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Title

Parental Expectations of Raising a Child with Disability in Decision-Making for Prenatal Testing and Termination of Pregnancy: A Mixed Methods Study

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Abstract

Objective: To examine attitudes toward prenatal testing and termination of pregnancy (TOP) among parents and obstetric providers in relation to their views on raising a child with disability.

Methods: An explanatory sequential mixed methods study. A survey among 274 parents and 141 providers was followed by interviews with 26 parents and 10 providers. Using multivariate analysis, the relationships between attitudes were examined. Thematic analysis was used to identify the reasons behind the attitudes.

Results: In comparison with providers, parents reported more positive attitudes toward raising a child with disability and more moral views about TOP. Providers reported more variations in attitudes toward offering prenatal testing and TOP. Significant associations were found between attitudes toward prenatal testing, raising a child with disability, reproductive autonomy, and TOP. Three major themes were identified: (1) meanings of parenthood from genetic tests; (2) views toward TOP and parental responsibility; and (3) implications of advanced extended prenatal genetic testing.

Conclusions: Perceived social-cultural norms of disabilities and parental expectations of raising a child with disability influence decision-making regarding TOP.

Practice Implications: As more conditions of the fetus are able to be detected, the social-cultural implications of the technology and disabilities need to be addressed in antenatal care.

Keywords: prenatal testing; termination of pregnancy; disability, parenting, mixed-methods

1. Introduction

Prenatal screening for fetal conditions has rapidly evolved in the last two decades. A significant advance in prenatal screening technology resulted from the discovery of the presence of placental cell-free DNA (cf-DNA) circulating in maternal blood [1] and the subsequent development of non-invasive prenatal testing (NIPT) based on sequencing cf-DNA [2]. While clinical applications of NIPT mainly focus on the three aneuploidies of trisomies 13, 18 and 21, where it is used as a laboratory-based prenatal screening, the test will be available through public healthcare systems in the UK [3] and Hong Kong [4]. Meanwhile, commercial providers offer expanded panels of NIPT to screen for sex chromosome conditions and other specific microdeletions [5]. As sequencing technologies advance and test costs decrease, cf-DNA sequencing will become more affordable to consumers, allowing for the potential identification of more treatable and non-treatable conditions and traits in pregnancy, including those associated with adult onset [6, 7].

Clinical and ethical concerns as to how these technologies could and should be utilized have been widely addressed in terms of resource implications for genetic counseling, clinical guidelines for genetic susceptibility (e.g., cancer and other adult onset diseases), patient autonomy, risk and benefits for future children, and distributive justice [2, 6, 8, 9]. Studies found that women reported a high level of interest in knowing about genetic conditions prenatally, particularly with the use of NIPT; some believed that it would be justified even in the absence of significant medical indication [10]. Central to discussions on prenatal screening are attitudes toward termination of pregnancy (TOP). Many congenital conditions have no therapeutic cure, leaving parents with one of two options: to continue the pregnancy and raise a child with illness or disability or to seek elective TOP. Early antenatal identification of numerous fetal conditions without the risk of miscarriage using sequencing technology is the ‘next frontier’ of prenatal testing, with the potential for misuse and parental misunderstanding of its limitations and potential consequences [6].

Social norms of disability and raising a child with disability are important in the context of advanced genetic testing. Parental decisions regarding antenatal care potentially have to be made under uncertainty, as it is unlikely for women to have had an experience of the condition before birth. Socioeconomic and cultural backgrounds and religious affiliations can influence decisions about prenatal screening and TOP [11, 12]. The family household context of perceiving disability as a disease burden that poses a risk of being socially excluded also affects decision-making [13,14]. Chinese culture has a long-prevailing belief and negative portrayal of disability [13-15]. Families of children with disability are often stigmatized and marginalized, reporting feelings of shame and ‘loss of face’ and being labeled an ‘unsuccessful family’, as their children with disability may be unable to have a career or may have difficulties in interpersonal relationships [16, 17]. The isolation of parents of children with disability is not uncommon. Chinese parents are not expected to state their concerns publicly or to seek support or sympathy from others [15, 18]. On the other hand, Chinese culture, which emphasizes social interdependence and promotes the Confucian virtues of filial piety and family-centeredness, entails the kin obligation that leads to greater fecundity and reproductive fitness in the next generation [19]. A family should consist of strong collective bonds, such that everyone assumes mutual responsibility and shows reciprocity in looking after each other [20]. Children with disability, however, are regarded as an inharmonious group in society and would be incapable of fulfilling the expectation of filial piety toward the family [21].

