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The impact of the emergence of COVID-19 on women's prenatal genetic testing decisions

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Abstract

Objective: We conducted a study to examine the impact of COVID on patients' access and utilization of prenatal genetic screens and diagnostic tests at the onset of the COVID-19 pandemic in the United States.

Methods: We conducted telephone interviews with 40 patients to examine how the pandemic affected prenatal genetic screening and diagnostic testing decisions during the initial months of the pandemic in the United States. An interview guide queried experiences with the ability to access information about prenatal genetic testing options and to utilize the tests when desired. Audio recordings were transcribed and coded using NVivo 12. Analysis was conducted using Grounded Theory.

Results: The pandemic did not alter most participants' decisions to undergo prenatal genetic testing. Yet, it did impact how participants viewed the risks and benefits of testing and timing of testing. There was heightened anxiety among those who underwent testing, stemming from the risk of viral exposure and the fear of being alone if pregnancy loss or fetal abnormality was identified at the time of an ultrasound-based procedure.

Conclusion: The pandemic may impact patients' access and utilization of prenatal genetic tests. More research is needed to determine how best to meet pregnant patients' decision-making needs during this time.

Key points

What is already known about this topic?

- Prenatal genetic screens and diagnostic tests are a core component to the delivery of high-quality, evidence-based prenatal care.
- It is critical that pregnant patients have the information and resources to make an informed decision about a growing array of prenatal genetic screening and diagnostic testing options.
- In the decision-making process, pregnant patients commonly weigh the risks and benefits of gaining genetic information about the fetus with the risks and benefits of the available screens and diagnostic tests.

What does this study add?

- The pandemic has led to significant changes in healthcare delivery and insurance benefits for prenatal genetic testing, raising key questions about how pregnant patient are weighing

the risks and benefits of the available prenatal genetic screening and diagnostic testing options against the risks of COVID exposure by presenting to a healthcare facility for testing.

- COVID-19 appears to impact how women view the utility of prenatal genetic testing, including how they weigh the risk and benefits of prenatal genetic screening and diagnostic testing in addition to when in the pregnancy they may elect to undergo testing.
- The COVID-19 pandemic has resulted in increased levels of concern and anxiety that may be encountered by pregnant women in the testing process, raising awareness of the need for additional resources to support patients' decision-making during the pandemic.

1 | INTRODUCTION

Prenatal genetic screening tests and diagnostic tests (collectively referred to as prenatal genetic tests in this manuscript) are a core component of delivering high-quality, evidence-based prenatal care.[1–4] This includes prenatal genetic screening tests performed by analyzing maternal serum or ultrasound and diagnostic tests performed by amniocentesis or chorionic villus sampling.[2] Prenatal genetic tests are highly time-sensitive as delays can have significant implications for obstetric outcomes.[5,6] Thus, it is critical to understand if and how the pandemic may affect patients' ability to access prenatal genetic tests in an informed and timely fashion during this time.

It is currently unknown if and how the COVID-19 pandemic may affect pregnant women's decision-making about the use of prenatal genetic tests. A rapid and massive response to the virus took place across healthcare systems, with telehealth implementation as a core component of these changes to mitigate the risk of viral exposure among patients, healthcare providers, and communities.[7] This approach helped maintain prenatal care delivery while avoiding the possible risks associated with an in-person visit, a strategy particularly relevant to pregnant patients because of the known and unknown implications of COVID-19 for maternal and neonatal outcomes.[7] Yet, in-person visits are required for those patients who elect for prenatal genetic testing. The decision to proceed with testing requires the patient to have a blood draw or ultrasound-based procedure. These processes entail presenting to a healthcare facility and breaking social distancing to be in close proximity to a clinician performing the procedure. How pregnant patients will consider the risks of COVID exposure in their decisions about if to undergo testing, what kind of test to use, and when to have testing performed are unknown.

