



Attitudes of Filipino parents of children with Down syndrome on noninvasive prenatal testing

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Abstract

Globally, there has been an increasing uptake of noninvasive prenatal testing (NIPT). In the Philippines, the test is currently available through private laboratories and can be availed by families who can afford the out-of-pocket cost. In a country where elective termination of pregnancy is not an option, the question arises as to the relevance of this testing, even among health professionals. This is an exploratory qualitative study that explored the attitudes of Filipino parents of children with Down syndrome (DS) toward NIPT using thematic analysis of in-depth interviews. Study participants acknowledged the value of NIPT in providing early diagnosis and, subsequently, emotional, mental, spiritual, and financial preparation. This said, they also emphasized that such early detection may cause anxiety and even thoughts of termination for some, despite abortion being against the law and predominant religious beliefs. For those undergoing NIPT and receiving positive results, study participants highlighted the need to receive proper and nonbiased counseling from both health professionals and parents who have children with DS.

Keywords Down syndrome · Noninvasive prenatal testing · Parents · Qualitative · Phenomenology

Introduction

Down syndrome (DS) is a chromosomal abnormality that results from the presence of a third copy of chromosome 21 and is the most common genetic chromosomal disorder worldwide. The birth prevalence ranges from 1:319 to 1:1000, with a higher risk being associated with the older

maternal age group (Akhtar and Bokhari 2020). It is the top reason for genetic consultation in the Philippines (Padilla and Cutiongco-de la Paz 2016). Diagnostic tests using chorionic villi sampling (CVS) or amniocentesis can confirm the diagnosis prenatally but are invasive and carry a risk of abortion of the fetus when the procedure is done (Messerlian and Palomaki 2015; Rink and Norton 2016; Wilson et al. 2013). On the other hand, prenatal screening tests for DS identify whether a fetus has a low or a high chance of having a condition. The newest type of screening, which is called NIPT, is performed from 10 weeks of pregnancy and involves the measurement of circulating cell-free DNA (cfDNA) in the maternal blood (Messerlian and Palomaki 2015; Rink and Norton 2016; Wilson et al. 2013). The accuracy of the test varies among the conditions and the population being tested but has been reported to be as high as 97% sensitivity and 99.9% specificity for DS in high-risk obstetric populations (Taylor-Phillips et al. 2016). Compared to first-trimester screening, NIPT or cfDNA screening has higher sensitivity for detection of DS, a lower false-positive rate, and a higher positive predictive value (Norton et al. 2015), with the accuracy even better for the high-risk obstetric population (Taylor-Phillips et al. 2016). There has been an

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increasing uptake of the NIPT since its release to the global market (Chetty et al. 2013).

Previous studies have explored the attitudes of different sectors regarding NIPT showing that the test has been generally viewed as favorable by healthcare providers and expectant women for its accuracy and safety (Lewis et al. 2013; Van Schendel et al. 2017). Parents of children with DS expressed that having NIPT done allowed them better preparation and provided them with a positive birthing experience because they were already able to grieve and deal with the diagnosis before the birth (Kellogg et al. 2014; Van Schendel et al. 2017; Valentin et al. 2019). Some also acknowledge that screening for associated health problems in the fetus such as cardiac defects can also be done early, which will be advantageous for anticipatory care (Kellogg et al. 2014). Parents also reported that they value the ability to make personal choices but felt that the prenatal screening and diagnostic procedures were presented to them by providers as routine rather than optional tests (Kellogg et al. 2014; Valentin et al. 2019). Some mothers felt pressure to terminate with a positive result, and some also felt that there was not enough information available about DS and living with DS during pregnancy, or that the information provided was incorrect or very technical, biased, and negative, despite greatly improved health outcomes for DS over the years (Inglis et al. 2012; Kellogg et al. 2014; Van Schendel et al. 2017; Valentin et al. 2019). They suggested that more up-to-date information is given, and those expectant parents should also be able to hear from support groups or other parents of children with DS so they can have a better picture of what raising a child with DS is like (Van Schendel et al. 2017; B. G. Skotko 2005).

As NIPT is seen to have less barriers (more accessible and acceptable) compared to the previous testing algorithm, it is also feared that screening will be normalized, which will lead to less acceptance of DS in society (L. Bryant 2014; Van Schendel et al. 2017). Parents fear the rise in terminations, increase in discrimination, and reinforcement of society's negative attitude toward those with disabilities (Kellogg et al. 2014; Valentin et al. 2019).

In the Philippines, the index of suspicion for the diagnosis of a chromosomal abnormality is commonly raised prenatally through a congenital anomaly scan during the second trimester of pregnancy (Abarquez et al. 2009). However, NIPT is already available, and there are currently at least three laboratories that offer noninvasive prenatal testing in the country, with prices ranging from 24,500 to 55,000 Php or 491–1103 USD (“prenatal peace” n.d.; “noninvasive prenatal testing” 2020; “panorama noninvasive prenatal testing” n.d). There are two characteristics of the Philippines that may make the situation regarding prenatal testing unique. First, the Philippines is a predominantly Catholic country, with 80.6% of the population identifying as Roman

Catholics (Bueza 2015). Secondly, termination of pregnancy is not allowed by law in the country, and prenatal diagnosis is aimed toward anticipatory guidance and preparation for the birth of a child with birth defects (Cutiongco-de la Paz 2006). There have been contrasting views on the ethics of offering to screen when termination is not possible (Baltantyne et al. 2009; Truitt 2015). Mothers of children with a prenatal diagnosis of DS who chose to continue with the pregnancy share the perspective that the utility of the test lies in allowing preparation for a child with special needs and being able to obtain resources and knowledge prior to the birth (Hurford et al. 2013). It then becomes a question of balancing the benefit of preparation versus the anxiety it may bring (Michie 2020).