Chinese individuals in Hong Kong share traditional Chinese culture, emphasizing harmony, family solidarity, strict parental control, and academic excellence as paramount socialization goals [22]. The prevailing contemporary Chinese cultural norms of perceiving disability as a burden pose clinical implications for how prenatal testing is perceived, and TOP decisions are made based on knowledge of fetal conditions [23]. Most studies have described women's attitudes toward prenatal testing [24-26] but have been limited in their examination of their interrelationships with women's views toward TOP and disability. The objective of the mixed methods study was to examine how Chinese parents' and obstetric providers' views on disability affect decision-making for the uptake of prenatal testing and TOP in relation to extended prenatal testing for aneuploidies other than common aneuploidies. To address the study objective, the following focal research question was examined: How do attitudes toward prenatal testing impact attitudes toward TOP in relation to parental expectations of raising a child with disability and reasoning about reproductive autonomy for each group of parents and providers? Other research questions included the following: Do attitudes toward prenatal testing and TOP vary by condition?; is there a difference in attitudes toward prenatal testing and TOP between the two groups?; is there a difference in attitudes toward parental expectations of raising a child with disability and reasoning about reproductive autonomy between the two groups?; and how do parents and providers decide to go for extended prenatal testing?

2. Methods

2.1 Participants

2.1.1. Survey. The study was approved by the institutional review boards. A survey was conducted between April and October 2017. Parents attending Down syndrome screening at two public hospitals in Hong Kong were invited to the study. The recruitment was conducted independently from the antenatal service by the researchers. Verbal informed consent was obtained. Parents completed and returned the survey questionnaire before undergoing their screening. Women consenting to participate whose spouse was not present were provided with a questionnaire to be completed and returned using a stamped self-addressed envelope. For providers, the contact details of obstetricians and midwives were extracted from the Hong Kong Medical Council Specialist Register of medical practitioners. They were contacted by email or phone and asked to complete and return the questionnaire if they were involved in participating in prenatal screening. After completion of the survey, they received vouchers for HKD$100 (≈ USD$13).

2.1.2. Interviews. Among the 415 respondents, 173 (41.7%) agreed to a follow-up interview and left their contact information; these respondents included 14 midwives, 17 doctors, 73 women, and 33 spouses. A subgroup was selected for interviews based on the survey respondents' demographic backgrounds of age (under and over 35 years old) and religion (with a religious affiliation or no religion), work sectors for providers, and their responses to prenatal testing and TOP. At the beginning phase of recruitment, we focused on the demographic characteristics and work sectors of participants. Interviews were conducted concurrently with data analysis. Preliminary thematic coding allowed us to identify the characteristics of participants to reach theoretical saturation [30, 31]. Later, the survey respondents who reported lower scores on the scale of reasoning about reproductive autonomy were invited for an interview. A total of 36 participants (10 providers and 26 parents) participated in interviews. All interviews with parents were conducted within three months after birth. Parents whose pregnancy resulted in a miscarriage or chromosomal abnormality were excluded from selection for an interview to prevent undue distress. Interviews were conducted by the first author, who has extensive research experience on the topic. Interviews lasted for up to one hour. Participants received a voucher for HKD$500 (≈ USD$65).

2.2. Measures

2.2.1. Quantitative. In addition to the questions on sociodemographic and professional backgrounds, the following measures were used. Parental expectations of raising a child with or without disability were assessed using the enrichment subscale of the Perceptions of Parenting Inventory [27]. Parents were asked, "What are your expectations of being a parent of this child when you have had all prenatal tests and the doctor has informed you that the baby is (i) healthy or (ii) disabled?” For providers, the word “you” was replaced with “patients”. Each of the items was assessed using a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The measure showed high internal consistency in the sample (healthy: α =.91; disabled: α =.95). Reasoning about reproductive autonomy was assessed using the Reasoning About Abortion Questionnaire (RAQ) scale [28]. The RAQ assessed the domains of moral reasoning about reproductive autonomy, and the value of the fetus on a 5-point Likert scale ranged from “strongly disagree” to “strongly agree.” The scale showed high internal consistency in the study sample (α=.85).