Given the potential effects of COVID-19 on maternal and neonatal outcomes and the importance of prenatal genetic testing for the delivery of high-quality prenatal care, we conducted a study to assess the pandemic's onset on women's decision-making for prenatal genetic testing. This time frame is significant as it represents the rapid influx of new information, policies, and procedures about the virus and the pandemic. These data are critical to developing COVID-19 strategies for the delivery of prenatal care that reflect pregnant patients' decision-making needs as they navigate the fast-paced and novel changes associated with the pandemic.

2 | METHODS

All research procedures were approved by the Institutional Review Board of the Cleveland Clinic Healthcare System. Participants were 18 years of age or older, English speaking, received outpatient obstetric care through Cleveland Clinic Healthcare System, and had a viable intrauterine pregnancy. We recruited pregnant women at outpatient centers within Cleveland Clinic Healthcare System between May and July 2020. This is a major healthcare system in Cleveland, Ohio that has over 10,000 deliveries a year. We selected this timeframe as it reflected the onset and first major wave of the pandemic in United States and Ohio (Figure 1). For reference, there were an average of 564 cases per day at the start of data collection in May, which doubled to roughly 1270 cases per day at the end of data collection in July.[8] During this time, telehealth was instituted across the healthcare system and, while encouraged, not required.

Participants were contacted by means of a recruitment letter. The recruitment letter indicated if the women were interested in sharing their knowledge and opinions of decision-making surrounding prenatal testing in light of the COVID-19 pandemic, to contact the research team for participation. Recruitment was structured to seek input from two groups of women who represent patients at different significant time points in pregnancy. One group included women in the first trimester of pregnancy to capture prenatal care needs, preferences, and experiences at the onset of the pregnancy and prenatal care delivery (Group 1). A second group included women in the second trimester, who had already considered or undergone prenatal genetic screening or diagnostic testing at the time of the interview (Group 2). Recruitment was continued until thematic saturation was reached.