This study aimed to explore the attitudes of Filipino parents of children with DS toward noninvasive prenatal testing (NIPT) in order to better understand the benefits and drawbacks of NIPT within the Filipino sociocultural, legal, and healthcare contexts.

Methodology

Study design

This study used a qualitative research design drawing from phenomenology and symbolic interactionism frameworks. Phenomenology is a research method that aims to develop insights from the perspectives of those involved by asking questions such as “What is this experience like?,” “What does this experience mean?,” and “How does the lived world present itself to the participant?” commonly use informal one-to-one interviews that are then transcribed and analyzed for themes and meanings so that the experience can be understood (Mapp 2008; Rodriguez and Smith 2018). Symbolic interactionism looks at how one, individuals act based on the meaning they give to things, two, that the meaning is different for each person based on their past experiences and three, how this meaning can be modified as they go through experiences in life and is significant to the participants' individual experience about DS, which may impact on how they view prenatal testing for the genetic condition (Dennis and Smith 2015). The consolidated criteria for reporting qualitative research (COREQ) checklist (See Supplementary Information 1) was used for the comprehensive reporting of this study (Tong et al. 2007).

Study setting and population

Participants were recruited through a purposive sampling method (Clarke and Braun 2013). An electronic recruitment poster was posted on the support group Facebook page of the Down Syndrome Association of the Philippines. The

interviews were conducted from February to April 2021. Participants were at least 18 years of age, Filipino, and had a child diagnosed with DS. Having another person with a disability in the household other than the child with DS was considered the sole exclusion criterion. The study received ethical approval from the University of the Philippines Manila Research Ethics Board, and all participants gave informed consent to participate. Recruitment continued until the point of data saturation.

Data collection procedure

Participants' sociodemographic information was obtained using a short online questionnaire. Online one-to-one semi-structured in-depth interviews were then conducted with the participants. This allowed for social distancing while still allowing nonverbal communication, as this study was conducted during the time of a coronavirus pandemic. The format also allowed participants to be interviewed at a time convenient to them (Iacono et al. 2016). Guide questions were formulated by the first author based on the study objectives and a review of related literature (Inglis et al. 2012; Kellogg et al. 2014; Valentin et al. 2019; Van Schendel et al. 2017). The questions were open-ended, with an opportunity for probing and follow-up questions in response to the content throughout the interview process (Supplementary Information 2).

The interviews were conducted by the first author, a female clinical geneticist, who underwent training in planning and conducting qualitative interviews. Three participants had previously been acquainted with the first author through attendance in Down syndrome seminars. No relationship was previously established between other participants and other investigators. Participants knew about the researcher being a geneticist but also that the research is being done as an academic requirement. The interviews were conducted online using the video conferencing software application of the participant's choice (Zoom, Google Meet, or Messenger) and lasted between 23 and 69 min (an average of 38 min per interview). The questions were given in English or Filipino based on the preference of each study participant. To ensure privacy, the interviewer was at her own residence and conducted the interviews when there was nobody around to hear what the informant was saying, and interviewees were told that they can choose a time when they can take the call without being heard by other people at home. Codes were assigned to each participant for confidentiality. Interview sessions were video or audio recorded with consent, with notes taken right after the interview and during the review of the recording.

The participants were given a brief explanation of the test characteristics of NIPT via a short slideshow presentation after obtaining the baseline awareness that respondents have regarding NIPT but prior to proceeding to questions about their opinions regarding it. The presentation was developed by the primary investigator from related literature but adapted to the Philippine setting (Kellogg et al. 2014; Smith et al. 2018; Van Schendel et al. 2017).

Data processing and analysis

The in-depth interview recordings were reviewed within 24 h and transcribed verbatim in the original language of the interview by a research assistant and/or by the primary investigator. All transcriptions were returned to the participants to validate for accuracy and increase the credibility of the data. There were only very minor corrections to some of the transcriptions, and there were no transcription errors that affected the ideas shared.

Data was analyzed using a thematic content analysis method with Dedoose, a web application for qualitative and mixed methods research. The first author again went through the recording and transcripts, carefully reading transcript line by line and generating preliminary codes. These initial codes were organized into potential themes, which were then sorted into major and minor themes. The investigator repeatedly carried out data collection and data analysis, until thematic saturation was achieved. Representative statements were selected for the categories developed by the researcher to explain the opinion under each theme. The selected excerpts were then translated to English and back-translated by an independent native speaker to ensure accuracy of the translation. Codes were verified independently by all the authors, who have considerable experience and training in qualitative research. The coding tree is available in Supplementary Information 3.

Results

Among those who expressed interest in joining, all participants gave consent, and no participant dropped out in the process. There were a total of 16 individual parents who joined the study—9 mothers and 7 fathers. The background characteristics of the participants are listed in aggregate data to safeguard their privacy (Table 1). Out of the participants, two had received findings in the prenatal tests suggestive of DS—one through nuchal translucency and one with NIPT. However, the mother who had a positive nuchal translucency test was told that it had normalized and they no longer expected a child with DS.

Table 1 Demographic data

Characteristic	
Sex	
Male	7
Female	9
Mean age of respondents, years	47
Age of respondents at diagnosis of child, years	
Mean (range)	33 (14–50)
Median	35
Level of education	
Low (elementary, some high school)	0
Medium (finished high school, vocational, some college)	7
High (finished college)	9
Religion	
Roman Catholic	11
Christian, not Catholic	5
Maternal age at birth of child	
Mean (range)	33 (14–44)
Median	32.5
Gender of child	
Male	8
Female	8
Number of other children, mean (range)	2 (0–4)
Number of children with DS	1
Mean age of child with DS, years (range)	13 (1–29)
Prenatal screening done during pregnancy of child with DS	
Yes	2
NIPT	1
Nuchal translucency ultrasound ¹	1
No	14
Diagnosis of DS	
Prenatal	1
At birth	15
Marital status	
Married	12
Single	1
Separated	3
Total household income	
Low-income (Php 23,000/month and below)	8
Mid-income (Php 23,000–140,000/month)	2
High-income (Php 140,000 and above)	6
Geographic location	
Luzon	15
Visayas	0
Mindanao	1

¹The mother was later told that this had resolved; hence, they no longer expected DS during the pregnancy.