Attitudes toward prenatal testing and TOP were assessed by an instrument composed of 30 conditions adopted from a previous study by Hewison and colleagues (2007) and, conducted by the coauthor (SA). Among the conditions from the original list, the conditions that were not considered clinically prevalent or socially relevant for a Chinese population were removed: phenylketonuria, cystic fibrosis, alcoholism, moderate and severe learning difficulty, and mental handicap. Instead, the following conditions of more relevance to the Chinese population in the study region were added: microcephaly, Down syndrome, dyslexia, attention deficit hyperactivity disorder, and disorder of sexual development. These conditions were chosen based on consultation with local experts in obstetrics and pediatrics. These conditions spanned from genetic abnormalities to disability conditions, such that they were placed across the spectrum of the original conditions. In each condition, a brief description of the clinical prognosis, life expectancy, and social life was provided.

For each condition, brief descriptions of the clinical prognosis, life expectancy, and social life were provided. Using the measure as a reference, we translated the condition descriptions into Chinese in consultation with local maternal-fetal specialists who provided prenatal testing counseling. The descriptions were refined according to the local context by obstetricians and prenatal testing counselors (DS). The final version of the measure was piloted with five women to evaluate content validity.

Respondents were asked to indicate the need for testing and intentions for TOP based on the description only to avoid prior misconceptions of the conditions. In the measure, parents were asked the following questions: (i) “Would you accept a prenatal test [for a condition]?” and (ii) “Would you elect to terminate the pregnancy if the test showed that the baby has the condition? For providers, the wording of each item was changed as follows: (i) Would you offer a prenatal test [for a condition]? and (ii) would you offer termination if the test showed that the baby has the condition? Respondents answered “yes”, “no” or “not sure”, assuming that the prenatal test would tell them whether the fetus does or does not have the condition and that TOP would be performed early in the pregnancy without a procedural risk.

2.2.2. Qualitative. A semi-structured topic guide was developed based on survey findings and existing literature on prenatal genetic testing on the following topics: (1) interest in undertaking prenatal testing for various conditions and termination of pregnancy; (2) raising a child with a disability; and (3) views of the applications of NIPT. The guide was reviewed by maternal-fetal specialists to ensure its content validity, relevance, clarity and cultural sensitivity before being translated into Chinese and piloted with two parents and two providers.

2.3. Analysis

2.3.1. Quantitative. Univariate analysis was used to report the frequency and central tendency of the study variables. Chi-square and Mann-Whitney U tests were conducted to compare group differences for categorical and continuous variables. The median score of the Perceptions of Parenting Inventory was used to categorize participants into two groups with lower and higher parental expectations of raising a child with disability. The relationships between attitudes toward prenatal testing and TOP for 30 conditions for the groups above and below the median were reported. Multiple logistic regression was used to examine the association between attitudes toward prenatal testing and TOP in each group, with parental expectations of raising a child with disability and reasoning about reproductive autonomy as covariates, with adjustments made for demographic backgrounds. Figure 1 shows the hypothesized relationships between the variables with potential moderators. Adjusted odds ratios (aORs) and 95% CIs for aORs were reported.

[Figure 1]

2.3.2. Qualitative. All the interviews were recorded, transcribed verbatim, translated into English, and imported into NVivo [29]. Thematic narrative analysis was used to identify key themes. A constant-comparative method of coding was used to create the themes. The analysis focused on explanatory investigations to better understand interviewees' thoughts, processes, and expectations regarding prenatal testing and pregnancy outcomes [30]. Member checking with experts was conducted to increase credibility and allow the transferability of findings to real-life settings [31].

3. Results

3.1. Quantitative Findings

The sample consisted of 415 individuals: 191 (46%) pregnant women, 83 (20%) partners, 49 (12%) midwives and 92 (22%) obstetricians. Table 1 shows the characteristics of participants.

[Table 1]

3.1.1. Parental Expectations of Raising a Child with or without Disability

Tables 2 shows attitudes toward raising a healthy child with or without disability. Parents and providers both reported significantly higher parental reward in raising a healthy as opposed to a child with disability in greater happiness, pride, fun, reward, sibling bonding and support, parental closeness, parental self-esteem and emotional reward (all ps $< .05$). Within the question of disability, parents reported more positive attitudes than providers (all ps $< .001$). No significant difference was found between the sub-group of women and spouses and obstetricians and midwives in the subgroup analysis.