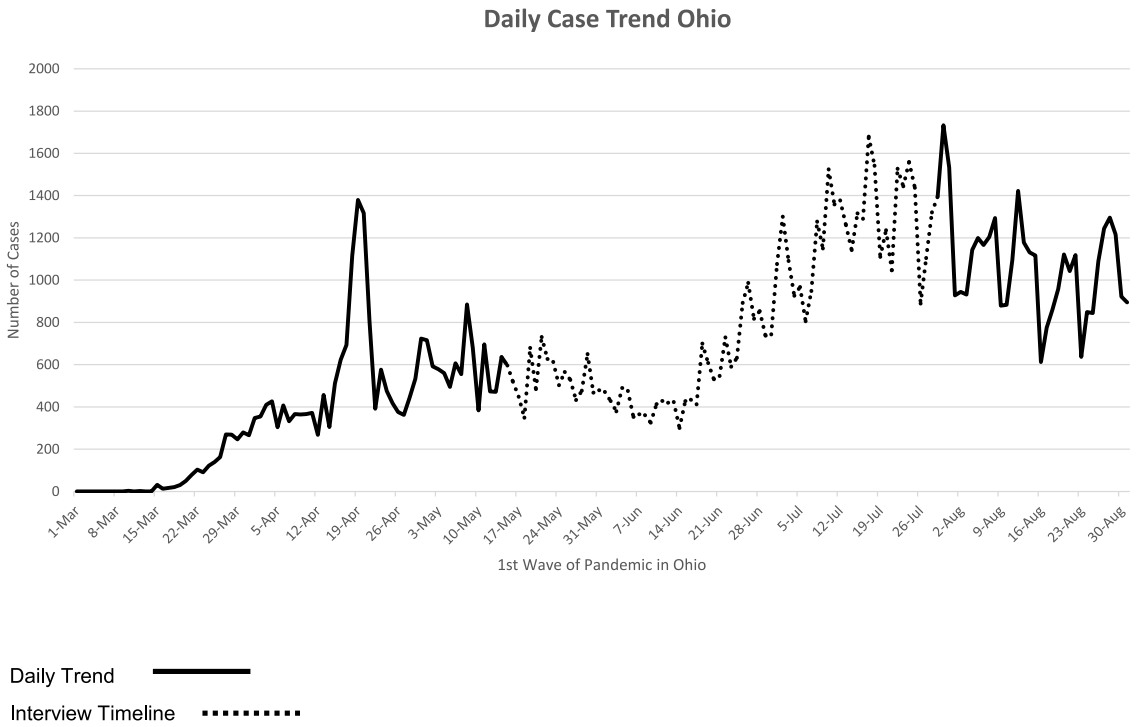

FIGURE 1 Trends in COVID cases during the study timeline

After an informed consent process, each participant participated in a telephone interview to maintain consistency with the healthcare system's recommendations for social distancing and patient contact for research purposes at the onset of the pandemic. Interviews were conducted by a member of the research team using a structured interview guide containing questions about knowledge and perception of the COVID-19 pandemic and the impact on their prenatal care (Appendix S1). Items specific to prenatal genetic testing inquired about participants' baseline perceptions of the benefits and limitations of screens and diagnostic tests and how they would weigh these risks and benefits against the potential risks of COVID-19 exposure by presenting for testing procedures. This guide was developed in conjunction with content experts in obstetrics, clinical genetics, medical decision-making, patient experience, and maternal-fetal medicine. With the participants' permission, the interviews were audio recorded for analysis.

Analysis was approached as an iterative and progressive process of data immersion, coding, memoing, and theme identification, an inductive process consistent with Grounded Theory.[9,10] We identified content domains and categories in transcripts to create a coding tree used to organize the data. A companion codebook was created to serve as a reference for the analysis. The transcripts were coded by two members of the team (R. Farrell and M. Pierce) using NVivo (version 12). The research team held weekly meetings to identify themes by reviewing data, coding, and analytic memos to resolve any coding disagreements. Themes identified were contextualized with information about the trimester of pregnancy, gravity/parity, and previous pregnancies.

3 | RESULTS

3.1 | Demographics

We contacted 115 (first trimester) and 139 (second trimester) patients for study participation. We recruited a total of 40 pregnant women to take part in the study: 20 in their first trimester (Group 1) and 20 in their second trimester (Group 2; Table 1). The majority (36) had already undergone prenatal aneuploidy screening or intended to undergo prenatal aneuploidy screening during the pregnancy. None of the participants had undergone prenatal diagnostic testing by the time the interview was conducted. Five participants had COVID-19 testing; all tests were negative.

Qualitative analysis identified three primary themes: (1) the impact of COVID-19 on the decision to undergo prenatal genetic testing, (2) the impact of COVID-19 on the timing of prenatal genetic testing decisions, and (3) heightened anxiety with the decision to undergo prenatal genetic testing. The themes and selected quotes are presented below with data from participant Groups 1 and 2 designated as G1 and G2. Additional data are included in Table 2.

3.2 | The impact of COVID on the decision to undergo prenatal genetic testing

The decision to proceed with prenatal genetic testing during the pandemic.

TABLE 1 Demographics

Demographics of participants	Total ($n = 40$)
Age	32.25 ± 4.54
Non-AMA (<35)	27 (67.5%)
AMA (≥35)	13 (32.5%)
Race	
White	34 (85.0%)
Black	4 (10%)
Asian	2 (5.0%)
Reproductive history	
Primigradiva	15 (37.5%)
Multigradiva	25 (62.5%)
Trimester of pregnancy	
First trimester	20 (50%)
Second trimester	20 (50%)
Prenatal genetic screening or diagnostic testing	
Undergone screening or diagnostic testing	36 (90.0%)
No screening or diagnostic testing	4 (10.0%)

Overall, we found that the pandemic did not significantly alter most patients' choice to undergo or defer prenatal genetic testing. Yet, it did impact how all participants considered the benefits and risks of testing and the emotional reactions they experienced in the process. Participants were aware of the possible risks of SARS-CoV-2 exposure by presenting for testing and the uncertainties of COVID-19 for pregnant women and newborns. These were factors they weighted in their decision-making process. However, the concern for COVID-19 did not often take priority in decisions to seek testing. As one participant stated, "*The reward greatly outweighed the risk*" (G2-10).