Thematic analysis

The major themes that were derived from the interviews with the participants are discussed here with representative quotes

from the study participants. Names have been removed for anonymity.

Theme 1: experience at diagnosis and journey to acceptance

Impact of diagnosis

The parents felt a wide range of emotions upon finding out that their child had DS, with the most common reported ones being feelings of anxiety, grief, and wondering why this happened to them. There were reports of bitterness, anger, and resentment in general and even toward the child.

“Of course, it was disbelief. And hope that it was just a dream. And I was worried about the future. The worst thing was thinking, “What will happen? What will happen to our child?” Maybe also the feeling that the baby boy, the boy that we had waited for a long time, wasn’t the boy that we wanted. That was nowhere in our world... And I wished for him to die. I did, I did. Because it was not easy... But we got a lot of support from family and friends who came.” - Mother 8, no screening done

Other parents were initially in denial until they received the confirmatory result of the chromosomal analysis or until they saw that their child really was not developing at par with age. Some felt helpless because they knew the diagnosis and knew that it was not something that can be changed.

After a positive NIPT result, a father initially felt helpless after the obstetrician had told him and his wife about the possibility of DS in the 8th month of gestation:

“I remember it being so bad. After leaving the clinic, I was speechless. My wife was crying... I felt like I had just received a sentence. It was as if I had been sentenced to something I had no control over. It was hard, it was difficult. Because we know about it, but we couldn’t do anything.” - Father 5, positive NIPT

However, his emotions changed at the time of the birth of their child a month after and he attributed this to his trust in God.

“That was the moment that I felt that the Lord told me not to worry, that <daughter’s name> is mine. And that time I felt that the Lord hugged me. That’s what I held on to at that time when my daughter was born. That time I had to bring her to surgery. All her 2D echo tests. I was feeling “Lord, you gave this to me. You will help us here.” So that was what I was feeling like—I wasn’t scared that time. “Lord help us go through this one because you gave it to us.” - Father 5, positive NIPT

One mother focused on the goal of the management of the baby and initially put up an emotional wall between her and her child due to fear.

“On the outside, people saw me as very strong, okay, and nurturing. But deep inside, I was struggling because aside from that diagnosis of Down syndrome, my fear was of losing him because of the three holes in his heart that was my major concern. So, I detached myself, I really do love my baby, but I somehow detached myself because of fear” - Mother 5, positive nuchal translucency test

The parents all remembered the initial disclosure of the diagnosis from their doctors, and how DS was explained to them. Almost all parents received the diagnosis in a straightforward manner from their obstetrician or pediatrician. Most parents were told that their child has a condition called DS based on the physical characteristics seen in their child. However, the majority of the parents did not receive further information about DS upon diagnosis, whether the diagnosis was made at birth or a prenatal test result was available. After learning about the diagnosis, several parents learned more about the condition by doing their own online research, by joining seminars, or getting information from other parents in the support group.

One father shared how they gathered information while they were preparing for the birth.

“Never in our family history did we have Down syndrome. We had to read a lot of articles to the point that sometimes we stopped reading them because it was very depressing... we really had to do our own research on what Down syndrome is. We asked questions from the OB, but the focus there was really on the pregnancy plan of my wife. We were also preparing to get a neonatal doctor for my daughter. But it was really more of the action step, not really what the condition was about.” - Father 5, positive NIPT

With the positive NIPT, they felt that they were prepared and moving toward acceptance at the time of the birth of their child.

“Well, you will never be ready, but financially, emotionally, physically, even spiritually, we were kind of prepared knowing that our daughter has Down syndrome.” - Father 5, positive NIPT

However, for the rest of the respondents, the journey to acceptance began after birth. One father shared that the most important step was getting information about the condition.

“The mindset that my wife and I had at that time was that we can’t remain afraid or nervous because it will affect first and foremost the baby and then our fam-

ily. We cannot live this way in fear. So we researched, and basically we didn’t want to prolong the agony. We wanted to get out of the situation as quickly as possible. We don’t want to stay here in the dark for our own good. So we asked. When we found out the truth, what Down syndrome is, we understood, what we should do, we really had relief as a family and as parents.” - Father 3, no screening done

Medical and behavioral challenges

The parents reported the journey of having a child with DS as a challenging one. Among the difficulties encountered are complex medical problems and behavioral concerns.

“She was in the NICU and had congenital hypothyroidism. There were three holes in her heart. When she was in the NICU, she needed oxygen. She had many devices attached to her.” - Mother 6, no screening done

Even after overcoming the initial difficulties, they still shared concerns about the medical conditions of adulthood and about the future.

“I feel like I’m scared because, of course, when you’re the parent of someone with a disability, of course, you’re also thinking, “When I get older, how will he be?” I think I get more emotional as he grows up, as I get older as well.” - Mother 4, no screening done

Support systems

The participants reported receiving helpful support from their family members and friends. The most commonly mentioned support provided by family members is helping with domestic tasks, particularly taking care of the child with DS and doing household chores to give the parents respite. One father described how his entire family helps out in taking care of his child:

“We get help from my in-laws, my parents, my brother, my wife’s sibling, my brothers-in-law, sisters-in-law, and mother-in-law. We help each other. So, it’s okay.” - Father 1, no screening done

Joining a support group was a universal theme in the majority of the interviews. Aside from receiving medical information about DS, the parents also appreciated being guided on what steps to take to help their child develop well. They shared how they are able to gather strength from other parents because they know what each one has been going through.

