Women's Reproductive Health

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/uwrh20

Reproductive Healthcare Access and Genetic Testing Decision-Making Among Women With Increased Likelihood of Having a Child With Autism

Andrea L. DeMaria, Chandler Dykstra, Hannah King, Riley Feliciccchia, Bridgette L. Kelleher & Carolyn E. B. McCormick

To cite this article: Andrea L. DeMaria, Chandler Dykstra, Hannah King, Riley Feliciccchia, Bridgette L. Kelleher & Carolyn E. B. McCormick (2022): Reproductive Healthcare Access and Genetic Testing Decision-Making Among Women With Increased Likelihood of Having a Child With Autism, Women's Reproductive Health, DOI: 10.1080/23293691.2022.2054669

To link to this article: https://doi.org/10.1080/23293691.2022.2054669

WOMEN'S REPRODUCTIVE HEALTH
https://doi.org/10.1080/23293691.2022.2054669

Taylor & Francis
Taylor & Francis Group

Reproductive Healthcare Access and Genetic Testing Decision-Making Among Women With Increased Likelihood of Having a Child With Autism

Andrea L. DeMaria[a], Chandler Dykstra[b], Hannah King[a], Riley Felicicchia[b], Bridgette L. Kelleher[b], and Carolyn E. B. McCormick[c]

[a]Department of Public Health, Purdue University, West Lafayette, Indiana, USA; [b]Department of Psychological Sciences, Purdue University, West Lafayette, Indiana, USA; [c]Department of Human Development and Families Studies, Purdue University, West Lafayette, Indiana, USA

ABSTRACT

This study aims to understand reproductive healthcare decision-making and perceptions among mothers of children with an increased likelihood of autism. Researchers conducted 18 interviews (February–November 2020) with women aged 23 to 59 years (37.07 ± 7.88) in the United States. Researchers used methods from expanded grounded theory to explore women's healthcare decision-making. Findings suggest that women pursue team-based care with an OB/GYN as their primary care provider, clear patient–provider communication delivers greater healthcare experiences, and inconsistent prenatal genetic testing communication yielded decreased opportunities and widespread misconceptions. Understanding reproductive healthcare access and decision-making among this population allows researchers to recommend interventions for improving overall health outcomes.

KEYWORDS
autism; ASD; genetic testing; healthcare decision-making; reproductive health

Introduction

Autism spectrum disorder (hereafter, "autism") is a neurodevelopmental disorder characterized by difficulties with social communication and repetitive and stereotyped behaviors (American Psychiatric Association, 2013). Approximately 1 in 54 U.S. children is diagnosed with autism (Kogan et al., 2018)—there is strong evidence for both genetic and environmental influences on the development of symptoms. Many factors that increase the likelihood of a child experiencing autism have been determined during the pre- and postnatal periods. Increased likelihood of having a child with autism has been associated with older maternal/paternal age at conception (Idring et al., 2014; Wu et al., 2017), preterm birth, low or high birth weights for gestational age (Abel et al., 2013; Kuzniewicz et al., 2014; Moore et al., 2012), and exposure to environmental hazards and toxicants pre- and postnatally (Lyall et al., 2017; Modabbernia et al., 2017; Rossignol et al., 2014). Despite the importance of the pre- and postnatal environment in autism risk factors, minimal research is available on healthcare access and decision-making among women who have a child

CONTACT Andrea L. DeMaria ademaria@purdue.edu Department of Public Health, College of Health and Human Sciences, 812 West State Street, West Lafayette IN 47907, USA.

with autism or who have an increased likelihood of having a child diagnosed with autism. The present study addresses this topic by exploring women's preferences, attitudes, and experiences with reproductive healthcare. Here, we summarize three key issues: healthcare access, personal and provider communication, and genetic testing decision-making. Understanding how these three areas intersect may help researchers make practical recommendations for interventions aimed at improving reproductive health patient–provider communication and overall health outcomes related to autism.

Healthcare Access

Accessing healthcare is a pervasive issue in the United States that is particularly prevalent among those with an increased likelihood of having a child with autism (Malik-Soni et al., 2021). There is limited research on reproductive healthcare experiences such as proximity to services, transportation barriers, and healthcare provider (HCP) preferences in women with increased likelihood of having a child with autism. The lack of information about reproductive healthcare access in this specific population likely reflects, in part, broader healthcare access issues that impact those seeking reproductive healthcare support. For example, access to women's health specialists, particularly in rural and low-income areas, continues to decline (Kaiser Family Foundation, 2019). These women face lengthy travel times, a lack of available public transportation, and increased planning to access care (Kaiser Family Foundation, 2019).

These access issues are particularly problematic for families living in under-resourced areas and those whose family needs require specialist care. Women who experience limited access to healthcare typically meet with primary care providers or family physicians rather than a women's health specialist (Nesbitt et al., 1990).

Communication with HCPs

Women vary in their preferred decision-making approaches from provider-driven to autonomous decisions (Molina et al., 2019). Previous studies have found that patient–provider communication plays a significant role in women's reproductive decision-making (Yirgu et al., 2020), and negative HCP experiences are particularly salient (Reed et al., 2017). Women prefer a personal and intimate style of communication with their HCP when discussing conceptive methods (Dehlendorf et al., 2013). Similarly, women experiencing pregnancy complications preferred a patient-centered approach that is tailored to accommodate their values and experiences (van den Berg et al., 2018). Furthermore, prior research has demonstrated that a team-based approach in women's healthcare settings is increasing among HCPs and has improved patient experiences and health outcomes (Slinkard Philipp & Stonehocker, 2018). More research is needed to further explore whom women choose to share and discuss their reproductive health decisions with and their preferences in HCP communication approach.

Communication With Partners

Communication with personal support systems is an integral part of any reproductive healthcare experience yet is largely unexplored in women with increased likelihood of having a child with autism. However, previous research suggests women often discuss their reproductive health decisions with their partners or other close family members (Jones et al., 2011; Yee & Simon, 2010) and that male partners have a significant impact on reproductive decisions (Grady et al., 2010). Among families affected by autism, several gender effects have been reported in terms of how partners respond to the diagnosis and engage in the child's care. For example, male partners who identify as fathers may have different reactions to an initial diagnosis and specific goals for their child diagnosed with autism, such as increased focus on independence and integration (Burrell et al., 2017). However, despite the importance of partner involvement and communication, many fathers are underrepresented in research studies that report primarily on the mothers' responses to their child's autism diagnosis and treatment (Frye, 2016).