Most participants viewed the benefits of learning about the fetus through prenatal genetic testing as greater than the risk of potential exposure to the virus in the process of undergoing testing. The reasons for those benefits fell into two broad categories. For one group, the benefits of prenatal genetic testing remained unchanged despite the pandemic. These women sought information so that they could make the decisions they felt were most appropriate for the future child and their family. As described by this participant:

> *"So, it [COVID-19] wasn't a deterrent because I wanted to have the test done more than I worried about getting COVID or giving COVID to other people"* (G2-12). While participants were aware of the limited knowledge about COVID-19 for pregnant women and newborns, this uncertainty often did not sway decisions about presenting to a healthcare facility for prenatal genetic testing. "*I actually was not as anxious about that [COVID-19] as just anxious in general that you just want the test to be good, right? You want positive results. So, that definitely was… that's something I would've felt no matter what, pandemic or no pandemic*" (G2-18).

For another group, prenatal genetic testing presented an additional benefit: a sense of greater reassurance during a time of great uncertainty caused by the pandemic. Uncertainties extended beyond the rapidly changing landscape of knowledge about COVID-19 for the general population and pregnant women in addition to emerging policies about infection control and management. The personal, financial, and social changes of the pandemic also raised profound questions about the kind of world their child would grow up in (particularly concerning caring for a child with a serious medical condition) and how they could best help prepare for those challenges during pregnancy. Among women who had already decided to undergo testing, this notion of reassurance further justified their choice to undergo testing while taking on the risks of possible exposure to the virus. Yet, for some, the need for additional reassurance during this time tipped the decision-making scales toward undergoing testing despite pre-COVID preferences to decline any form of screening or diagnostic testing. As described by a participant, "*I do feel that it [the decision about prenatal genetic testing] would change because right now it's such an uncertain time in the world and to be able to have options to be able to know what potentially could be happening with your child kind of eases you right now because it's so scary what's going on right now*" (G1-17). For these participants, the prospect of gaining reassurance they felt could be gained from prenatal genetic testing helped to counter the uncertainties for self and family resulting from the pandemic.

3.3 | The decision to decline prenatal genetic testing during the pandemic

Yet, for some, the pandemic presented too much of a threat. For these participants, the decision for testing was either delayed or deferred, even when it may have been seen as a value before the pandemic. As described by this participant who decided against testing during the pandemic, *"If all of this [COVID-19] wasn't going on, considering this is my first pregnancy and how I am, I probably would have went through with everything possible under the sun […]. But because it's [COVID] going on, I just kind of was like, 'Do I really need this done? Do I want to go through with that and be back at another appointment?' […] 'No. I don't really want to come back. I'll just come back in a month. I'll skip it.'"* (G1-03).

3.4 | The impact of COVID on the timing of prenatal genetic testing

3.4.1 | The decision not to postpone prenatal genetic testing during the pandemic.

Participants provided important insight into if and how COVID-19 may influence the decisions regarding the timing of prenatal genetic tests.

