, discuss ways of improving research processes, and experience moral support. Debriefing personnel may include research team members and/or supervisors. Importantly, debriefing sessions should not replace professional support, which may be necessary if researchers are seriously affected by the study. | Researchers should not underestimate the emotional impact of conducting interviews with individuals with ASD and their families. Reasons for this include listening to difficult experiences, being with participants who are emotional or have behavioural outbursts, and providing a supportive and nonjudgemental attitude throughout interviews. |
| 5b. | *Researcher health:* Importance of | Maintain a journal to manage the emotional impact | Journal keeping has been shown to help manage the emotional impact of being involved in qualitative research and also promote reflective | As outlined in section 5a., managing the emotional impact of conducting interviews with families living with ASD is an important issue in this |

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| | self-care | of conducting qualitative research. | thinking that facilitates data interpretation (Rager, 2005b). | research area. Journal keeping may be one strategy that assists with this. |
| 5c. | *Researcher health:* Importance of self-care | Space interviews apart to manage the emotional impact of interviewing. | Organising interviews over an extended period may contribute to researcher self-care as it reduces the intensity of conducting the interviews and allows time for reflection between interviews. | Adequately spaced interviews may be particularly warranted when conducting research with families living with ASD given the range of emotionally laded topics that may be inherent to the research topic. |
| 5d. | *Researcher health:* Developing and maintaining healthy boundaries | Be aware of the potential for boundary confusions. | Boundary confusion can occur when researchers or participants become unclear around the researchers' primary role (which is to collect data rather than being a friend or clinician). The potential for boundary confusion is high in qualitative research due to the personal nature of research topics and the supportive method in which they are conducted. Strategies to minimise boundary confusion include clearly outlining the roles of the researcher prior to interviews, having multiple researchers attend interviews, having transcripts read by other researchers to monitor boundary maintenance, and ongoing debriefing sessions for researchers. | Being aware of the potential for boundary confusion may be particularly important when conducting qualitative research with families living with ASD. First, children and individuals with ASD may find it difficult to understand the unique role of a researcher, particularly when interviews are conducted with a supportive nature and within the family home. Second, the emotionally laden topics that are often inherent to this research area may lead participants to become confused about the researchers' role. Additionally, researchers themselves may become confused about their role, particularly if they have a personal connection to the research topic and/or professional roles other than a researcher (e.g., counsellor, support worker, teacher, etc.). |
| 5e. | *Researcher health:* Developing and maintaining healthy boundaries | Consider the differences in power in the roles of researchers and participants. | In most research, there is a power difference between researcher and participant due to the researcher's in-depth knowledge of the particular research area. However, in qualitative research it is acknowledged, and even embraced, that participants are the expert in their own right as it is their personal experiences and opinions that are under investigation (Brinkmann, 2007). | It may be helpful to acknowledge the participants' unique role as "expert" regarding being an individual/family member living with ASD. Such acknowledgement may facilitate participants' sense of mastery and highlight the value of sharing their experiences in the research. |

*Note*.     ASD     =     autism     spectrum     disorder;     NTD     =     neurotypically     developing.

**FIGURE CAPTION.**

**Figure 1. Stages of qualitative research discussed in paper.**