Genetic Testing

Advances in genetic testing have led to the identification of important genes associated with autism; however, there is currently no genetic test for autism. There has been an increase in the quality and quantity of prenatal tests available for genetic disorders, many increasing the likelihood of an autism diagnosis. Previous studies have explored the perceptions, experiences, and attitudes of parents toward autism genetic testing (Chen et al., 2013; Johannessen et al., 2017; Wagner et al., 2019). Women and families hold generally positive views toward clinical genetic testing for autism, citing specific motivating factors for pursuing testing related to seeking out early intervention support and a feeling of advancing the larger body of autism research (Chen et al., 2013; Johannessen et al., 2017). Parents perceive the negative effects of genetic testing to be possible insurance discrimination, increased psychological stress upon being met with a positive test result (Chen et al., 2013; Johannessen et al., 2017), and concerns about privacy, confidentiality, and outside accessibility of their test results (Wagner et al., 2019). Genetic testing for autism may be beneficial for families when discussing future family planning (Chen et al., 2013; Johannessen et al., 2017).

Similar themes emerged regarding prenatal genetic testing and autism; while parents were largely in favor, concerns remained about personal values, procedure involvement, cost, and accuracy of results (Chen et al., 2015). The advancements of genetic testing in recent decades have brought about a call by professional societies for all women to have access to prenatal genetic screening and genetic counseling before genetic testing (Edwards et al., 2015; Minkoff & Berkowitz, 2014). This need has placed greater pressure on genetic counseling professionals in clinical and non-clinical settings (Hoskovec et al., 2018), resulting in a limited workforce, service limitations in some regions, and long wait times (Stoll et al., 2018). Alternatively, specific barriers to receiving prenatal genetic testing have not been as sufficiently studied, especially in genetic syndromes. Known barriers include HCP inexperience, deficiency of patient/provider knowledge, lack of awareness, and time and financial restraints (Aalfs et al., 2003; Baars et al., 2005; McClatchey et al., 2018). Research demonstrates a need for improved genetic education and awareness (Baars et al., 2005), especially among general practitioners (Aalfs et al., 2003) to improve access and decision-making (McClatchey et al., 2018).

Current Study

Despite existing autism literature, limited qualitative research exists. The purpose of this study is to understand reproductive healthcare decision-making attitudes and perceptions among mothers of children with autism or with varying levels of an increased likelihood of autism (genetic or environmental risks). The present study investigates women's unique reproductive experiences related to healthcare access, communication and decision-making, and perceptions of genetic testing. For this study, we are defining "reproductive health decision-making" as any decision that impacts reproductive health attitudes, behaviors, or outcomes.

Materials and Methods

This study explored women's reproductive health decision-making as part of a larger mixed-methods autism-related project, which aimed to understand the sociocultural, political, and systemic landscape of attitudes, beliefs, and policies that may impact telemedicine uptake among families at genetic, environmental, and clinical risk for autism. Interviews were conducted from February through November 2020. Qualitative methodology allowed for a rich exploration of women's perceptions and experiences and was essential in capturing the insights of an understudied population on a sensitive topic. Overall, 18 in-depth, semi-structured phone interviews were completed. Eligible participants were mothers, aged 18 years or older, with a child with autism ($n = 6$) or with a genetic syndrome that increases the likelihood of autism (e.g., Down syndrome, Angelman syndrome) ($n = 6$) or living in an area within Indiana with an increased exposure to environmental toxicants that are broadly associated with elevated autism rates ($n = 6$).

Recruitment

Participants were fluent in conversational English and lived in the United States and were recruited through flyers (in libraries, schools, restaurants, stores, and laundromats), Facebook advertisements, and direct email (prior research participants who agreed to be contacted again). In response to COVID-19, additional online recruiting measures were conducted using All IN for Health (https://allinforhealth.info), a platform that promotes health resources, research, and clinical study opportunities among Indiana residents. Participants were also asked to refer other eligible women to the study, allowing for snowball sampling (Berg & Lune, 2012). All participants completed an electronic screening questionnaire to ensure eligibility, a demographics survey, and an electronic consent form, which included consent to audio record, before the interview. Any contact information participants provided was kept separate from survey responses.

Interviews

Each of the 18 interviews lasted approximately 80 minutes (79.49 ± 15.49). All conversations were audio-recorded using the SoundNote iPad application. Participants received a $40 Amazon gift card upon interview completion for their valuable time and insights.

Table 1. Interview questions.

Topic	Primary question	Probing questions
Healthcare Access	Where do you or members of your family typically go to receive healthcare?	• What type of healthcare providers do you see? • How does your need determine where you go? • How easy or hard is it for you to get healthcare when you need it? • [If hard] Tell me about a recent challenge you experienced when trying to access healthcare. What is hard about getting healthcare? • Have you or someone in your family ever seen a provider through a telehealth consultation? For example, talking to a healthcare professional via videoconferencing, chatting, or phoning for a scheduled appointment.
Reproductive Healthcare Access	Where do you go to receive reproductive healthcare?	• Tell me about the healthcare providers you see here. • How are you satisfied with the care you receive? Dissatisfied? • Is this location/healthcare team where you delivered your child?
Pregnancy Experience	Tell me a bit about your pregnancy experience with your child [with autism, genetic disorder, or most recent pregnancy].	• How often did you see a healthcare provider? • What type of information did you receive about genetic testing? Was this information what you expected? More? Less? • Did you choose to have any tests done? Which ones? Why or why not? • Would you recommend this healthcare plan for your own future pregnancy or that of someone close to you?
Healthcare Communication, Decision-making	Tell me about a time when you discussed your health with family or friends either before making an appointment or before making a final decision.	• What about a decision about your child's health? • Do you typically take a family member or friend to healthcare consultations with you? • [If yes] What role do they play? How did the provider treat them? Would you have preferred a greater or lesser role? • [If no] Tell me about your preferences in attending consultations alone.
Diagnosis, Genetic Testing	When did you receive a diagnosis for your child, and can you describe the process?	• What type of genetic testing was utilized? • Did you feel like you were explained the diagnosis well enough by the doctor?
Genetic Testing	Were there any difficulties/strains you encountered during the genetic testing process?	• What were some questions, if any, that you had for the doctor about the diagnosis and the next steps? • Would you have preferred to receive the diagnosis earlier? How did the timing of receiving the diagnosis effect the treatment/intervention availability/options?

The semi-structured interview guide (see Table 1) allowed flexibility for the researcher to add/modify questions or their order and enabled participants to introduce new and relevant concepts during the interview process. Interviews began with general questions about the participant and her daily routine to build rapport and increase comfort level and disclosure (Berg & Lune, 2012). Researchers then inquired into various aspects of reproductive health decision-making, healthcare delivery, and motherhood outcome priorities among women who have varying levels of increased likelihood of having a child with autism. Participant characteristics can be found in Table 2.