TABLE 2 Additional qualitative data

Theme	Illustrative quotes
The impact of COVID on the decision to undergo prenatal genetic testing	"I think me finding out what's wrong is more beneficial than thinking about coronavirus. Yeah, there is a risk." (G1-08) "Above all … the health of my child … I think about the health of my child a little bit more than my health with a lot of things. So I figured this was something that was recommended for me to get done. I just wanted to get it done and make sure everything was okay with him. So, I felt as long as I was taking all the precautions, I could take to get the testing done and people around me were taking those precautions as well, and I wasn't touching my face and I was washing my hands, I felt okay going to get them done." (G2-16) "Being prepared if anything was off … especially in the current climate of things going wrong. Cause (sic) it kind of feels like everything that can go wrong is going wrong right now and just having the mindset of being prepared and knowing." (G2-02)
The impact of COVID on the timing of prenatal genetic testing decisions	"I think I would want to have it done when I need to have it done. It's normally done at a certain week and if I am at that point and have orders to do it, I would do it. The coronavirus won't stop me from doing it, you know." (G1-08). "I wasn't going to do anything with the results [referring to the prior pregnancy]. I wasn't going to terminate the pregnancy and there was also less anxiety with my previous pregnancies. In this pregnancy, I'm older. Things are going on with the world. So, I was looking for that reassurance." (G1-13) "If I get let in the building and I think there's a huge swam of people in the lab, I think I would come back at a different time" (G1-13). "I don't know what I would do. I don't know if I would terminate the pregnancy, but that is an option that you would have early on rather than later" (G1-02).
Heightened anxiety associated with the decision to undergo prenatal genetic testing	"I think it is a more high anxiety thing. […] So going anywhere is stressful, especially where there is sick people. So I guess when I have to go anywhere, whether it is for the genetic testing or not, I don't think that is a deterrent for me having to go to the hospital and considering if I was going to have the genetic testing […], or to go to the hospital to have testing done. There is definitely a level of stress that comes along with that" (G1-02) "I'm putting myself into a setting that medically maybe it wouldn't be ideal to go into if you didn't have to right now" (G2-18) "When I went for my 20-week anatomy scan, while I was waiting for the doctor to come in, I had a little moment of panic like, 'What if something is wrong and I am by myself? I have to hear this information by myself?' that was unnerving" (G2-03).

Overall, most participants discussed that they did not or would not have postponed testing during the pandemic. For some, this was due to the desire to have information about the chance of a fetal abnormalities early as possible in the pregnancy, a factor that was not swayed by the pandemic. *"I wouldn't want to push it off till later. I would want to know right away if there was an issue"* (G2-11). There were additional benefits to seeking prenatal genetic testing earlier in the pregnancy as opposed to later because of the challenges presented but COVID-19. For this participant, early testing afforded a greater opportunity plan for a child with a serious medical condition amidst the physical, financial, and social challenges posed by the pandemic:

> *"In a time of uncertainly, if you're going to have a complication or something that's going to impact what you want to do going moving forward, it might just be easier to just know it like as soon as possible. […] If I were to find out earlier and if the test can tell me definitively that something is very wrong with my pregnancy to the point where it's not going to be viable, I would rather know that and then not have to be going through a pandemic pregnant and then having to deal with that at a later date."* (G2-18).

There was also the recognition that delaying testing may not be an effective strategy to avoid the threats posed by the pandemic. As described by this participant, "*I felt like this pandemic was going to be unpredictable and was going to be a while for things to settle down anyways. I thought that the pregnancy weeks would come a lot faster than the pandemic settling down*" (G2-23).

Participants were cognizant of the potential for pandemic-related delays to access healthcare, including accessing both the personnel and the healthcare facilities required for testing. One concern participants had was that, if they did not proceed with prenatal genetic testing when it was initially offered, they might not be able to access it later due to unanticipated COVID-19-related delays. This participant reflected on her experiences during the early pandemic, *"With that [the pandemic] happening, my second ultrasound*

did get rescheduled […] So I did have a concern that, if the COVID-19 protocols increased, that [testing] would be pushed back out of the timeframe it needed to happen in, just because of more craziness and chaos that was going on outside" (G2-07). This concern also applied to participants who had already initiated testing and sought follow up testing to evaluate an abnormal result, leaving them in limbo between learning of a potential issue and obtaining the information needed to make key prenatal care decisions until a later time in the pregnancy (particularly relevant for time-sensitive maternal-fetal interventions or termination) or after birth. *"The elective appointments and surgeries were being canceled. There was [sic] less people [healthcare providers]. So, I felt like it was better to get it done more quickly"* (G2-20).