3.1.2. Reasoning about Reproductive Autonomy

Table 3 shows reasoning about reproductive autonomy. Providers and parents both reported that women should have the right to reproductive autonomy and control of their own bodies by having the right to decide to terminate a pregnancy. No difference in the reasoning was found between the groups. However, in regard to the value of the fetus, parents reported more values about abortion and the fetus than providers that abortion is not morally acceptable; and the unborn fetus is a viable human being with rights (all ps $< .05$). Likewise, no significant difference was found in the sub-group analysis.

[Table 2 and 3]

3.1.3. Attitudes toward Prenatal Testing for 30 Conditions

Figure 1 shows the percentages of parents' and providers' attitudes toward utilizing or offering prenatal testing for 30 conditions. The dotted and dashed lines show the percentages of the groups of the lower and higher scores by the median of the measure of raising a child with disability. Parents showed variation in views about whether they would use prenatal testing ranging from 68.2% to 94.2% across conditions. Providers had more variations in attitudes toward offering prenatal testing depending on the nature of the condition ranging from 27.7% to 94.3% across conditions. Both parents and providers showed a high interest in using or offering prenatal testing for Down syndrome, anencephaly, cleft lip, achondroplasia, quadriplegia, Duchene muscular dystrophy, Fragile X, Turner's syndrome, Klinefelter syndrome, and Huntington disease. For other conditions, significantly few providers than parents would offer vs utilize testing for Alzheimer's (32% vs. 79%), obesity (28% vs. 68%), deafness (44% vs. 78%), schizophrenia (36% vs. 77%), autism (43% vs. 75%), blindness (47% vs. 81%), bowel cancer (37% vs. 78%), epilepsy (39% vs. 79%), diabetes (35% vs. 77%), ADHD (38% vs. 77%), dyslexia (37% vs. 75%), low intelligence (46% vs. 78%), sex of child (55% vs. 70%). Overall, their attitudes toward prenatal testing were not found to be associated with those toward raising a child with disability. Both lower and higher scored group reported similar percentages except for a few conditions. Providers with lower expectations of raising a child with disability reported higher interests than those with higher expectations in testing for ADHA (52.4% vs 36.1%) and Alzheimer's disease (43.8% vs. 22%) (all ps < .05).

[Figure 2]

3.1.4. Attitudes toward Termination of Pregnancy for 30 Conditions

Figure 2 shows the percentages of parents' acceptance of and providers' offering of TOP based on the conditions. The level of interest in accepting versus offering TOP varied among parents and providers ranging from, respectively, 78.8% to 6.2% and 91.5% to 2.1% across conditions. Overall, both groups were in favor of TOP for the five conditions, including anencephaly, trisomy 13 or 18, quadriplegia, Down syndrome, Duchenne muscular dystrophy. Higher associations between TOP and attitudes toward raising a child with disability were found. Providers who had lower expectations of raising a child with disability were more likely to TOP with conditions of bowel cancer (21.0% vs 5.6%), schizophrenia (29.5% vs 11.1%), epilepsy (12.4% vs 2.8%), Alzheimer's disease (17.1% vs 2.8%), ADHD (11.4% vs 2.8%) and Autism (23.8% vs 5.6%) (all ps < .05). The differences were significant among parents. The majority of parents with lower or higher expectation of raising a child with disability equally find necessary to terminate a pregnancy for Tuner's syndrome (76% and 73%) and unnecessary for conditions including cleft lip (83% and 88%), deafness (80%, 88%), obesity (94% and 94%), autism (90% and 91%), ADHD (91% and 94%), dyslexia (93% and 93%), and gender (95% and 92%). For the remaining conditions, parents with lower expectations of raising a child with disability were significantly more likely than those with higher expectations to consider TOP (all ps <.05).

[Figure 3]

3.1.5. Multiple Regressions for Termination of Pregnancy for 30 Conditions

Table 4 and 5 show the results of multiple logistic regression analysis for TOP based on the 30 conditions among parents and providers with three key variables of 1) attitudes toward prenatal testing, 2) reasoning about reproductive autonomy, and 3) parental expectation of raising a child with disability. Overall, across two groups, accepting TOP in providers and offering TOP in parents was positively associated with attitudes toward prenatal testing and reasoning about reproductive autonomy. Participants who supported women's autonomy in decision making for TOP and disagreed on the moral value of the fetus were more likely to accept or offer TOP.