“Especially when we attended the early intervention seminar of the Down Syndrome Association of the

Philippines. It was really a big relief for us that we had met new friends. We realized we are not alone; there are many of us. There are families ahead of us who are there, you can feel their sincerity that they're here to help and to guide and be your friend. That alone was really liberating for us." - Father 3, no screening done

Some parents mentioned the eligibility for the person with disability (PWD) card as a form of government support. A few also reported that they were able to access therapy sessions for free or at a subsidized cost ("our mayor is very loving to special children. Occupational therapy is free. Speech therapy is free."—Mother 7, no screening done). However, some also felt that government support is not enough for parents of children with DS ("there's so little government support here as it is. I feel like you're pretty much on your own."—Mother 9, no screening done), thus highlighting that there is inconsistency in the quality of disability support available through the government.

Coping

Through the interviews, the parents shared positive attitudes that appeared to be helpful in their coping and overall growth in their journey as parents, growing in confidence after getting through the initial stage of navigating the medical complications. They shared manifestations of how they unconditionally love and are loved by their child with DS.

"When your child is born, like what we have experienced, right? After all the things that we've gone through. My child's medical record is this thick. (Shows a hand span) Maybe even more. Because it has piled up through the years. In spite of that, you can't think of aborting or whatever or backtrack and say I wish it didn't happen. Because you love your child. Because your child has eyes, has a heart, and she smiles." - Father 6, no screening done

The participants also related how proud they are of the accomplishments of their children.

"Now that she's bigger, she's a dancer, a member of the city's dance group. She leads Zumba, and I'm happy because she is able to share what she has... And she's working even if she has DS. She is working and she is a regular employee." - Mother 3, no screening done

Some parents revealed how participating actively in support groups, which included activities like spreading awareness about DS and providing emotional support to other parents, has been therapeutic for them as well and was a way of "paying it forward" in appreciation of the support that they received from other parents in the past.

"We're thankful that we have not limited it to ourselves, that we're able to reach out to other families. And that we can tell them that we've been through what they are going through now and that we can also challenge them. Hopefully we can do this for a long time." - Mother 8, no screening done

The parents shared that they considered having a child with DS as a blessing because of how they bring joy and touch the lives of the people around them.

"I feel that one special child can touch the hearts of 800. Because they change the lives of a lot of people, the people around them. That's the way we look at it, so should we change them? Maybe not." - Father 6, no screening done

One parent verbalized his commitment to take care of his child despite the overwhelming emotions that he felt at diagnosis.

"After I recovered a bit, I went back to my daughter in the nursery. I told her, "I promise you, whatever this Down syndrome is, I will never leave you. We will go through this together." That's my promise to her." - Father 3, no screening done

God's will and providence

Throughout the interviews, a recurrent theme was the strong faith in God that all the participants had. The participants shared how they turned to God in prayer during the difficult times in their journey. Furthermore, most of the parents believed that they had a child with DS because it is the will of God, and that God has a purpose for allowing it to happen. They shared that believing in this also gave them confidence to face the challenges because they felt that God knew that they are capable of handling them.

"He has a purpose for me. Among so many parents, why was it given to me? There is a reason why... Now I can tell myself that his purpose is there because I learned so much. I also helped a lot of other people when I was given a child like this... The Lord gave her to me." - Mother 6, no screening done

The parents believed that the Lord has also equipped them to care for their child by giving them blessings and miracles in the course of their journey.

"I guess it goes back to the providence of the Lord because He allowed it. The schooling, the therapy sessions, we feel blessed because He provided it for us. Not only financially but also the support system. Even

the good doctors, the specialists and other families as well.” - Father 5, positive NIPT

To sum up the experiences of the parents, they shared that despite all the challenges, they felt positive about the journey of their family.

“It’s been difficult. It has been a long journey. It has been filled with so many colorful and rich experiences, not all are good. We’ve had adventures that were really scary. I guess this was something. That’s why we can go on and on and talk to you and share our experience. Because we think that it has been a good journey. Would I want to do it over again? Maybe not. I’m old already. But I’d say it’s good. It’s good, it was difficult. Of course, we love our child with all our heart.” - Mother 8, no screening done

Theme 2: NIPT is available, simple, and safe, but not affordable

Less than half the participants were aware of prenatal testing for DS prior to the interview, with only a few particularly knowledgeable on NIPT. All participants find that the current price of NIPT in the country is too expensive.

“If someone does not expect to have a child with Down syndrome, she will not bother to take a test at that price.” - Mother 7, no screening done

While most are impressed with the accuracy of the test, some still are wary of the consequences of the false positives and false negatives.

“Well that’s a very high accuracy rate even if there’s a 1% chance of missing the diagnosis, but the 99% of mothers will be able to confirm and that it’s really a good number.” - Mother 5, positive nuchal translucency test

“I don’t think that we need that test because if it’s not 100%... There are so many stories that people in the USA who say they’ve gotten a test for Down syndrome but then the baby doesn’t have Down syndrome and you’re terminating a baby.” - Mother 9, no screening done

Some participants commented on the safety of the test and find the simplicity of the blood test favorable.

“I’m against amniocentesis, I don’t like that because it might even compromise the baby and the mother... It’s the first time I’ve heard of NIPT. I now know that it is just a blood test.” - Father 3, no screening done

Theme 3: NIPT will allow you to prepare

Majority of the parents shared a perception that earlier diagnosis allows better emotional preparation.

“So I think rather than getting surprised, like what we experienced, having the shock of your life, at least you can find out already, prepare well, and then you will be emotionally ready when the child arrives.” - Father 3, no screening done

“I’ve also heard of a parent... who learned of the condition of their child even before the child was born... It helped her and she wasn’t as much of a crybaby as we were after the birth.” - Father 4, no screening done

Another advantage that was seen by the participants is that NIPT would allow earlier access to information, either through own research or by attending seminars.

“I can get additional information, that sort of thing. What do I need to tackle? What do I need to buy, things to do, medications, things like that. So just, what can I do to prepare?” - Mother 4, no screening done

Furthermore, a few parents also mentioned being able to prepare financially for the birth of the child by saving, contacting organizations and their insurance company.