Table 2. Participant characteristics.

Variable	*n* (%) or mean ± SD
Age	37.06 ± 7.88
Relationship status	
Single	4 (22.22)
Living with a partner	3 (16.67)
Married/civil union	11 (61.11)
Highest level of education	
High school	2 (11.11)
College	5 (27.78)
Graduate school	8 (44.44)
Other	3 (16.67)
Race/ethnicity	
White	14 (77.78)
Black or African American	3 (16.67)
Region of United States	
Midwest	13 (72.22)
South	4 (22.22)
West	1 (5.56)
Employment status	
Employed full time outside of the home	8 (44.44)
Employed part time outside of the home	5 (27.78)
Not employed outside of the home	5 (27.78)
Insurance type	
Private health insurance from my job or my partner's job	12 (66.67)
Medicaid	3 (16.67)
Other	1 (5.56)
I do not currently have health insurance	1 (5.56)
Income	
$5,000 or less	2 (11.11)
$20,001–$49,999	3 (16.67)
$50,000–$99,000	4 (22.22)
$100,000–$149,000	5 (27.78)
$200,000 or more	1 (5.56)
I prefer not to answer	3 (16.67)
Household size	
1–3	4 (22.22)
4–6	12 (66.67)
7–9	2 (11.11)

Note: Items that do not add to 100% reflect missing data.

Analyses

Researchers transcribed interviews verbatim, including memos and observer comments to maintain reflexivity (Rubin & Rubin, 2012). Techniques from grounded theory and thematic analyses provided the basis for constant comparative data analysis, highlighting the personal experiences of the participants (Braun & Clarke, 2006; Corbin & Strauss, 2008). Participant words and phrases were used as in vivo codes (Corbin & Strauss, 2008), aligning with the expansion of grounded theory to incorporate existing theoretical constructs (Corbin & Strauss, 2008). HyperRESEARCH 4.5.1 facilitated coding and analysis through data input and organization. A codebook was developed based on initial transcription readings, which provided the in vivo codes based on participants' words, interview guides, and existing scientific literature.

Following the initial reading, researchers discussed the codes that best reflected the data and extant literature and solidified the codebook. Then, they worked closely and systematically to complete line-by-line open coding, which allowed for initial reflection on content and meaning established in the data (e.g., what is being said) (Braun & Clarke, 2006; Corbin & Strauss, 2008). Following open coding, the researchers completed axial coding to identify relationships among codes and to broader categories and patterns, allowing codes and categories to be compared to theoretical concepts and extant literature to better explain the data. This process included identifying where codes overlapped, reducing redundant codes, and adding new codes. A constant comparative method was used to identify emergent themes following axial coding completion (Corbin & Strauss, 2008). Themes and subthemes reflect the incorporation of multiple codes that best reflect the data linkages (Braun & Clarke, 2006). Researchers met frequently to discuss emerging patterns and themes and ensure consistency. All discrepancies were resolved via consensus. First-order themes encompassed overarching patterns in the data, while second-order themes, or subthemes, allowed for delineation between the varying levels present within each theme.

Ethical Considerations

The first author's institutional review board approved this study. All research procedures conformed to all ethical principles for medical research among human participants. Participants were adequately informed of the study and were notified of their right to withdraw participation at any point in the interview without explanation. Participants also provided both written and verbal informed consent to participate in the interview and to be audio-recorded (for transcription purposes). Upon transcription completion, interview audio files were destroyed from electronic devices. Demographic forms did not have a section for participant names, as the forms were used to provide de-identified information about the interview sample. Interview consent forms were kept separate from the data and demographic forms and kept in a secure, password-protected folder.

Results

Three emerging themes resulted: (1) healthcare access related to convenience, team-based care, and the use of OB/GYNs as primary providers; (2) communicating healthcare decisions individually and/or with partners, family, and HCPs; and (3) genetic testing awareness, barriers, and facilitators. Each theme is noted below with subthemes and representative participant quotes.

Healthcare Access: "It Can Be Kind of Difficult … "

During discussions of healthcare and healthcare access, participants noted where they go to receive reproductive healthcare and described ease of access. Many participants sought healthcare based on various factors or preferences, such as convenience and team-based approach to care, and often utilized OB/GYNs as primary care providers.

Convenience

When and where participants sought healthcare often stemmed from convenience. One participant recalled using the healthcare facility provided by her work, "This last time I did my, very convenient, I just did my annual well-being check with like the female stuff with a general practitioner." When searching for a new HCP, this participant shared, "I did some research for when we were family planning. I wanted somebody that was going to be relatively simple to get to from work," emphasizing convenience when seeking reproductive healthcare services. Similarly, another participant described satisfaction in accessing care through work, "I'm kind of spoiled." Proximity of a healthcare facility to one's workplace has been shown to be a relevant factor in ease of access. Other participants received health insurance through their work, impacting where they received care. When asked about where she receives healthcare, a participant said, "we use [hospital group name] if we need like a hospital or any other type of services because I work there. That's what my health insurance is through." Discussion of healthcare access within the workplace provided insight into the significance of convenience when pursuing care.

Another factor impacting healthcare access was location (i.e., proximity to home). Many participants sacrificed their preferred healthcare facility due to inconvenient location. One participant noted:

> I didn't deliver [at the research hospital] cause they're not close to where we live. Um, so we actually chose [another location]. Which is my favorite hospital around. (Laughs) They're just really great, my OB is there. I just really like the hospital, it's probably 15 miles from our house. If we had lived closer for sure I would have delivered at [the research hospital].

Moreover, some women felt that healthcare facilities in closer proximity were more convenient and accessible. One participant explained, "I delivered at [a hospital], and that's maybe 20 minutes away. So, I guess for the area we are in its easy to access the healthcare." These narratives on women accessing healthcare with an emphasis on proximity to their location shows the importance distance has in healthcare access.

In contrast with choosing care based on distance and convenience, some participants chose HCPs who offered multiple services. One participant recalled being more concerned about what reproductive health services were offered, as she explained, "I chose it due to proximity and, um, because they will allow you to have a water birth. It's like the only place in [my city]." Similarly, one woman utilized a "private clinic or a clinic you know five minutes up the way." This participant had chosen what was local but also preferred the experience and services provided, voicing her satisfaction as, "Oh they do fantastic. They helped deliver our daughter when she was born. They're a great clinic." Another woman noted, "It wasn't my regular hospital, I had a hospital that was closer by but I went to that one just cause I like the care that they gave me," emphasizing quality of care and services over convenience. Additionally, a participant described receiving reproductive healthcare in same clinic as all her other healthcare services as, "it's very helpful." This highlighted the importance of convenience and, more specifically, a team-based health approach to women's healthcare.