3.4.2 | The decision to postpone prenatal genetic testing during the pandemic

At the same time, some participants spoke of the intent or decision to postpone prenatal genetic testing. For some, this decision pertained to the status of the pandemic at the time of the available window for testing. This was a time with rapidly evolving information about COVID-19 in addition to shifting policies with respect to healthcare delivery and COVID-prevention among healthcare systems and communities. For this participant, the factors occurring at the onset of the pandemic would have affected decisions about test timing: *"I probably would have considered testing later, in the early spring when I was still more newly pregnant. I feel like that was right at the height of the pandemic, or at least it felt like it was […] If the option for later had been there, I probably would have gone to it later"* (G2-16). For others, the timing of testing was influenced by how they perceived the threat of COVID exposure when presenting for testing. *"If I get let in the building and I think there's a huge swarm of people in the lab, I think I would come back at a different time"* (G1-13). This was a factor that was influenced by participants' trust in the healthcare system to control infection exposure. It was also influenced by a sense of trust or distrust in the choices and actions of other patients who were in the healthcare facility at the same time to prevent COVID-19.

3.5 | Heightened anxiety associated with prenatal genetic testing

Participants who sought prenatal genetic testing despite the concerns of COVID-19 reported the anxiety they experienced in the process. Participants were conscious of the risk of exposure to the virus when presenting for testing. *"I think, for me, it was more important to get my prenatal screenings done, but I was aware of the risk I was taking"* (G2-23). For these women, the process of presenting for testing was a source of anxiety. As described by this participant, *"I want to do what's best for me. But, at the same time, my anxiety about being in a doctor's office or being in a space where I know there are potentially sick people nearby […] I didn't want to be there. It wasn't like, 'Oh, I feel so comfortable and so safe here. I want to take my time, whatever and whatever.' It was more like, 'Ok. Let's get this done so I can leave because I don't want to be there'"* (G1-03). However, many elected to proceed with their choice despite the potential concern and distress resulting from presenting for testing.

For some participants, their concern was heightened due to the location where they had to present for testing. One concern pertained to being in a healthcare facility where many other patients were seeking care and the choices those patients may make concerning infection-prevention approaches (e.g., social distancing, wearing masks). As described by this participant, *"I'm also not really thrilled about going to the lab just because I know that those are generally busier places and it's harder to control the number of people"* (G1-16). There was also concern about presenting for testing in a hospital setting where COVID-19 patients were being treated. *"I want the safety and security of being in a building where you know it's not a hospital like the outpatient setting. I just felt more comfortable with because there's not a floor above me of COVID patients"* (G2-20).

Participants discussed another significant concern: fear and anxiety of being alone during the testing process. As a result of visitor restriction policies, many participants underwent ultrasound-based screening and diagnostic testing procedures without a partner or support person. This was a concern for women who wanted to share the experience of seeing the fetus with a partner. Yet, for many, the concerns pertained to the possibility of learning about a fetal abnormality or demise by themselves during periods when visitor restrictions were in place. As described by this participant, *"The nuchal translucency and the blood draw, the screening test… for that I was still pretty nervous about the health of the fetus. I was more worried about finding out by myself"* (G2-23). For participants in this study, the fear of being alone was unexpected—something most did not anticipate or fully realize the implication of until the time of the ultrasound appointment.

4 | DISCUSSION

The COVID-19 pandemic has dramatically altered the delivery of prenatal care. While telehealth quickly replaced in-person prenatal care visits, the utilization of prenatal genetic screens or diagnostic tests continues to require patients to present to a medical facility in person. An effective COVID-responsive healthcare delivery model must ensure that patients can access accurate, timely, and patient-centered information about their testing options. In addition, for those patients who elect to proceed with screening or diagnostic testing, it is critical that patients feel that they can safely access those tests amidst evolving information about infection control policies. However, a greater challenge is ensuring these resources are in place while continuing to overcome barriers to patients' informed decision-making about prenatal genetic testing observed prior to the pandemic.[11,12] Given the importance of prenatal genetic testing in prenatal care delivery, this study examined whether and how patient concerns about COVID-19 at the onset of the pandemic may impact access and utilization of prenatal genetic tests.