“The parents, so that they can be aware of where they can bring the child and see who can help them. They can ask the government offices or the organizations that help children with DS.” - Mother 3, no screening done

So medically somehow we were being prepared at the same time financially as well. Because we had to seek help from our insurance provider.” - Father 5, positive NIPT

They believed NIPT will also allow access to comprehensive medical care, including being able to find specialists to address medical concerns.

“To be honest, it prepared us so much, that NIPT test. We had to research, and there was even the double bubble sign. Our daughter needed surgery right after. It was not the Down syndrome that was the concern; it was the duodenal atresia that we needed to address.” - Father 5, positive NIPT

Theme 4: NIPT may cause anxiety and abortions obtained illegally or abroad

On the other hand, some participants felt that there is no value in early diagnosis because there will be no definitive

change in the management of the child and the pregnancy anyway.

“If the kid is born, even if you can detect it, what will you do then? What is your intervention if you see there that there is a genetic issue when you can’t correct that? We consider these kids as God’s gift, and our God is a perfect God... If there is intervention for it, if there is something, we can do about it, then maybe. If we see something and then we can intervene, then that could be meaningful.” - Father 6, no screening done

Several participants said that knowing the diagnosis earlier also will cause anxiety, and would rather enjoy the pregnancy instead.

“Then you’ll be worried for 30 weeks. It’s also nice to enjoy the pregnancy” - Mother 8, no screening done

Will NIPT lead to abortion?

A few parents mentioned that they are thankful that abortion is not allowed by both the law and the predominant religion in the country, at the same time recognizing the other factors at play.

“Well I’m very happy that abortion is illegal here so it cannot just be done anytime we find out that a child has Down Syndrome” - Mother 5, positive nuchal translucency test

“We are a religious country, we are also afraid of that. But on the other hand, our poverty rate is high.” - Father 6, no screening done

The father who had undergone NIPT shared that they were determined to push through with the pregnancy even if the result was positive, but acknowledged that for some families it might lead to termination.

“In our case, we knew that the management of the pregnancy wouldn’t change. But it can be prone or it can be a trigger for termination. In other countries that are happening, right? It depends on the family.” - Father 5, positive NIPT

In this study, about half of the participants feared that the availability of NIPT will still lead to a higher number of abortions in the country, either through illegal means or by couples availing of the procedure by traveling to neighboring countries. The idea of abortion was never brought up by the interviewer, hence all instances that this was mentioned were initiated by the participants without any prompting. The words used by participants included “termination,” “abortion,” “hindi ituloy ang pagbubuntis (*not continue the pregnancy*),” and “ipalaglag (forced miscarriage).”

“Maybe when there is such a test, the parents will be encouraged not to continue their pregnancy, something like that... Even if it is forbidden. There is always a way, especially if the one who wants it has money.” - Father 1, no screening done

“I just also feel like people who have the resources that want to, if they’re willing to pay that much, they will go abroad and have terminations anyways... Even if they’re not terminating here, they would go abroad and do it another country. It’s so easy to go to China or Taiwan, or Singapore or other countries.” - Mother 9, no screening done

Some participants mentioned that they are against the test because of religious beliefs.

“We consider these kids as God’s gifts, and our God is a perfect God. Our God does not make mistakes. We cannot say that these kids are mistakes. If you consider them as gifts, “you are peeking at His gift.” You are excited, but this is God’s gift. This is life. God is perfect. This is perfect for you. Then you peek. And then you seem to not like his gift right from the start. That’s because you haven’t seen the wonder of the gift.” - Father 6, no screening done

They shared that if they did not have their child with DS, they would have missed out on the blessings and miracles that they experienced throughout their journey in taking care of an individual with DS.

“But I think it would be a shame. I think we would have missed out on a lot and a lot of blessings and so and I’m glad that that option wasn’t available to us because I don’t think I would have been able to make the right decision also. - Mother 9, no screening done
“If we believe that our God is perfect, we put our trust in a perfect someone who doesn’t make mistakes. All the things that are happening in our lives, whether he is a special child or whatever, it is all part of a perfect plan that’s good for us.”-Father 6, no screening done

Theme 5: Long term consequences include better prenatal care and “opening Pandora’s Box”

Some participants said that the availability of NIPT will be acceptable and will have a positive impact on DS patients in the long run because they will be given appropriate and timely care with proper support in place.

“We will to encourage to refer the parents, first, for genetic counseling and also to the Down syndrome Association of the Philippines, for the parents’ side of things. We can just assure them that we will walk hand

in hand with them throughout the journey.” - Father 3, no screening done

“I suppose that the effect is more positive because the parents are more prepared and they are the primary support system of the child, more immediate attention and appropriate support for the child can be given, ultimately.” - Mother 5, positive nuchal translucency test

On the other hand, some expressed the belief that prenatal testing will have an effect on terminations and that this is related to the value being placed on, and the perception of suffering in the context of disabilities in society.

“If you see people that are differently-abled or that have developmental delays they are productive citizens of society and sometimes what they give us is more than that. It’s just not like, ok they can produce or work how many hours or they’re doing this much for the economy. But actually they are great teachers. They teach us so much about life, about what are the important things in life, and different qualities. And to not have that around in some societies, it’s going to be kind of sad that you think that in the future, they’re not going to have that around. And it’s like to say that someone is not good enough to be born or good enough to be in this earth.” - Mother 9, no screening done

Some expressed that prenatal testing would be bordering on eugenics and may lead to testing and abortions for different types of disabilities in the future.

“We will not be too different from Hitler then. If there is a birth defect, what do we do?” - Father 6, no screening done

“You cannot test for autism, you can’t test for other developmental delays that are not according to genetics or the chromosomes. So what would that be like if you can test that? You would just terminate anyone that has autism, terminate anyone that has global delays, terminate anyone.” - Mother 9, no screening done

Some of the participants felt that the availability of this test will open the abortion debate in the country.

