

Appendix 1: Study Protocol

“Navigating the Medical and Social Merry-Go-Round”:

Understanding the Caregiving Experiences of Parents from Racialized Backgrounds that Care for Children Living with Autism Spectrum Disorder (ASD)

Submitted to the Holland Bloorview Research Ethics Board

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1. Introduction and Background

In this study, we will explore the caregiving experiences of parents who identify themselves as visible minorities residing in Canada that care for a child with autism spectrum disorder (ASD), their interactions with pediatric health care services and their understanding of cultural stigma and its effects.

Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects approximately 1 in every 66 children in Canada (Government of Canada, 2018). The prevalence of autism is thought to be increasing in Canada and exerts a negative impact on child and family health. Although ASD cross-cuts social position and location — such as gender, race, culture and social class — there is an alarming paucity of literature on the experiences of parents of visible minorities caring for children with ASD; indeed, the existing scholarship has mainly been conducted with white parents and lacks both theoretical and methodological approaches that are attentive to issues of race and culture.

For the purposes of this study, visible minorities are defined as people other than Aboriginals who are not white in colour or Caucasian in race (Statistics Canada, 2011). In the broader literature, it is well documented that visible minorities face racism when accessing health care services (Lovelace, Robertson, & Tamayo, 2018). Further, identifying as Black, Latino (referring to race), or poor (referring to socioeconomic status) is also associated with lower access to health care services (Liptak et al., 2008). The existing literature that does include a consideration of race and culture has found that Latino and Black children with ASD face greater challenges to receiving high-quality health care and are diagnosed almost a year later than white children, often receiving fewer speciality services (Magana, Lopez, Aguinaga, & Morton, 2013; Liptak et al., 2008). Further, although the reasons are not known, parents of visible minority children express difficulty comprehending what autism means and are confused over the heavily medicalized jargon used by health professionals (Bilgin & Kucuk, 2010; Jegatheesan, Fowler, & Miller, 2010). Parents of visible minorities also adopt alternative etiological perspectives on autism, believing it to be the “mother’s fault” or to be caused by environmental exposure, to name a few (Jegatheesan et al., 2010; Lovelace et al., 2018; Sakai et al., 2019). Parents who identify themselves as visible minorities caring for children with ASD also report racist health care encounters (Lovelace et al., 2018).

Although the existing literature has been pivotal to deepening our understanding of the barriers that parents of visible minority children with autism face, there are several notable *limitations to this scholarship*. The literature has not been sensitized by theoretical and methodological frameworks that are attentive to racial and cultural issues, such as post-colonial theory. Post-colonial theory is a sociological theory that takes a critical approach toward the understanding of race and race relations (Bhaba, 1994). It is the dominant sociological theory used in studies of race and racism (Bhaba, 1994). At root, it suggests that Euro Western countries and people come to understand visual minorities through

imagined assumptions about the other (Bhaba, 1994). Post-colonial theory is critical to use in sociological studies on race (Bhaba, 1994). The research has also not examined how culture influences the way that ASD is experienced by parents or the impact of stigma on parents' caregiving experiences. Thus, the purpose of this study is to explore the experiences of parents of visible minorities caring for a child with ASD, the impact of cultural stigma on parents, as well as their interaction with pediatric health care services. Other sociodemographic factors, including race, culture, language, education, socio-economic status, and religion, are extremely relevant to discussions about race and ASD. However, although there is an association between being a visual minority and being of lower SES status, in this qualitative study, we are exploring experiences of parenting among visual minority parents only. Associations with other factors such as class and education are not being explored in this foundational pilot study and will feature prominently in our future work. Mediating and moderating research is generally not a part of the qualitative paradigm. Specifically, in this study we will investigate the following research objectives:

- a) To explore the experience of parents of visible minorities who provide care to a child with autism.
- b) To explore the impact cultural stigma has had on parents of visible minorities while caring for a child with autism.
- c) To understand the interaction between parents of visible minorities and pediatric health care services.