In regard to the relationship with parental expectations of raising a child with a disability, participants who perceived reward from raising a child with a disability were associated with decreased odds of accepting TOP in parents and offering it in providers. Among providers, parental expectations of raising a child with disability were associate with decreased odds of offering prenatal testing for the conditions relating to genetic susceptibility, such as epilepsy (aOR=.89), Alzheimer's diseases (aOR=.092), schizophrenia (aOR=.93), and cancer (aOR=.91), autism (aOR=.93) and dyslexia (aOR=.90). Among parents, the parental expectations were associated with decreased odds of accepting prenatal testing for almost all conditions except obesity, autism, ADHD, dyslexia, and sex of the child.

Demographic variables were also found to be associated with attitudes toward TOP for some conditions. Among providers, education was associated with increased odds of TOP for absent/dysfunctional limb (aOR=3.52) and religion was associated with decreased odds of TOP for sexual development disorder (aOR=.35), quadriplegia (aOR=.24), neurofibromatosis (aOR=.26), thalassemia (aOR=.44), and low intelligence (aOR=.33). Whereas, in parents, age was associated with increased odds with attitudes toward TOP for Down syndrome; being female was associated with decreased odds of TOP for Huntington's disease (aOR=.50), schizophrenia (aOR=.51), diabetes (aOR=.47), low intelligence (aOR=.44), ADHD (aOR=.35), and dyslexia (aOR=.32); and education was associated with decreased odds of TOP for sex of the child (aOR=.61) (all ps < .05).

[Table 4 and 5]

3.2. Qualitative Findings

3.2.1. Meaning of parenthood from genetic tests: negotiating parental responsibility

Not unexpectedly, parents expressed a strong desire to have a healthy child with positive life prospects as the ultimate goal of their pregnancy. Phrases such as "attaining health" or "achieving a good life" were commonly used. Parents both welcomed and were supportive of the use of genetic technology in antenatal care and pregnancy management as a way of achieving a child's physical well-being, enjoyment of independent life, freedom from diseases, or reduced mobility. When this "attaining health" goal was challenged, parents felt responsible for intervening and thought that the additional information provided through genetic testing was valuable, as they perceived disability to be associated with a poorer quality of life for the child and would wish to know during pregnancy about any conditions affecting their child's health.

> I believe the child with affected conditions [structural abnormalities] could be miserable after birth. It would be beneficial to know earlier. (Woman, 29 years old)
>
> When I look at children in a wheelchair, I perceive that their quality of life must be lower than healthy children. When they grow up, they realize they are different from others that may cause them lower self-esteem. They would feel unhappy. (Woman, 30 years old)

Parents reasoned that while a child with disability is just as loved, the child nevertheless is disadvantaged compared to their contemporaries, as society was believed to regard disability as undesirable and to be avoided.

> Our society remains socially closed, excluding people with disability. For example, when children with autism have problem behaviors in the public transport, like being

> hyperactive or making noise, the public, instead of demonstrating empathy, immediately showed a disliking face toward the parents and the child. (Woman, 36 years old)

Parents disagreed that prenatal genetic testing implied a lack of societal value for an individual with disability and instead talked about parental genetic responsibility for their ‘kin’, that is, their extended family. While parents regarded an unborn fetus as a viable human being with rights, they would nevertheless still undergo testing to ensure an “abnormality”-free pregnancy.

> I value the life of a disabled child no less than others. Taking care of a child with disability requires special needs. It will be an irresponsible decision if parents decide to give birth to a disabled child without being prepared to sacrifice themselves. (Woman, 34 years old)

Similarly, obstetric providers expressed that prenatal genetic testing would help parents understand their options and adjust to any uncertainties they might face during an “abnormal pregnancy”. It should be viewed as an essential step to prepare parents for the birth of a child.

> All is about preparation. Prenatal testing does not encourage parents to give up the baby upon diagnosis of abnormality. Parents, as the immediate caregiver, have to be told enough about the potential issues they may face in the future, such as a child’s long-term medical needs, and parents’ emotional and physical burden. (Midwife, 30 years old)
>
> Prenatal testing assists in perinatal care planning in many ways. A friend of mine discovered the baby carried a heart defect during the pregnancy so that the doctor worked with the pediatricians and cardiologists right away upon delivery. Parents would not be panicked when the baby admitted into the newborn intensive care unit (NICU). Instead, when the baby is born, both parents and the medical team would be well-prepared. (Midwife, 40 years old)

With a lack of societal support, children with disability are likely to be heavily dependent on their caregivers. Parents talked about parental responsibility and anticipated hardship in taking care of a child with disability. They did not see taking care of a child with disability as a rewarding experience as much as having a healthy child.