“There will always be these politicians and these congressmen and senators who will pick up that opportunity and say, this is it. If you know, why not (give the option to terminate)? “There must be an option,” there. That will happen because they will say parents have the right to decide for their future. They already know, why haven’t they been given the chance, it’s their right.’ The discussion on abortion and all this will open again.” - Father 4, no screening done

“It might open Pandora’s box.” - Mother 8, no screening done

Theme 6: recommendations for NIPT in the Philippines—access, disclosure of results

The opinions of the parents were varied as to who should have access to the test. Some believe nobody should have access to this test.

“I think nobody should. Because, once it becomes known, it’s possible to spread the word. When you have money, you can get all the information. So maybe no one should be able to access.” - Father 1, no screening done

A few believed that every pregnant mother should be able to access the test.

“For me, maybe everyone. It should just be for everyone. At least they will know ahead of time... they will know right away.” - Mother 4, no screening done

Others stated that those with high-risk pregnancies such as advanced maternal age, identified anomalies on ultrasound, or significant family history should be given priority.

“I suppose, for example, if there is a finding in the nuchal translucency test, they should be able to access the test if there is a suspicion.” - Mother 5, positive nuchal translucency test

“Those who are, like me, I’m 35, those who are pregnant beyond that. Those delicate pregnancies, they’re probably the ones who should also avail of that.” - Mother 3, no screening done

One parent emphasized that the attending physician should decide who should have the test.

“For me, I guess, maybe it is not for all. It is not like contraceptives that everyone can take. I think it should really be upon the discretion, for example, of the doctor or the OB, if the patient requires that. Because if you make it available for everyone, then it becomes, you act as God already in that sense. So personally, I don’t really subscribe to that thinking.” - Father 5, positive NIPT

Amid the varied opinions on who should have access, even participants who had reservations about the availability of NIPT believed that the laboratories cannot be prohibited from offering the test, and that parents who wish to have the test cannot be stopped with respect to their free will.

“We can only talk to those who have positive results. We can’t convince people not to take the test. Because we can’t stop these clinics from doing what they do. That’s a business. They have a market, they make money, they have a good business. And I think it’s a simple playbook that they copied from advanced

countries. We won't be able to stop development of tests. But the question is, "How will you tell the parents? What advice will you give them?" - Father 4, no screening done

The participants stated that they have to be in the right state of mind when they receive the results, and that receiving the results in a state of fear will result in making decisions they will regret. They believe that proper counseling is needed for a positive result, and that health professionals need to be trained on how best to give the news.

"I feel like offering the chance here without offering counseling that goes with it or offering the support that goes with it, it's like giving a toddler a sword but not telling them how to use it. Or giving them a knife and not telling them how to use it." - Mother 9, no screening done

"[There has to be] training for medical practitioners when the results are given... I don't know if there's a way to lighten the impact of communicating the news. And as my wife was telling me, more information when the results are given." - Father 5, positive NIPT

The participants felt that hearing from medical professionals alone will not be enough for prospective parents, but there has to be a conversation with parents who have children with DS to see the whole picture of what life is like having a child with the condition.

"Sinabi mo na magkaka-anak ka na may Down syndrome, what's next? (You said that they are going to have a child with Down syndrome, what's next?) At least give our number, they can contact us. It shouldn't be just "Every child with Down syndrome deserves a phone call," (referring to slogan of the Down Syndrome Association of the Philippines) but 'Every pregnant mother bearing a child with Down syndrome deserves a phone call.' That's why if more people avail of this procedure, perhaps the Down Syndrome Association will also have to work on it. So that we will be able to educate or tell whoever is going to give the news." - Mother 8, no screening done

"Instead of just listening to the counseling from the doctor, I think if you had counseling from the parents, if you can just see how a child is or a young adult is with Down syndrome, you can talk to a family first, not just listening just to the medical side, then you can make your own choice. Do the doctors really know how they are? And the way they give the news obviously they think it's a negative thing, they make it like it's a negative thing. And then also if you can just have all the information first, then make a choice. If you can actually see if the kids will grow up and how they are, listen to the families and the family's account of

it, then you can make an educated decision." - Mother 9, no screening done

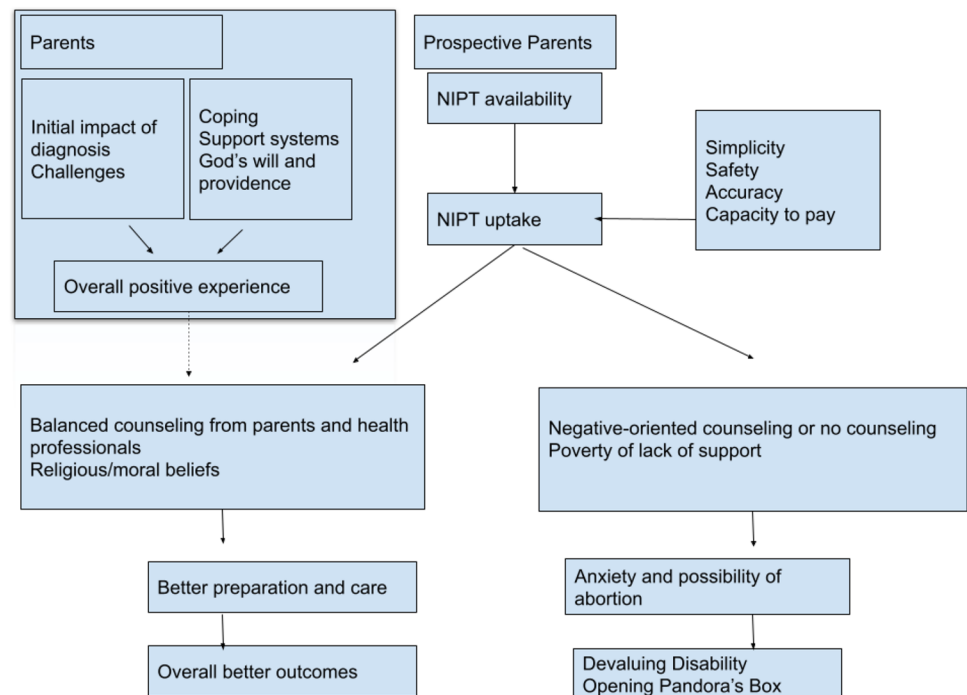
The majority of parents recommended that parents with a positive test should join a DS support group to be guided on their journey.