2. Research Design

This research team is seeking approval from the Holland Bloorview Research Ethics Board to conduct this study. Here, we follow Maxwell's (2013) stepwise sequential process for the design of high quality qualitative studies. We will undertake a qualitative arts-based research study. Using general advertisements in various languages at the Holland Bloorview ASD clinic, ASD-based community centres, and snowball sampling, we will aim to recruit between 15 - 20 participant parents who provide care to a child with ASD and identify themselves as visible minorities. A list of potential ASD community centres, who will be contacted post-REB approval, will be submitted to the REB. We will seek parents from across Canada. In keeping with our post-colonial understanding of race and culture that is resistant to biological labels, we will encourage parents to self-identify as visible minorities and not pre-define what these parents are by using pre-existing racial categories such as Black or Latino. Indeed, avoiding such pre-determined labels is entirely compatible with our philosophical assumptions and theoretical framework. Fifteen to twenty is thought to be a sufficient sample size to yield saturation in the qualitative data (Dworkin, 2012). *Conceptually*, the study will be guided by Homi K Bhabha's *post-colonial theory (1994)*. Here, we understand the relationship between the "West" and "East" as one that is born out of structural differences and power imbalances. Grounded in a long legacy of Western domination through the colonial process, the West understands the East often through the lens of the imagined Other. Although East-West relations are invariably more complex in our global world today, post-colonial theory will allow us to take up the term "racialized" in way that does not denote biological differences (Bhabha, 1994). Rather, racialization is a socially and historically contingent process that implicates the mobilization of often forced power relationships. Culture is taken to be the systems of meaning that particular groups hold at historically and socially contingent moments (Bhabha, 1994). This study will be grounded in the **narrative tradition** (Fredriksson, 2001). This will allow parents the opportunity to tell their stories in a way that is sensitive to time, history and place. The use of the narrative tradition will also elevate parents to the esteemed position of "storyteller" while literally and symbolically gesturing at the importance, value and inherent worth of their stories to us as researcher-listeners (Fredriksson, 2001). *The inclusion criteria, for this study, consists of (1) parents who identify as visible minorities, and (2) care for a child with ASD.* Since we are asking parents to tell us their story and journey with race and ASD, we feel that narrative traditions are appropriate.

3. Methodology

This study will be grounded in the **narrative tradition** (Fredriksson, 2001) . This will allow parents the opportunity to tell their stories in a way that is sensitive to time, history and place. The use of the narrative tradition will also elevate parents to the esteemed position of "storyteller" while literally and symbolically gesturing at the importance, value and

inherent worth of their stories to us as researcher-listeners (Fredriksson, 2001). A semi-structured interview and a draw and write task will be included, which presents participants time to share their experiences and stories. Since we are asking parents to tell us their story and journey with race and ASD, narrative traditions are appropriate.

4. Methods

Interested participants will be guided through the informed consent process (Appendix 5). A variety of different methodological tools will be employed in the study, including a questionnaire, interview and image making using a draw-and-write technique.

Demographic Questionnaire

A brief self-reported demographic questionnaire will be administered to the participants and collected prior to the interview. This questionnaire will consist of questions related to the participants' age, gender, socio-economic status, education, language and, ethnicity, as well as whether they have a child diagnosed with autism (Appendix 4). Questions related to socio-economic status and education will be collected to narratively describe the sample in articles. However, mediators, moderators or associations will not be analyzed right now due to insufficient time and funds.

Interview

Participants will be invited to Holland Bloorview Kids Rehabilitation Hospital for a one hour semi-structured interview which will be audio-taped and transcribed. Participants will also have the option of meeting in their home or in a quiet community space if they so choose to their liking. In an effort to reduce language barriers, we will ensure that there is at least one other English speaking family member that attends the interview with the participant and/or money from Dr. Moola's start up budget to pay for an interpreter. At the interview, the research team will explore the experience of parents of visible minorities who provide care to a child with autism. There will also be discussions around cultural and racial stigma, and experiences related to the interaction between parents and pediatric health care services (See Appendix 2 for interview guide).

Draw-And-Write Activity

At the end of the semi-structured interview, participants will be provided with a package containing art supplies such as pencils or pastels. Participants will use these supplies to create images and write narratives of what it is like to parent their child with ASD, using the draw-and write-technique (McWhirter, 2014). (See Appendix 3 for Drawing and Writing activity guide). The draw-and-write technique is thought to be particularly useful for social groups as another mode of communication. This does not require expert artistic skills. (McWhirter, 2014). It might potentially be a suitable approach when working with parents of visible minorities (Guillemin, 2004). Participants will be given 4-5 weeks to complete this part of the study. The completed images can either be mailed or given in person at Holland Bloorview or a community space of the participant's liking. The draw and write technique has been used effectively with adults who suggest disrupting fundamental associations between children and art (Guillemin, 2004). Rather, art is an activity that all people, regardless of age, can engage in (Guillemin, 2004).

If participants are unable to meet in person, we will provide them with the opportunity to participate in the interview via Zoom (video conferencing) or telephone. The demographic questionnaire can be mailed to Holland Bloorview along with the completed art task.

5. Participants

Using general advertisements in various languages at the Holland Bloorview ASD clinic, ASD-based community centres, and snowball sampling, we will aim to recruit between 15 - 20 participant parents who provide care to a child with ASD and identify as visible minorities. We will seek parents from across Canada. A list of potential ASD community centres, who will be contacted post-REB approval, will be submitted to the REB. We will encourage

parents to self-identify as visible minorities and not pre-define what these parents are. This sample size is appropriate for a qualitative research study and is likely to yield saturation in the data (Dworkin, 2012).