Team-Based Care

Team-based care provided both convenience and additional healthcare access to women seeking reproductive care. When discussing their experiences with a team-based approach, participants noted the increase in services provided. One woman spoke on her involvement with a clinic:

> You would have a midwife and I think she had like a helping assistant that was like you know. Would talk about certain things like caring for a baby. Like how many diapers do you think you go through in a day, are you going to breastfeed or bottle-feed, what are your resources, room, sleep, you know contraceptives after you know having a baby, and domestic stuff. Just normal everything, like don't smoke when you have a baby.

In addition to seeking increased access to care, some participants voiced greater satisfaction with team-based care. One participant shared, "I feel like they gave me more better care rather versus somewhere else that I would have went." Similarly, another participant explained her experience with a team-based approach to her prenatal care and delivery of her child:

> I feel like they all seemed to know me. And know kind of how what my thoughts were a lot of the stuff they were helping me with. Whereas if I had gone to the regular doctor they would have been like okay. I mean they listen to me but I didn't feel as like … they knew me as well.

Additionally, participants using team-based care voiced less reluctance when having to see an alternate HCP. One woman described this as, "So it's either her or there's a nurse practitioner there. I see them back and forth, they're kind of a team that work together." Increased access and satisfaction demonstrate the importance of a team-based approach to women's healthcare.

OB/GYNs as Primary Care Providers

Many women spoke highly of their OB/GYNs, and some switched to using their OB/GYN as their primary care provider. One woman described greater trust in her HCP: "Um, actually my primary care physician was also an OB/GYN. So, um, after having like a bad experience. … Um, I just started going to her." Similarly, another participant spoke of her current OB/GYN and expressed feelings of gratitude, "I consider him my primary doctor. He's my favorite doctor in the world." Many women who had moved to use an OB/GYN as their primary care provider emphasized communication and personalized care. One participant noted, "I was really comfortable with him. Um, he listened to me." She continued to say, "He would take all the steps needed to make sure that I felt comfortable before leaving." Similarly, another woman spoke of her HCP, "she was so great at explaining things to us, and um. She didn't really go over our heads as far as medical terminology." Additionally, participants voiced greater HCP trust when the relationship felt more personal. One participant spoke of her relationship with her HCP: "because of our history I mean she's seen me through all my pregnancies. Everything that we've had going on so. Um, I just—she's somebody that I wholeheartedly trust. And, am confident in my care with her." These satisfactory healthcare experiences highlight women's preferences for HCPs, communication, and access.

Communicating Healthcare Decision-Making: "I Would Always Ask My Husband or Family Members"

Researchers asked participants to share with whom they typically discuss their reproductive health concerns and decisions. Participants described various preferred communication methods with social support networks and HCPs or lack thereof.

Independent Decisions

Participants expressed varying levels of comfort when discussing their reproductive health with others. Some women described these discussions as "private" and preferred to keep reproductive health matters to themselves. One participant shared, "I kind of keep everything else to myself. And the grandma … the only thing I talk about is the kid's health. But my health I mean I don't feel the need to you know like go on … you know it's kind of like private I feel like," indicating a contrast between sharing her reproductive health compared to discussing her child's health. Another woman voiced personal autonomy as she stated, "I don't discuss that with people. Because I don't want anyone's opinion, because in the end I'm responsible for myself and um I just want to live life how I want to live life." Similarly, some participants chose to make reproductive health decisions independently from others, including their partners. For instance, one woman recalled decision-making during labor and noted, "I basically made them by myself cause I told him I wanted it all-natural." Therefore, these participants demonstrated a preference for independence in both reproductive health communication and decision-making.

Partner and Family Influence

Many women preferred to communicate with their partners when discussing reproductive health. A participant shared, "My husband. I usually discuss with him about what type of contraceptives or what type of birth control I'm gonna be taking." Similarly, one woman explained, "The only person I ever discussed that with was probably my ex-husband." Another participant emphasized exclusively communicating with her partner, "I mean my husband for sure, but no one else." When asked specifically whether she talks to her partner about her reproductive health, one woman said "Yeah, we definitely do. We are pretty open." In addition to discussing reproductive health with a partner, other women cited family as another source of communication. One woman said, "Yeah, one time me and my husband discussed an appointment I had and then I went to go see the specialist. But I wouldn't … I would always ask like my husband or my family members before I went to go to an appointment." Similarly, another participant said she usually "crowdsources" with family about input related to her health, suggesting a strong partner and family influence in her health choices.

Many participants specifically mentioned communicating with their mothers. One woman recalled:

> Usually I just keep everything private with myself, but when I was pregnant with my stillborn. Um, if I was in labor or not, but I was still in a lot of pain, but I called my mom. And would tell her, you know she was telling me go up to the hospital and get checked.

Echoing this, another woman described consulting with her mother, "I'll call her and ask her 'hey have you heard about this or do you know anything about that?' Just to kind of see what she knows and what she's experienced too." Thus, participants' partners and family members were both preferred sources of reproductive health communication, and their opinions and experiences influenced women's decisions.

HCP Communication

Communication is an essential part of any healthcare experience. Some women recalled positive experiences communicating with their HCPs:

> It was going well, I had um, a private doctor since my C-section in 2011. So, I was really comfortable with him. Um, he listened to me whenever I said I just had a pain I didn't feel comfortable with he would allow me to come in, um, and be seen. And if I needed testing or an ultrasound, um, he would make all the. … He would take all the steps needed to make sure that I felt comfortable before leaving.

Further, one participant also remembered clear communication, specifically related to her pregnancy, "She just really took the time to walk us through what we were facing." Some women highlighted their HCPs' willingness to answer their questions as a part of their satisfaction with their healthcare experience. For instance, "Whatever questions that I have. Even if after an appointment, I have anything to ask I call up, they have nurses, and if the nurses are not able to decide she'll give me a call back after checking with the doctors." This emphasizes the importance of HCP accessibility and engagement to some women.

Other patient–provider communication experiences were described negatively. One participant explained, "Basically, everything our doctor told us I didn't follow. And I am so glad I didn't. He painted a picture that was horrible for our family." Another woman expressed she had issues "battling [her] pediatrician to get answers," which made it difficult to make decisions for her child's special needs and healthcare. Some women recalled receiving inaccurate information about their child's diagnosis after birth:

> Then also one of the tests came back finally that said oh she has um, isolation on chromosome 15. Which means she either has … one of two things. She either has Angelman's syndrome or she has Prader-Willi syndrome. Um, and the doctor who told us this in the NICU was like 'I've never heard of either of these so I Googled it last night.' And I was like well … I could have done that. Then the other doctor got the results and told them to us. And gave us … (pause) uh misinformation and old information about Prader-Willi syndrome. (Pause) And also since he Googled it he didn't get correct information.