> If a child has disability with a long-term illness that requires self-care management every day, the quality of their parents' lives will be affected. When ordinary families spend time going shopping and watching movies, I have to take care of my child with disability after work. I will not be able to enjoy the time with my child as much as others. (Spouse, 30 years old)

3.2.2. Views toward termination of pregnancy

Parents' decision to decide to electively terminate an "abnormal" pregnancy was primarily dependent on the perceived severity of a condition and whether they were able to commit to immediate and long-term care. Parents regarded any life-threatening medical condition characterized by a short lifespan or long-term medical care as "suffering" and requiring parental intervention. Parents also considered the importance of functional independence skills when they talked about the quality of life of the future child.

> I see 'suffering' when the disease has no cure or treatment, such that children require continuous extraordinary care throughout life, frequent hospital admission, heavy dependence that could not live independently. I do not want to bring the baby to the world destined to suffer (from the illness). My baby will suffer from intolerable pain; we will experience difficulties. (Women, 30 years old)
>
> Low intelligence is not a problem but the skills to earn a living to survive. In this sense, Down syndrome is not acceptable, as he may not have self-care ability or fail to communicate with others normally. My presence is important to take care of him. (Spouse, 33 years old)

Parents regarded raising a child with disability as being more difficult than raising a healthy child, impacting both family financial security and social interaction with family members and peers, and they questioned whether they had the knowledge and ability to provide care. Additional considerations included the children's future educational opportunities and employability and thus future abilities and whether the child would subsequently be able to care for himself or herself later in life.

> We parents may not have sufficient knowledge about how to take care of a child with disability and his/her conditions. Governmental, such as medical and educational services, and social supports for children with special needs, do affect my consideration in TOP. (Spouse, 41 years old)

Parental obligation emerged in the discussion of whether the diagnosis confirmed an "abnormal" pregnancy. Parents, especially expectant mothers, felt that they would socially and mentally struggle if they decided to give birth to a child that they believe was destined to endure potential mental and physical lifelong hardship. Parents particularly expressed remorse and would blame themselves for leaving a child with disability without potential familial or societal support after they themselves had passed away. Parents thought that opting for TOP was not shameful and was preferable to continuing with the pregnancy and giving birth to a child with a disabling trait and thought it irresponsible to give birth to a child who was beyond one's ability to provide care.

> Parents care for all, and health is the most important. My child with disability will be complicated when I pass away; my spouse passes away; everyone passes away. It is imprudent to depart my life and neglect their living. (Woman, 29 years old)

Among parents with a religious affiliation, two sets of views were observed in discussions of TOP. The first group committed themselves unequivocally to religion and sought religious convictions upon the reveal of an "abnormal pregnancy." For example, they viewed Nick Vujicic (an Australian Christian evangelist born with tetra-amelia syndrome, characterized by the absence of arms and legs) as an inspirational witness of God’s faith and hope, thus believing that an abnormal pregnancy should not be easily given up. Another group regarded themselves as quasi-religious and was less committed to the teachings. They expressed that although a decision to TOP may conflict with religious teachings, realistic deliberations should be prioritized.

> When it comes to reality, I struggle with religious teaching that guides us to preserve life regardless of its defects. I, nevertheless, cannot neglect realistic limitations as I am the major caregiver. Perhaps, I am not an earnest Christian. I believe the health and the prospective life of the baby are more important than religion. (Woman, 29 years old)

Obstetric providers’ discussions about the severity of a condition were based on medical notions, including fetal viability and medical complications shortly after birth. They did not have an overt opinion toward TOP, as they believed that the reproductive autonomy of couples prevails. They were, however, concerned that the noninvasive feature of prenatal testing might make it more acceptable for parents to test for the conditions, which are not usually considered severe enough for TOP. Providers considered their role to only encompass assisting women in making a decision and providing an unbiased opinion.

> Doctors are only responsible for providing objective explanations and lead the conversation when parents hesitate. To make an informed decision, they, not us, need to weigh the benefits against the risks. Our role is to tell them what problems the baby with the affected condition may encounter in the long-term. (Obstetrician, 36 years old)

However, while they acknowledged that any child impairment may make life more difficult, providers expressed uncertainty and concern in regard to counseling parents who wished to selectively terminate a viable pregnancy due to non-lethal conditions or physical anomalies such as cleft lip versus the parents’ wish for reproductive autonomy. While providers could provide details of possible medical or surgical interventions after birth, many parents considered it cruel or undesirable to subject a child to repeated surgery.