"It would be good if parents get engaged with those who have children with Down syndrome, especially parents who have undergone NIPT. It's a big thing that you know the person you're talking to knows your heart. It's a big thing to hear "you'll be ok, you'll be fine. We know you have a lot of questions, you have this fear of the unknown." When you've told the story and you have a basis to say that the child can be okay, their child is happy and the family is okay, I think these are the things that will help." - Father 3, no screening done

Discussion

The themes generated from the participant interviews were used to explain the participant's experience and their views toward NIPT (Fig. 1). Parents of individuals with DS have been through the journey, which they have described as difficult, but overall a positive one. They believe that prospective parents who may be able to avail of NIPT which at this point is still dependent on capacity to pay, can benefit from hearing from their experiences and by reflecting on their own beliefs, and use the information to prepare for the birth of their child. On the other hand, if appropriate counseling is not available, the test might increase anxiety and lead to abortion if they are unable to accept the child's condition.

The data gathered from this study gives us a better understanding of what life with Down syndrome is like and what the overall experience means to the parents—one of many challenges, especially with adjusting to the initial diagnosis and dealing with the medical concerns but eventually being filled with joy and love resulting in an overall a positive experience through the help of support they received from other parents and from their own families. Thus, drawing from the symbolic interactionist framework, their attitudes toward NIPT reflect these different aspects of their experience. The acknowledgement of difficulty in the initial encounter with the diagnosis leads them to appreciate the value of NIPT in allowing better preparation and access to medical care. The meaning they have attributed to their children as being a blessing leads them to reject the idea that some parents might opt to terminate children will DS. Still, the attitudes of Filipino parents of children with DS toward NIPT shown in this study were complex and varied.

Fig. 1 Conceptual framework from themes generated

Lived experiences

The emotions they felt and the initial experience in receiving the diagnosis were consistent with previous studies on Filipino families, including how they felt more positive and were able to understand the diagnosis better after they obtained information from the support group and did their own research (Villa 2016). The parents admitted that they encountered challenges in raising a child with DS, particularly regarding medical and behavioral concerns. But like parents from similar studies, they valued the overall experience and expressed that the loving relationship they have with their child has brought joy, meaning, and an overall positive impact on their lives and how they view the world (How et al. 2019; Skotko et al. 2011; Valentin et al. 2019). They were thankful for the support that they have received along the way from their own family, recognizing that their child has brought their family together with several members stepping in and contributing in different ways, something that is not surprising in the Philippine context (Villa 2016). They recognized as well the support from the entire “village” or community, including the support group, early intervention seminars, and therapy (How et al. 2019).

NIPT test characteristics

As a prenatal test, parents in this study agreed that NIPT is a safe alternative to amniocentesis (diagnostic testing from either chorionic villi sampling or amniocentesis is currently not offered in the Philippines and would have been

accessible only to parents who would undergo the procedure abroad), which is associated with a risk for spontaneous abortion (Van Schendel et al. 2017).

Benefits of NIPT

In concordance with other studies, parents who participated in this study recognized the benefits of NIPT such as safety, earlier diagnosis allowing for preparation in terms of better anticipatory care, gathering information, and accepting the diagnosis (K. J. Ahmed et al. 2015; How et al. 2019; Kellogg et al. 2014). Similar to the experience of parents who chose not to terminate a child with DS diagnosed prenatally, our participant reported using the lead time after NIPT to find appropriate medical resources and connect with the DS community (Hurford et al. 2013). The couple had no doubt in their mind that they will continue with the pregnancy whatever the result of the NIPT would have been, consistent with findings that the decision to continue a pregnancy is usually established prior to even doing the test.

Disadvantages of NIPT

On the other hand, some parents were aware that in other countries, prenatal diagnosis for DS has been shown to lead to higher termination and subsequently lower prevalence of DS (Deng et al. 2015; Maxwell et al. 2015). Like parents of children with DS in other parts of the world, our participants also expressed a fear that the availability of NIPT locally would lead to increased terminations for a positive prenatal

diagnosis (Kellogg et al. 2014; Van Schendel et al. 2017). However, because termination is illegal in the country at this time, the parents postulated that this would be in the form of underground or illegal abortions, or by parents availing of the procedure in neighboring countries where abortion is legal. The participants expressed that while religious beliefs and the value of life are emphasized in the predominantly Catholic country, the high poverty rate and absence of affordable quality health care might push parents to terminate. In a 2008 study, nearly 17% (560,000) of 3.4 million pregnancies were aborted despite legal and religious restrictions, with dire health and economic concerns believed as grounds for considering or attempting an abortion (Gipson et al. 2011). A study in Hawaii showed that among the different ethnic backgrounds, Filipinos and Pacific Islanders had lower uptake of prenatal diagnosis compared to the Far East Asian and White population, but the rate for terminations for prenatally diagnosed DS in Filipinos was 82%, and similar to the White population (Forrester and Merz 1999). A more recent study showed that the termination rate for DS among 21 Filipino study participants in California was 80% compared to 87% for all races (Shaffer et al. 2006). Yet, the participants reported themselves to be strongly against abortion and believing that this strong faith in God shared by most will prevent abortions in the country to a certain extent. Indeed, in other countries, religious and moral beliefs have been shown to have the greatest impact on continuing a pregnancy despite a prenatal diagnosis of DS (Hurford et al. 2013; Skotko 2005).