Many women described having to advocate extensively for themselves and their children. One woman described having to educate her doctors herself:

> So, I feel like I told all of his providers right away. You know, um just so that they could, they could um, if they didn't ha—I didn't know if our pediatrician was really familiar with Angelman's syndrome. I wanted to make sure his doctor knew what they were dealing with and um. 'Cause I certainly didn't know and I wanted to make sure his provider knew.

Another woman echoed a similar self-advocacy sentiment: "I feel like it's my responsibility almost sometimes to research what interventions might be needed and then bring them up [during healthcare visits].” Participants engaged in self-advocacy to compensate for communication barriers.

Prenatal Genetic Testing: “I Definitely Preferred Having It” vs. “Oh, This Is Scary”

During discussions of pregnancy and motherhood, participants were prompted to share about pre- and postnatal genetic testing experiences. Many women recalled not being offered genetic testing during their pregnancy, as one participant stated: “No. I feel like they didn’t.” Similarly, one woman shared, “Um, I don’t think really any that I can remember,” while another expressed, “There was no information about genetic testing when I was pregnant the first time.” In sharp contrast, other participants voiced having been offered prenatal genetic testing. Emphasizing the disparity between those offered and not, one woman explained, “It’s like something that everybody does … It’s like a simple blood draw. Like they do it like at 12 or 15 weeks.” Another woman recalled, “I can’t remember exactly what they were offering, but I know there was definitely an option.” Participant experiences highlighted differing testing opportunities, including receiving little to no information at all. Regarding this, one participant stated, “They really basically didn’t offer much information about it. And they didn’t offer any information about the other genetic screens that [were] just starting to get popular at the time.” Participant responses varied from receiving detailed explanations to getting vague descriptions of prenatal genetic testing. Thus, the opportunity to receive genetic testing and the degree to which a participant was informed of their options greatly differed.

Accepted Testing

A primary motivator to partake in prenatal genetic testing was knowing a result could alleviate worry during pregnancy. One woman explained, “But that was just … my peace of mind. I’d done it with … I think my previous two pregnancies. So, I just wanted it done.” Another participant echoed a similar rationale:

> I was asked “do you want to go ahead with a genetic test” that’ll tell you if the child has genetic issues, specifically Down syndrome or something? And I was like “yeah, yeah please do that.” So, yeah. Whatever test was possible I got it done because I already had, uh, my son with autism so I was just being extra cautious.

In continuation, other participants felt that prenatal genetic testing would allow time to prepare in the event of receiving an abnormal result. One woman shared, “I definitely preferred having it and being able to get used to the idea … as opposed to finding out at birth.” Another woman explained her desire to undergo testing as “mainly because my husband was super nervous about it. His mom was a physical therapist and had worked with a lot of kids with a—like some major disabilities. So, he’s always been like very nervous about that.” Other participants pursued prenatal genetic testing opportunities to “cover their bases,” as one woman stated: “They did all of the typical stuff they have to do and then they asked if I wanted to do extra testing and I was like ‘nope, I’m good.’” Another woman simply shared, “I had wanted it done because I could.” Overall, choosing to engage in prenatal genetic testing related to easing worry, past testing history, and personal preferences.

Denying Testing

In contrast, other participants recalled denying genetic testing offers by citing a variety of rationalizations. Many women chose to forego prenatal genetic testing, voicing concerns of harming the unborn child, "Yeah, that's part of the reason I didn't want to do it too. I just was … afraid of … doing something that like … harm the baby. And, just, it made me nervous." Another participant expressed a similar feeling of apprehension, stating:

> [The provider] said "we should really do an amnio for the fetus, and you might um, it might have a problem." And I was just like, "yeah, I'm not going to do an amnio because that could abort this baby that I've been trying to conceive."

One woman echoed this fear by sharing, "Like they get the amniotic fluid so it's kind of like oh, this is scary, and I didn't want to." When further explaining the decision to deny genetic testing, another participant shared her thought process: "I guess the risk of, any risk to the baby was more than we were willing to put in being as we were. Very low risk of them being a problem in the first place." For these women, prenatal genetic testing opportunities did not outweigh perceived risks or fear.

Other participants deemed genetic testing unnecessary, expressing how an abnormal result would not influence their attitudes and decisions. One woman shared, "You know we just, prior to going into that pregnancy since that was our second one we knew we weren't going to do any of the genetic testing. … Our decisions would never change whether we had a prenatal diagnosis or something." A few other participants voiced a similar outlook, expressing that their pregnancy decisions were independent of a genetic test result: "Plus I was like … even if she has Down syndrome or something I'm not going to abort the baby now, so what's the point in being tested?" This was further echoed by another participant:

> We'll check for like spina bifida, but you know, I just. I know I will be really anxious. And it's going to be what it's going to be. I didn't plan on terminating, so I actually kind of declined some of the prenatal testing.

For some participants, personal beliefs and values superseded prenatal genetic testing measures.

For the remaining women, genetic testing offers were denied based on misunderstanding or a false sense of security upheld by an HCP. A lack of understanding in the genetic testing process was demonstrated by a handful of women who stated, "Because, um, everything was fine they said 'oh' like baby was healthy, so I didn't need to." Another participant shared a similar rationale, voicing trust in having no prior family history of intellectual or developmental disabilities or autism:

> I said "no" that I don't want to have genetic testing done just because, like I said, we don't have anyone in our family that has any disabilities, or you know that we could think of so we didn't really think anything of it.

Other participants denied prenatal genetic testing, voicing trust in an HCP who claimed it was not needed. One woman explained, "[the HCP] said there was nothing wrong with the ultrasound or anything like that so there's no reason to have it done. So, she just offered it and we declined." Another participant shared a similar experience with their HCP in the following lines:

> I had asked about, you know, just in general like would it be worthwhile for me to get done, being you know. Being with me you know being me diabetic anything you know. Something worth you know looking into. And cause you know I've trusted my doctor for a long time. And, and they told me. They told me … not something I need to worry about.

Genetic testing misconceptions and perceived patient–provider trust guided participants' decision-making surrounding denied offers.