> Parents not only abort a baby with Down syndrome but also for non-genetic conditions, such as cleft lip and palate that could be solved by surgeries. Parents remained unconvinced and believed it is cruel to let to have so many operations and decided to abort. I am not compelled by their decision but got no choice. (Midwife, 47 years old)

3.2.3. Social implications of prenatal genetic testing

Many participants expressed the need for more prenatal testing and favored potential future testing advances. Women, in particular, welcomed advances in prenatal diagnosis and considered greater knowledge more beneficial. Both parents and providers did not think reproductive technologies served as a means to promote abortion but rather to improve reproductive autonomy.

> Today's tests aim to advise if they give birth to a baby with problems. It is not about morality but a good thing for children. Some say that it is like killing life, but parental responsibility is a concern too. If they undergo termination of pregnancy, they could get rid of it earlier. This is why there are so many tests for both mother and father. (Midwife, 31 years old)

The speed and breadth of genomic technology advancement affect providers' ability to offer proper consultation. Providers felt challenged in their roles and responsibilities as to whether they failed to uphold professional fidelity and integrity, especially when the clinical significance of any identified genomic abnormalities reported by diagnostic laboratories or clinical phenotypes remained unknown at the time of testing but may or may not be found to carry clinical significance in the future. Providers reasoned that more tests do not provide immediate benefits for the child but instead may provoke maternal anxiety. They equally voiced their concern about whether pregnant women could be sufficiently informed about multiple conditions and tests to make the right decision.

4. Discussion and Conclusion

4.1. Discussion

The study demonstrated that attitudes toward prenatal testing and TOP varied for 30 different fetal conditions and between parents and obstetric providers in relation to their views on raising a child with disability. Both parents and providers expected that raising a child with disability was less rewarding than raising a healthy child. The study findings also suggested that both groups' decision-making regarding the willingness to undergo or to perform TOP was affected by their views on prenatal testing, reproductive autonomy, the status of the fetus from a moral perspective, and disability. The findings from a sequential qualitative study provided contextual explanatory information. Parents stated that their expectations for their future child were mostly based on the conventional notion of attaining health or achieving a 'socially desirable' good life. When their child's health was challenged, parents supported extended prenatal testing and believed it provided them with reproductive autonomy by minimizing the possibility of any disabilities or conditions. Similar to other studies [32, 33], most parents were keen to undergo prenatal testing for a range of conditions, particularly those perceived as severe, including trisomies, thalassemia, microcephaly, and anencephaly. Parents felt obliged to undertake prenatal testing because of a sense of responsibility irrespective of different cultures [34, 35]. They wished to avoid feelings of disappointment, guilt, self-blame, shame, and stigma in a society where having a child with disability is considered a punishment for past bad deeds [36, 37]. Parents also need to consider the financial burden of raising a child with disability, but the uncertainty of the severity of illness and disability and the costs of intervention invoked parental anxiety, which in turn led to the consideration of TOP [38]. The findings were consistent with both clinical management and the observed choices of pregnant women, as well as societal and familial impact studies on caring for a child with Down syndrome in Chinese populations. For example, a study showed that few women (<1%) opted not to have further testing after a high-risk result from Down syndrome screening, while nearly 85% with an intermediate risk (1:250 to 1:1200) opted to undergo an elective NIPT [39], suggesting that Chinese women preferred maximum information, ideally as early as possible in the pregnancy, and were willing to accept the increased risk of a procedure-related loss if an invasive diagnostic test were needed. The finding is consistent with the desire to avoid having a child with disability. Some women have reported that having a baby with disability such as Down syndrome would be a much more significant adverse life event than having a procedure-related loss [40].

Providers expressed their opinions from the aspects of clinical significance and implications based on the nature of diseases, the severity of complications, life expectancy, and treatment availability. They observed the need for extended testing as a means to enhance reproductive autonomy through the ability to make informed reproductive decisions. They argued that the evolving trend in detecting more conditions is rather detrimental in leading to issues relating to excessive screening (possibly over-diagnosis), especially as the understanding of illness extends beyond medical discourse and into how society responds to those who are afflicted and those living with the experience of the illness [41]. As reported in the US [42, 43], providers were inclined to offer genetic tests for conditions with known clinical significance but were much less interested in adult onset predispositions and non-medical traits. The reluctance could be explained by a lack of preparedness or by discomfort with their role in giving patients access to a range of fetal genetic information, especially variants of unknown significance, which remains difficult for clinical interpretation in a meaningful way given the shortage of genetic counselors [43-46].