6. Informed Consent

If participants express interest in the study via phone, email or in person, they will be asked to complete a written informed consent form. The research coordinators, Nivatha Moothathamby and Methuna Naganathan will obtain consent from the participants. The research coordinators will explain the consent form (Appendix 5) to parents and emphasize the voluntary nature of the study. Participants will then be asked to sign the consent form. The consent forms will be mailed to Holland Bloorview or given in person during the interview. An interpreter will be arranged to translate the consent form if the participant does not speak English. All consent forms will be stored securely in a locked filing cabinet in Dr. Moola's office.

7. Deception

This study will not use deception. There will be no study information withheld from the participants. Further, no misleading information will be given to the participants in order to deceive them.

8. Feedback/Debriefing

A one page summary of the results will be given to the participants at the end of the study, which will summarize what we found in the study. Further, after we have studied participants' images, they will be mailed back to the participants for their keeping. Publications will be made available to participants if they request them.

9. Risks/Benefits

We do not anticipate any additional risks associated with this study. There is a possibility that participants may feel sad or sensitive when talking about their experiences, but researchers will inform participants that they can take a break during the interview or skip over parts that they do not feel comfortable sharing. They will also be provided with a psychological services resource list, if necessary (Appendix 6). Participants will also be allowed to withdraw from the study at any point.

Conclusions from this study may lead to the development of a pediatric hospital-based intervention to help build social support among parents of visible minorities who care for children with ASD, to assist them in better navigating the health care system and cultural stigma. It would be one of the foreseen, anticipated benefits from this study. There will also be powerful implications for parents of visible minorities caring for a child with autism, such as enhanced understanding of the effects of racism and stigma during health care encounters, as well as the impact of culture on understandings of ASD. Members of the scientific and public community may also benefit indirectly from learning new knowledge and enhancing current understanding of ASD by drawing attention to the social lives, worlds, and dilemmas to parents that face social and structural barriers.

10. Anonymity/Confidentiality

All efforts will be made to keep the data confidential and/or anonymous. Participants will be assigned an alpha numerical code to maintain anonymity and confidentiality. The document which links participants' names to the list of codes (see example in Appendix 11) will be stored in a locked filing cabinet in Dr. Moola's locked office. All consent forms, demographic questionnaires, interviews and drawings will also be given an alpha numerical code and stored in a locked filing cabinet in Dr. Moola's locked office. Digital copies will be made of the drawings and writing to facilitate analysis. These will be encrypted in a password protected hospital computer. Audiotaped interviews will be transferred onto the secure Holland Bloorview computer network and immediately coded with the corresponding code for the documents mentioned above. Seven years after the study is completed, all paper, digital, and audio data will be shredded by Dr. Moola. If any personal information was accidentally released, we would report the privacy breach to

Holland Bloorview's privacy officer and work with the Holland Bloorview REB to create a safety plan.

11. Anticipated Results

It is anticipated that we may also find that visual minority parents that care for a child with ASD also experience encounters of discrimination and feeling misunderstood in pediatric care environments. However, the detailed and descriptive nature of this qualitative investigation will help us to really understand the nuances and complexities that this particular demographic of children, youth, and parents, face. Thus, it is highly likely that we will also derive new knowledge. Our purposeful sampling strategy definitely has limitations and we will account for it in the papers that we publish. It is likely that the participants who contact us are ones that are more comfortable discussing such issues. They may also be families that are more accustomed to research. There is a risk that we will entirely miss segments of the visual minority ASD continuum who do not feel comfortable approaching us and we will account for this in our limitations.

At the moment, since we have a small budget and a very short funded study window, we are not doing a particular study on mothers and fathers experiences of ASD at the intersection of race, gender and ASD. However, we will note any emerging gender differences and take this into consideration in our limitations and future studies.

12. Compensation

Participants will be compensated for participating in the study. They will be reimbursed for all travel costs. They will also receive an honorarium in the form of a gift card (see budget in Appendix 10)

13. Dissemination

The results from the study will be disseminated through publications and conferences, so that others have the opportunity to learn about the experiences of parents of visible minorities that care for a child with autism. We will publish a few papers in leading academic journals and present our findings at conferences and community presentations.

We will engage in several forms of knowledge mobilization and dissemination. We will publish in leading academic journals in sociology, race, and childhood disability and try to get funding to attend a conference (Nivatha and Methuna to present). We also have a small budget to house a small exhibition of parents artistic creations. We will definitely reach out to Loiuise Kinross for the Bloom magazine as well and mobilization knowledge using social media platforms.

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