Awareness or Lack Thereof

Discussion of prenatal genetic testing revealed a general lack of awareness among participants. Many women relied on friends as a source of prenatal genetic testing education, as one woman stated, "I was aware of it, but I was only aware of it because I've had friends who went and were able to like find out the sex really early." Similarly, one participant's unfamiliarity was revealed while discussing with her peers, "Some people that I know in my like birth groups have like the whole karyotype of what their kids' DNA looks like. … And I'm like 'well I don't know anything about that.'" Another woman voiced her unawareness of prenatal genetic testing as, "It honestly wasn't a blip on my radar." This participant continued on to say, "even though we had done genetic testing with [in vitro fertilization]. Um, I just didn't think I needed to." Other participants were under the impression their HCP could not provide prenatal genetic testing, as one woman stated, "They pretty much told me … it's a long, drawn-out process. … That it's something that requires you to go see a geneticist. … It's not something that my doctor could just do." Deficiency of prenatal genetic testing knowledge was common among participants and manifested as a barrier.

Discussion

This study aimed to understand how women with different levels of increased likelihood of having a child with autism make decisions about reproductive healthcare and genetic testing. In-depth interviews were conducted with 18 mothers living in the United States with a child with autism or with a genetic syndrome or living in an area within Indiana with an increased environmental toxicant exposure. A grounded-theory approach to thematic analyses identified reoccurring themes related to experiences, attitudes, and decision-making.

When discussing their reproductive healthcare, many women spoke of convenience as a major factor in choosing and accessing healthcare. In some cases, participants displayed a preference for healthcare services offered through their workplace due to convenience and increased accessibility. Other participants prioritized location over the preferred place of care by choosing healthcare facilities and HCPs based on proximity to work or home. The use of local clinics by participants emphasized the importance of individual communities having healthcare facilities for greater healthcare access. In addition to proximity, participants also showed a strong preference toward team-based care and having their HCPs all in one location. There was also a notable shift in women choosing their OB/GYNs to act as their primary care providers, which was typically attributed to a narrative of established trust and enhanced communication. This is especially important, as OB/GYN providers may be viewed as the lead HCP in a team-based approach to reproductive healthcare and beyond. Participants in this study displayed the importance ease of access in healthcare has as well as what women seek when it comes to their reproductive healthcare. Additionally, participants' strong emphasis on ease of access and team-based care may cue HCPs and policymakers on the best approach to improve accessibility in women's healthcare.

Participants varied in the extent that they shared their reproductive health decisions with others and with whom they preferred to communicate. Preferences for involving others in reproductive health communication stemmed from the perceived need for support, validation, or confirmation in decision-making. Women often identified their partner as the primary or sole confidante for reproductive health discussions. Alternatively, participants also mentioned seeking guidance from their mothers or other trusted family members and described the impact they have on their reproductive health decisions. In some cases, other women preferred to remain private about their reproductive health due to reasons centered around independence and personal autonomy. HCPs should address individual communication styles and account for influences that partners and family members may have in reproductive health decisions. At the HCP level, women described both positive and negative experiences with communication. Results indicate that clear communication and HCP accessibility are essential components to patient retention and satisfaction, aligning with and extending the limited body of research on healthcare and assessment experiences of parents with children with autism and/or neurogenetic syndromes (Bultas, 2010; Bultas et al., 2016; Kelleher et al., 2020). Deficits in these areas by HCPs should be addressed through targeted interventions focused on patient communication. Thus, understanding HCP communication strategies that are the most effective for women may inform critical areas of improvement within healthcare settings.

Participant experiences illustrated a dichotomy in prenatal genetic testing opportunities. While some participants voiced having been offered prenatal genetic testing, others described never receiving the opportunity. Thus, a perceived lack of consistency in HCP-offered prenatal genetic testing became apparent. Participant discussion surrounding the type of prenatal genetic testing information they received drastically varied. Similarly, of the women offered genetic testing during pregnancy, a polarization emerged surrounding the decision-making process, building off prior literature on parent attitudes of prenatal genetic testing (Johannessen et al., 2017). Some women described "peace of mind" as their primary motivator to accept prenatal genetic testing, while others denied testing based on perceived risks, lack of importance, and general misunderstanding. For some participants, trust in an HCP who deemed the pregnancy to be healthy replaced the need for prenatal genetic testing, further illustrating the impactful role HCPs share in providing genetic testing education and services (Chen et al., 2013).

Misconceptions about prenatal genetic testing procedures heavily influenced the decision-making process. In addition to described barriers of limited genetic counselors and services in rural areas (Stoll et al., 2018), a critical barrier to prenatal genetic testing access was insurance coverage. However, other barriers stemmed from a lack of awareness and general understanding about how and why genetic testing is done, which aligns with prior literature demonstrating limited awareness and access among Asian and low–socioeconomic status groups (Chen et al., 2013). This study demonstrates the need for consistent, patient-centered messaging to improve patient education on prenatal genetic testing purposes and procedures. Intervention efforts should target HCPs, especially OB/GYNs, to increase awareness and address prenatal genetic testing misunderstanding among pregnant women, especially those with such an increased likelihood. An increase in patient education on prenatal genetic testing may improve access and better equip women to make informed decisions during pregnancy and beyond.

Strength and Limitations

This study had several strengths. Researchers received graduate-level training in interviewing techniques before the start of data collection. The in-depth interviews allowed researchers to capture a rich understanding of reproductive health decision-making experiences. All researchers followed a semi-structured interview guide to maintain a framework while fostering greater discussion; however, multiple team members conducting interviews could have led to minor differences in data collection and interpretation during the interview process. The research team met biweekly to discuss updates and ensure that team members were of mutual understanding. Additional meetings were conducted during data analysis to maintain consistency throughout coding and theme development. However, results should be interpreted in the context of some limitations. Results may not be generalizable across different populations, including other geographic locations or sociodemographic groups, though these findings may transfer to other contexts and samples. However, this study generated new knowledge of reproductive health decision-making attitudes and perceptions among an at-risk population. Our diversity in stakeholder identities helped incorporate a broad spectrum of perspectives, but our within-group sample size was not sufficient to support subgroup analyses. Future studies may benefit from a larger sample size to explore how demographic and regional differences impact reproductive healthcare decision-making for at-risk women, as well as incorporating perspectives of autistic women and mothers.

Implications and Conclusions

Our findings offer insight into women's unique perspectives of reproductive healthcare access, communication, and decision-making. Understanding these experiences allows for the translation of research to healthcare practice and yields many practical recommendations to address women's specific healthcare needs and preferences. Intervention efforts should focus on the development of patient-centered approaches as the standard of care for making shared decisions in reproductive health, including genetic testing. Further, HCPs should seek to better understand patients' preferred communication styles and recognize the influence partners or family members have on decision-making. Implementation of team-based approaches could be considered to increase reproductive health access among this population. Last, strategies should emphasize increased patient education across healthcare settings to reduce barriers in reproductive healthcare and genetic testing access to empower women's reproductive health decisions.