Long term consequences of NIPT

Because the participants saw children with DS as a blessing to their families and other people in the community, they worried that NIPT is linked to the idea of disability being devalued in society as a long-term consequence of the test's availability (How et al. 2019; Kellogg et al. 2014; Valentin et al. 2019; Van Schendel et al. 2017). The reference to Hitler in one of our interviews reflects the belief that prenatal screening is a form of eugenics because of its effect on devaluing and preventing the birth of people with disabilities. This concept has been previously described as “contemporary eugenics” which, although not on a population level of implementation in the Nazi Era, potentially leads to similar outcomes (Thomas and Rothman 2016). Concerns regarding the long-term effects of NIPT on individuals with Down syndrome in society have led to the creation of a “Don't Screen Us Out” campaign in the UK, in which families have voiced out that NIPT may only worsen the “culture of informally eugenic anti-disabled discrimination” (dontscreenusout.org). Some of the participants in this study expressed fear that this attitude will extend to other conditions with developmental delays, leading to discrimination

based on genetic characteristics and loss of diversity in society, which bioethicists have warned against (International Bioethics Committee 2015; Nuffield Council on Bioethics 2017).

Recommendations from participants

Participants in this study felt that disclosure of positive results should be coupled with a balanced counseling which discusses not only the difficulties but also the positive aspects of having a child with DS (Kellogg et al. 2014; Nuffield Council on Bioethics 2017; Valentin et al. 2019; Van Schendel et al. 2017). Our participants believed that medical professionals may only know one side of the story of DS and may be relying only on the worrisome aspect of medical complications (Kellogg et al. 2014; Valentin et al. 2019). In order to ensure that prospective parents receive complete information, the participants recommended that they also be given the opportunity to talk to parents who have had the experience of raising a child with DS (How et al. 2019). This was related to the realization parents came to after going through the experience that “Things aren't as bad as they seem” (How et al. 2019), and they warned against possible consequences of finding out the diagnosis before birth when “they haven't experienced the wonder of the gift,” as one of the participants in the study shared.

Comments

While there were very minor variations in the maternal and paternal experiences in terms of immediate reactions to the diagnosis and financial support received, there were no significant differences in their overall experience in raising a child with DS and in their perspectives toward NIPT.

One observation from the differing opinions in this study is that those who spontaneously gave statements clearly opposing NIPT also gave statements saying that it will lead to abortion despite being illegal in the country. On the other hand, those who gave statements clearly in favor of NIPT availability either (1) did not mention abortion at all during the interview, or (2) gave either of these two statements—that they are glad that abortion is illegal in the country or that they believe the consequence of doing NIPT will depend on the beliefs and acceptance of the family undergoing the test.

Perhaps because termination of pregnancy for DS is not yet a tangible reality and with some parents believing that it will not become an option in the country, participants in this study did not yet focus on the possible long-term consequences of fewer individuals with DS—isolation,

reduced support for, and negative attitudes toward those who have the condition, which was themes noted in some studies (How et al. 2019; Lewis et al. 2013; Van Schendel et al. 2017). There was no concern about specific aspects of termination, such as being pressured to schedule the procedure immediately, or about how earlier availability of NIPT can allow termination before the mother and fetus are able to bond (How et al. 2019; Van Schendel et al. 2017).

Strength and limitations of the study

This study has several strengths. First, to our knowledge, it is the first research on this topic in a highly religious country wherein prenatal diagnosis is only being recently introduced and where abortion for any indication is illegal and stigmatized. The participants in this study have given further validation to the value of faith in establishing an individual's perspectives and decisions on this matter. Second, the inclusion of fathers and mothers as participants, as well as the diversity in socioeconomic status, educational attainment, and even language is spoken allowed us to examine different points of view. One limitation of this study is that all participants were recruited through a support group on a voluntary basis, with the awareness that a sampling bias may result from differences between individuals who are members of support organizations and those who are not. These may include differences in advocacies, help-seeking behavior, or parenting styles. Secondly, the exclusively online method of recruitment and interviews meant that only the families who have access to the internet were included. It would be useful to conduct a follow-up study when the health situation improves since the population that does not have internet access is likely to belong to lower economic classes, a situation that could have a different bearing on the potential participants' attitudes. Furthermore, there are no study participants whose children did not survive, thus unintentionally leaving out a potential study population that could have further enriched the understanding of attitudes to NIPT. The primary investigator is a clinical geneticist who has been working with and advocating for better inclusivity and access to healthcare for persons with genetic disorders and with associated disabilities. This could have been a source of bias in the analysis of the data.

Conclusion

Filipino parents of children with DS acknowledged the value of noninvasive prenatal testing in providing early diagnosis and subsequently emotional, mental, spiritual, and financial preparation, but also recognized that such early detection may cause anxiety and even thoughts of termination for

some, despite abortion being against the law and predominant religious beliefs. With the understanding that the test is already available, although out of reach financially for the majority of the population, they emphasized the need for proper counseling for the parents undergoing the test and receiving positive results. It was highlighted that the counseling should come not just from medical professionals but also from parents of children with DS for a more truthful account and a complete picture of what life is like raising a child with the condition. Health professionals should be trained to give a diagnosis in a balanced manner that incorporates essential explanations as well as expressions of empathy without bias for negativity. Health professionals should be made aware of the value of support groups and of advising the parents to talk to and learn from those who went through similar experiences before them. It is also evident from findings in this study that pretest counseling for parents before they decide to do the test also needs to be reinforced. Pretest counseling should emphasize that the purpose of the test will be to provide the opportunity for better preparation in the event of a high-risk result rather than to change the outcome of the pregnancy.

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Declarations

Ethics approval and consent to participate The study received ethical approval from the University of the Philippines Manila Research Ethics Board UPMREB 2020–0776-01. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients being included in the study.

Conflict of interest The authors declare no competing interests.

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