Our study sheds light on two major factors that may interfere with patient's ability to make informed decisions about their prenatal genetic testing options and access these tests during the pandemic. First, the study findings highlight the increased complexity of the prenatal genetic testing decision-making process during the pandemic. We found that during the pandemic, participants expanded the number of risks and benefits they weighed in the decision-making process, adding to the existing set of risks and limitations already associated with prenatal genetic testing. For instance, participants incorporated the possible risks of exposure to SARS-CoV-2 by presenting for testing to the decision-making process. The risk of COVID did not represent one single concern. Instead, COVID presented a series of additional risks and implications to consider. This included not just the risks of exposure for themselves and the pregnancy but, more significantly, the risks, implications, sense of culpability, and feelings of regret if their children and other adults in the family became ill as a result of the decision to present to the healthcare facility for testing. These risks, in addition to those associated with prenatal genetic testing, presented an array of different implications for the pregnancy and family.

The decision-making process also entailed an expanded view of the potential benefits of prenatal genetic testing. Participants in this study sought prenatal genetic testing as a source of reassurance during the pregnancy, a finding consistent with other studies.[13–15] Yet, for participants in this study, there was a greater urgency for reassurance in response to the numerous medical, personal, financial, and social uncertainties caused by the pandemic, something that some felt could be gained from prenatal genetic testing. In fact, some were interested in gaining as much genetic information about the fetus as possible in an effort to obtain the degree of reassurance they felt they needed during this time. This reassurance was seen as an additional benefit that they incorporated into decision-making. For those who underwent testing, this consideration provided further justification for their decision. For others, this perceived benefit led to the decision for testing when they would not have considered it prior to the pandemic. Notably, there was no discussion of the uncertainties that can come with prenatal genetic testing. Yet, this is an important consideration in the decision-making process, particularly in the post-test setting when potentially unexpected or uninterpretable results may be received.[16,17] This finding raises the question of how we can help patients balance the reassurance they seek during the pandemic with a realistic view of the questions that may not be answered by prenatal genetic tests or may arise in the testing process.

Key drivers in the decision-making process were notions of responsibility and obligation to make choices about prenatal genetic testing during the pandemic that would best benefit a newborn and family. Other authors have observed this decision-making factor, a concept often referred to as the "Good Mother" which describes a self and society-imposed sense of obligations for pregnant women to take on or avoid risks for the benefit of the child.[18,19] Our study highlights that this factor and the pressure to "make the right decision" was further amplified during the pandemic when patients considered the risks and uncertainties that may come with the decision to utilize prenatal genetic tests, defer them to a later time in the pandemic, or decline testing altogether during the current pregnancy.

A second major factor to impact the decision-making process was anxiety. It is recognized that increased levels of anxiety and distress can negatively affect the decision-making process, presenting challenges for obtaining medical information and processing it in a way, that is, consistent with one's values and preferences.[20,21] Studies have shown that pregnant patients frequently experience anxiety and uncertainty during prenatal genetic testing.[13,22,23] Yet, the COVID-19 pandemic has provoked a series of other concerns for pregnant women considering prenatal genetic testing, sources of anxiety that have not been fully identified with past infectious disease threats.[24,25] As described above, the pressure to make "the right decision" weighed heavily on participants. In addition, there was concern about the ability to access the healthcare system and tests in a timely manner due to both disruptions in healthcare provision and the feeling of trust and safety in the clinical environment. As the COVID-19 pandemic has led to unprecedented changes in healthcare delivery, it is not possible to compare these concerns with pregnant patients' experiences considering other infectious threats. Yet, the sequelae of delays and barriers to prenatal care and prenatal genetic tests are well-documented apart from the pandemic.[5] Such issues are particularly significant among those who already face barriers to early prenatal care,[6] raising the concern of further exacerbation of inequities and healthcare disparities resulting from COVID-19.[26,27] Given these concerns, it is critical to ensure that preventable delays to patients' access prenatal genetic test access are avoided.