Understanding reproductive healthcare access and decision-making among this population enables researchers to recommend practical interventions for improving patient–provider communication and overall health outcomes.

Acknowledgements

The authors would like to thank members of their project team who are not coauthors in this work, including Rose Mason, Felicia Roberts, Taylor Halligan, Aparajita Pesaladinne, Henry Ludwig, Meagan Carrero, and Mehreen Hassan.

Ethics Approval and Consent to Participate

This study was approved by the Purdue Institutional Review Board (IRB-2019-582). All study participants provided written informed consent, including consent to be audio-recorded.

Authors' Contributions

The study and study materials were conceived and designed by ALD, CM, and BK. Data were collected by ALD, CD, and CM. HK transcribed all audio recordings. All authors shared responsibility for data analysis and interpretation. ALD, CD, HK, and RF drafted the manuscript with multiple revisions throughout the drafting process by CM and BK. All authors read and approved the final manuscript.

Disclosure Statement

No potential conflict of interest was reported by the author(s).

Availability of Data and Materials

The data set used and analyzed for the current study are available from the corresponding author upon reasonable request.

Funding

This project was supported with funds from the Purdue Discovery Park Big Ideas Challenge Competition (PI Kelleher). CM received support from the National Center for Advancing Translational Sciences through a Career Development Award (KL2TR002530).

ORCID

Andrea L. DeMaria http://orcid.org/0000-0002-5450-0444
Bridgette L. Kelleher http://orcid.org/0000-0001-7966-1837
Carolyn E. B. McCormick http://orcid.org/0000-0002-1015-0809

References

Aalfs, C. M., Smets, E. M. A., de Haes, H. C. J. M., & Leschot, N. J. (2003). Referral for genetic counselling during pregnancy: Limited alertness and awareness about genetic risk factors among GPs. *Family Practice*, *20*(2), 135–141. https://doi.org/10.1093/fampra/20.2.135

Abel, K. M., Dalman, C., Svensson, A. C., Susser, E., Dal, H., Idring, S., Webb, R. T., Rai, D., & Magnusson, C. (2013). Deviance in fetal growth and risk of autism spectrum disorder. *The American Journal of Psychiatry*, *170*(4), 391–398. https://doi.org/10.1176/appi.ajp.2012.12040543

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Baars, M. J. H., Henneman, L., & ten Kate, L. P. (2005). Deficiency of knowledge of genetics and genetic tests among general practitioners, gynecologists, and pediatricians: A global problem. *Genetics in Medicine*, *7*(9), 605–610. https://doi.org/10.1097/01.gim.0000182895.28432.c7

Berg, B., & Lune, H. (2012). *Qualitative research methods for the social sciences*. Pearson. /content/one-dot-com/one-dot-com/us/en/higher-education/product.html

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Bultas, M. W. (2010). *The mother's perspective: Understanding more about health care experiences of the preschool child with autism* [Ph.D., University of Missouri – Saint Louis]. http://search.proquest.com/docview/814885215/abstract/6B196C952380419CPQ/1

Bultas, M. W., McMillin, S. E., & Zand, D. H. (2016). Reducing barriers to care in the office-based health care setting for children with autism. *Journal of Pediatric Health Care*, *30*(1), 5–14. https://doi.org/10.1016/j.pedhc.2015.08.007

Burrell, A., Ives, J., & Unwin, G. (2017). The experiences of fathers who have offspring with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*(4), 1135–1147. https://doi.org/10.1007/s10803-017-3035-2

Chen, L. S., Xu, L., Dhar, S. U., Li, M., Talwar, D., & Jung, E. (2015). Autism spectrum disorders: A qualitative study of attitudes toward prenatal genetic testing and termination decisions of affected pregnancies. *Clinical Genetics*, *88*(2), 122–128. https://doi.org/10.1111/cge.12504

Chen, L. S., Xu, L., Huang, T.-Y., & Dhar, S. U. (2013). Autism genetic testing: A qualitative study of awareness, attitudes, and experiences among parents of children with autism spectrum disorders. *Genetics in Medicine*, *15*(4), 274–281. https://doi.org/10.1038/gim.2012.145

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. SAGE.

Dehlendorf, C., Levy, K., Kelley, A., Grumbach, K., & Steinauer, J. (2013). Women's preferences for contraceptive counseling and decision making. *Contraception*, *88*(2), 250–256. https://doi.org/10.1016/j.contraception.2012.10.012

Edwards, J., Feldman, G., Goldberg, J., Gregg, A., Norton, M., Rose, N., Schneider, A., Stoll, K., Wapner, R., & Watson, M. (2015). Expanded Carrier Screening in Reproductive medicine-points to consider: A joint statement of the American College of Medical Genetics and Genomics, American College of Obstetricians and Gynecologists, National Society of Genetic Counselors, Perinatal Quality Foundation, and Society for Maternal-Fetal Medicine. *Obstetrics and Gynecology*, *125*(3), 653–662. https://doi.org/10.1097/AOG.0000000000000666

Frye, L. (2016). Fathers' experience with autism spectrum disorder: Nursing implications. *Journal of Pediatric Health Care*, *30*(5), 453–463. https://doi.org/10.1016/j.pedhc.2015.10.012

Grady, W. R., Klepinger, D. H., Billy, J. O. G., & Cubbins, L. A. (2010). The role of relationship power in couple decisions about contraception in the US. *Journal of Biosocial Science*, *42*(3), 307–323. https://doi.org/10.1017/S0021932009990575

Hoskovec, J. M., Bennett, R. L., Carey, M. E., DaVanzo, J. E., Dougherty, M., Hahn, S. E., LeRoy, B. S., O'Neal, S., Richardson, J. G., & Wicklund, C. A. (2018). Projecting the supply and demand for certified genetic counselors: A workforce study. *Journal of Genetic Counseling*, *27*(1), 16–20. https://doi.org/10.1007/s10897-017-0158-8

Idring, S., Magnusson, C., Lundberg, M., Ek, M., Rai, D., Svensson, A. C., Dalman, C., Karlsson, H., & Lee, B. K. (2014). Parental age and the risk of autism spectrum disorders: Findings from a Swedish population-based cohort. *International Journal of Epidemiology*, *43*(1), 107–115. https://doi.org/10.1093/ije/dyt262

Johannessen, J., Naerland, T., Hope, S., Torske, T., Høyland, A. L., Strohmaier, J., Heiberg, A., Rietschel, M., Djurovic, S., & Andreassen, O. A. (2017). Parents' attitudes toward clinical genetic testing for autism spectrum disorder—Data from a Norwegian Sample. *International Journal of Molecular Sciences*, *18*(5), 1078. https://doi.org/10.3390/ijms18051078