Parents' decision to undergo TOP following testing was based on their perceptions of reduced quality of life for children with disability. They talked about the internal sense of contentment when a pregnancy is confirmed to be normal and distress when the pregnancy is confirmed to be abnormal. This reflects the collectivist culture of Confucian philosophy that emphasizes harmony as the fundamental unit in the family, in which the goal is to foster relationships through reciprocity, sentiment, and kinship networks. Confucian philosophy also stresses the importance of education and scholarship to enjoy upward social mobility in a civilized society. Parents, particularly Hong Kong Chinese parents, play a significant role in providing care, elevating children to a high quality of life, and being responsible for leading the next generation to success by providing physical, emotional, social and intellectual support to their children. Therefore, potential parents prioritize the characteristics of their children that will conform to these family efforts and resources expended for care and social norms that are considered appropriate for individuals with disabilities, even in reproductive planning.

The quantitative and qualitative findings indicated that providers supported women's decision-making for TOP independent of their moral reasoning about it. In the interview, they tried to be "value-free," considering abortion a means to exercise patient autonomy. As the prenatal testing panel expands, however, providers felt it clinically unnecessary to screen for all the conditions or ethically impossible to terminate a pregnancy merely for knowing about a condition. They reconciled their identity as a medical provider, noting the crucial need to suppress self-bias and offer a nonjudgmental, open-minded, and caring attitude in their consultations on prenatal testing and TOP. Providers sometimes felt helpless due to the lack of formal guidance [47]. Unsurprisingly, pregnant women who came to the clinic for TOP often received an unsympathetic attitude from health professionals [48]. The gaps in the translation of scientific advances into clinical practices should be identified and addressed to improve the quality of care.

There are several limitations to the study. The study relied on questions that could have been subject to self-report bias, and some individuals may have responded in a socially desirable manner. Although the descriptions of conditions were provided in the questionnaire to ensure that respondents answered the questions with an equal amount of information, it is possible that the respondents did not fully read or clearly understand all the descriptions. Lay attitudes, history, social environment, and media coverage might have influenced participants' views and understanding of the severity of each condition. The large sample size, however, enabled us to gain sufficient statistical power to minimize potential bias. In the regressions of TOP among providers, the higher odds of offering TOP in certain conditions, such as Fragile X syndrome and schizophrenia, resulted from an imbalanced distribution of responses fitting in the regression analysis. A cross-tabulation of offering prenatal testing and TOP yielded a very few cases (less than 10) in the cell of "yes" for offering TOP for these conditions. Due to the imbalanced proportion, the regressions yielded higher odds than did the regressions for other conditions. Thus, these findings should be interpreted with caution. The study did not assess participants' prior experience with disability, which is known to influence attitudes toward TOP. The qualitative study was small in scale and was confined to the local population. Thus, the findings may not be generalizable to other populations, which may have different cultural values and healthcare systems. However, it is important to understand the issue in a specific local context to develop patient-centered antenatal care services.

4.2. Conclusion

Decision-making for prenatal testing and TOP for various fetal conditions among parents and providers was influenced by their views of the social, cultural, and medical implications of the conditions, parental expectations of raising children with disability, reproductive autonomy, and moral value of the fetus. Perceptions of the severity of fetal conditions are context-dependent, which affects parents' consideration of TOP. Discrepancies between high rates of favoring knowledge of fetal conditions and variability in willingness to undergo TOP for specific conditions highlight the need for structured prenatal counseling and education specific to conditions in advance of NIPT.

4.3. Practical implications

There are clinical and ethical considerations in testing the fetus in the absence of medical indications, as testing for more conditions arguably does not enhance parents' reproductive autonomy. The extended prenatal testing panel identifying fetuses with conditions challenges the conventional belief of what good parenting is. Parents are now asked to make decisions about their unborn child is in utero after determining whether their offspring have chromosomal conditions, are carriers for recessive conditions, or have the potential for significant adult-onset diseases for which medical interventions may not be available. As more conditions of the fetus are able to be detected, the social-cultural implications of the technology and of disabilities need to be addressed in antenatal care. Multidisciplinary discussions about the normative accounts of reproductive autonomy in the context of the widening scope of genomic technology advancements are required to inform patient-centered genetic counseling practices.

Conflict of interest

The authors declare that they have no conflict of interest.

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