Another source of anxiety was noted: the fear of being alone and without their partner or support person when a fetal abnormality or pregnancy loss was diagnosed. Some participants found themselves undergoing an ultrasound-based procedure without their partner as a result of visitor restriction policies. For many, this was an unexpected feeling, something that they did not realize until the testing procedure was taking place. This is significant for several reasons. Studies show that many pregnant women elect to include a partner or other support person in the prenatal genetic testing process and several other aspects of prenatal care, a finding also noted among our participants.[28–31] There are emerging data during the pandemic about the impact of separation of a pregnant woman from her partner during labor and delivery,[32,33] in addition to data about patients' decision-making during COVID-19 when separated from their families at the time of acute medical decision.[29,34] While such research is ongoing, our study demonstrates that it is also important to investigate the impact of isolation at the time of prenatal genetic testing procedures for pregnant women and their families.

These findings of increased decision-making complexity and associated anxiety highlight the need for further research focused on ensuring that patients can make informed, value-reflective decisions during the current pandemic and future similar public health emergencies. While this study sheds light on patient and healthcare-based factors that impact access to prenatal genetic tests, other important changes have taken place at the level of healthcare systems and policy that are not reflected in our findings and may also further

complicate the informed decision-making process. For instance, some insurers have changed their coverage benefits or preauthorization requirements for cell free fetal DNA screening in response to COVID.[35–37] As a result, a subset of patients will now have access to a larger set of prenatal genetic testing options, some of which they may not have considered prior to presenting for prenatal care. While such changes will expand access during the pandemic, they also raise additional questions about how to best prepare patients for changing prenatal genetic testing options amidst the pandemic and future public health emergencies that cause major disruptions in the lives of patients and society.

As a first step, it is important to recognize factors resulting from the pandemic that may interfere with pregnant patients' ability to make informed decisions about their testing options. This recognition will pave the way to develop infrastructure and tools to support patients' decision-making during the pandemic. Such resources may include identifying members of the healthcare team who can follow-up with patients after the visit, help answer questions, and support the shared decision-making process. This follow-up could also include a mechanism to assess patients' anxiety in the interval between the clinical encounter, particularly around seeking prenatal care and prenatal genetic testing during the pandemic. Given the emerging data regarding increased levels of psychological distress among pregnant women as a result of COVID-19[38,39] and the evidence of the implications of anxiety and mental health on prenatal and postpartum outcomes,[22,23,40] it is critical to mitigate the impact of compounded stressors that could impact decisions, test-associated decisional satisfaction, and obstetric outcomes during the pandemic.

While this study provides insight into the impact of COVID-19 on patients' prenatal genetic testing decision-making, there are limitations to consider. We utilized qualitative methods to identify emergent themes among a sample of patients at a single healthcare system. Thus, our sample size is limited, as is the racial and ethnic representation among the sample population. Our sample may not have included women's perspectives who may have elected not to present for prenatal care during the pandemic. Further qualitative and quantitative research is needed to continue to explore the factors that may impact patients' access to prenatal care and prenatal genetic testing during this time.

5 | CONCLUSION

Our study sheds light on the impact of COVID-19 on patients' decision-making needs and preferences during the uncertainty of the pandemic. These findings demonstrate the need for effective tools and strategies to ensure that patients' informed access to prenatal genetic tests is not impaired by the pandemic. This is significant as such barriers that emerge during the time period of the pandemic may have a long-term indelible impact on women, their families, and their future family building decisions. As a next step, it is critical to further understand the nature, extent, and impact of COVID-19 on women's ability to access prenatal genetic tests in a timely and informed manner, with implications not just for patient care during the current pandemic and future public health events that cause major disruptions in healthcare delivery.

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CONFLICT OF INTEREST

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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