Jones, R. K., Moore, A. M., & Frohwirth, L. F. (2011). Perceptions of Male Knowledge and Support Among U.S. Women Obtaining Abortions. *Women's health issues*, *21*(2), 117–123. https://doi.org/10.1016/j.whi.2010.10.007

Kaiser Family Foundation (2019, November 14). Beyond the numbers: Access to reproductive health care for low-income women in five communities – Executive summary. *KFF*. https://www.kff.org/report-section/beyond-the-numbers-access-to-reproductive-health-care-for-low-income-women-in-five-communities-executive-summary/

Kelleher, B., Halligan, T., Garwood, T., Howell, S., Martin-O'Dell, B., Swint, A., Shelton, L.-A., & Shin, J. (2020). Brief report: Assessment experiences of children with neurogenetic syndromes: Caregivers' perceptions and suggestions for improvement. *Journal of Autism and Developmental Disorders*, *50*(4), 1443–1450. https://doi.org/10.1007/s10803-020-04363-0

Kogan, M. D., Vladutiu, C. J., Schieve, L. A., Ghandour, R. M., Blumberg, S. J., Zablotsky, B., Perrin, J. M., Shattuck, P., Kuhlthau, K. A., Harwood, R. L., & Lu, M. C. (2018). The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics*, *142*(6), e20174161. https://doi.org/10.1542/peds.2017-4161

Kuzniewicz, M. W., Wi, S., Qian, Y., Walsh, E. M., Armstrong, M. A., & Croen, L. A. (2014). Prevalence and neonatal factors associated with autism spectrum disorders in preterm infants. *The Journal of Pediatrics*, *164*(1), 20–25. https://doi.org/10.1016/j.jpeds.2013.09.021

Lyall, K., Croen, L., Daniels, J., Fallin, M. D., Ladd-Acosta, C., Lee, B. K., Park, B. Y., Snyder, N. W., Schendel, D., Volk, H., Windham, G. C., & Newschaffer, C. (2017). The changing epidemiology of autism spectrum disorders. *Annual Review of Public Health*, *38*, 81–102. https://doi.org/10.1146/annurev-publhealth-031816-044318

Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., Fuentes, J., & Frazier, T. W. (2021). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatric Research*, *2021*, 65. https://doi.org/10.1038/s41390-021-01465-y

McClatchey, T., Lay, E., Strassberg, M., & Veyver, I. B. V. d. (2018). Missed opportunities: Unidentified genetic risk factors in prenatal care. *Prenatal Diagnosis*, *38*(1), 75–79. https://doi.org/10.1002/pd.5048

Minkoff, H., & Berkowitz, R. (2014). The case for universal prenatal genetic counseling. *Obstetrics and Gynecology*, *123*(6), 1335–1338. https://doi.org/10.1097/AOG.0000000000000267

Modabbernia, A., Velthorst, E., & Reichenberg, A. (2017). Environmental risk factors for autism: An evidence-based review of systematic reviews and meta-analyses. *Molecular Autism*, *8*(1), 13. https://doi.org/10.1186/s13229-017-0121-4

Molina, F., Dehlendorf, C., Gregorich, S. E., & Kuppermann, M. (2019). Women's preferences for and experiences with prenatal genetic testing decision making: Sociodemographic disparities in preference-concordant decision making. *Patient Education and Counseling*, *102*(3), 595–601. https://doi.org/10.1016/j.pec.2018.10.019

Moore, G. S., Kneitel, A. W., Walker, C. K., Gilbert, W. M., & Xing, G. (2012). Autism risk in small- and large-for-gestational-age infants. *American Journal of Obstetrics and Gynecology*, *206*(4), 314.e1–314.e9. https://doi.org/10.1016/j.ajog.2012.01.044

Nesbitt, T. S., Connell, F. A., Hart, L. G., & Rosenblatt, R. A. (1990). Access to obstetric care in rural areas: Effect on birth outcomes. *American Journal of Public Health*, *80*(7), 814–818.

Reed, R., Sharman, R., & Inglis, C. (2017). Women's descriptions of childbirth trauma relating to care provider actions and interactions. *BMC Pregnancy and Childbirth*, *17*(1), 21. https://doi.org/10.1186/s12884-016-1197-0

Rossignol, D. A., Genuis, S. J., & Frye, R. E. (2014). Environmental toxicants and autism spectrum disorders: A systematic review. *Translational Psychiatry*, *4*(2), e360. https://doi.org/10.1038/tp.2014.4

Rubin, H. J., & Rubin, I. (2012). *Qualitative interviewing: The art of hearing data*. SAGE.

Slinkard Philipp, M., & Stonehocker, J. (2018). Women's health outpatient care teams: Focus on advanced practice providers. *Clinical Obstetrics and Gynecology*, *61*(1), 76–89. https://doi.org/10.1097/GRF.0000000000000333

Stoll, K., Kubendran, S., & Cohen, S. A. (2018). The past, present and future of service delivery in genetic counseling: Keeping up in the era of precision medicine. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, *178*(1), 24–37. https://doi.org/10.1002/ajmg.c.31602

van den Berg, M. M. J., Dancet, E. A. F., Erlikh, T., van der Veen, F., Goddijn, M., & Hajenius, P. J. (2018). Patient-centered early pregnancy care: A systematic review of quantitative and qualitative studies on the perspectives of women and their partners. *Human Reproduction Update*, *24*(1), 106–118. https://doi.org/10.1093/humupd/dmx030

Wagner, K. E., McCormick, J. B., Barns, S., Carney, M., Middleton, F. A., & Hicks, S. D. (2019). Parent perspectives towards genetic and epigenetic testing for autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *50*(9), 3114–3125. https://doi.org/10.1007/s10803-019-03990-6

Wu, S., Wu, F., Ding, Y., Hou, J., Bi, J., & Zhang, Z. (2017). Advanced parental age and autism risk in children: A systematic review and meta-analysis. *Acta Psychiatrica Scandinavica*, *135*(1), 29–41. https://doi.org/10.1111/acps.12666

Yee, L., & Simon, M. (2010). The role of the social network in contraceptive decision-making among young, African American and Latina Women. *The Journal of Adolescent Health*, *47*(4), 374–380. https://doi.org/10.1016/j.jadohealth.2010.03.014

Yirgu, R., Wood, S. N., Karp, C., Tsui, A., Moreau, C. (2020). You better use the safer one… leave this one": The role of health providers in women's pursuit of their preferred family planning methods. *BMC Women's Health*, *20*(1), 170. https://doi.org/10.1186/s12905-020-01034-1