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Why should the baby live or not live? Decisions of Turkish pregnant women regarding the fate of pregnancy when there are fetal anomalies

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Abstract

This study investigated the decisions of pregnant women regarding the fate of pregnancy in cases of fetal anomalies. Using a cross-sectional approach, data were gathered through a structured survey with hypothetical fetal anomalies. The data were analysed using SPSS 23.0. The preference for continuation of pregnancy was 58.7% in anencephaly and 92.4% in Down syndrome. The decision to continue the pregnancy was mainly justified by scruple, sin, and the baby's right to life. The reasons for terminating the pregnancy were the baby's short life expectancy, being exposed to discrimination, and not being forced to live a life of pain and suffering. Turkish pregnant women considered the anomaly in the fetus when choosing to continue or terminate the pregnancy. Considering that the preferences arose not only from religious and cultural factors but also from the risks associated with the diagnosis, it is imperative to manage these issues in prenatal diagnostic counselling offered to parents. *(Afr J Reprod Health 2025; 29 [2]: 94-105).*

Keywords: Prenatal tests; anencephaly; Down syndrome; maternal decision-making

Résumé

Cette étude a examiné les décisions des femmes enceintes concernant le sort de la grossesse en cas d'anomalies fœtales. En utilisant une approche transversale, les données ont été recueillies au moyen d'une enquête structurée portant sur d'hypothétiques anomalies fœtales. Les données ont été analysées à l'aide de SPSS 23.0. La préférence pour la poursuite de la grossesse était de 58,7 % dans l'anencéphalie et de 92,4 % dans le syndrome de Down. La décision de poursuivre la grossesse était principalement justifiée par les scrupules, le péché et le droit du bébé à la vie. Les raisons pour lesquelles la grossesse a été interrompue étaient la courte espérance de vie du bébé, le fait qu'il était exposé à la discrimination et qu'il n'était pas contraint de vivre une vie de douleur et de souffrance. Les femmes enceintes turques ont pris en compte l'anomalie chez le fœtus lorsqu'elles ont choisi de poursuivre ou d'interrompre la grossesse. Étant donné que les préférences découlent non seulement de facteurs religieux et culturels, mais également des risques associés au diagnostic, il est impératif de gérer ces questions dans le conseil en diagnostic prénatal proposé aux parents. *(Afr J Reprod Health 2025; 29 [2]: 94-105).*

Mots-clés: Tests prénatals ; anencéphalie; Syndrome de Down ; prise de décision maternelle

Introduction

There is a tax-funded, free health system in Türkiye, and prenatal screening (PS) is performed on all pregnant women within the scope of prenatal care. Being the sole purchaser of health services for the entire population, the Social Security Institution covers the cost of screening tests other than non-invasive prenatal testing. PS tests, which are routinely offered to all pregnant women regardless of their risk status, inform parents about the health status of their babies, provide guidance for them in the decision-making concerning the pregnancy, and emotionally prepare them for the birth of a baby with special needs and proper health services despite potential complications or developmental problems[1]. Obstetricians and gynaecologists in Türkiye tend to recommend prenatal diagnostic tests to avoid legal consequences in cases where PSs indicate a risk[2]. The detection of a congenital anomaly in a fetus is a difficult experience for couples that may radically change their hopes and plans for the future[3]. In such a case, parents are faced with the decision to continue or terminate the pregnancy. The attitude toward the decision may vary depending on the genetic counselling received, the knowledge and approach of the physician who diagnosed the anomaly, the couple's beliefs, culture, education, and the support they receive. Although medical termination of pregnancy is legal in Türkiye, cultural framework and societal attitudes toward termination of pregnancy are crucial factors that impact women's decisions and experiences[4]. Despite the widespread use of prenatal tests, there is a relatively small body of research on pregnant women's decisions regarding test results suggesting an anomaly[5]. This study investigated whether continuation or termination of pregnancy was preferred by Turkish pregnant women when an anomaly was detected in the fetus, the reasons behind the decisions reached by the pregnant women, and the factors which affected their decision. It is critical to understand the impact of not only medical knowledge but also social, cultural and religious pressures in such situations. By examining the intersection of social norms, personal values and medical considerations, this study will contribute to improving prenatal counselling services, particularly in supporting women to make informed decisions beyond the clinical diagnosis of fetal anomalies.

Methods

Study design and sample

This descriptive and cross-sectional study was conducted in the perinatal diagnosis and treatment unit of a university hospital in the west of Türkiye. In this unit, an average of 150-200 pregnant women received prenatal testing per year. Women who were receiving prenatal care, had, or were going to have a prenatal diagnostic test, did not have any pain or ache that might affect the interview, and consented to the study were included in the study. Pregnant women who could not speak Turkish were excluded from the study. The number of attendances at the unit in 2019 (3934) was taken as the basis for determining the sample number. The sample size was determined as 351, with a confidence interval of 95% and a margin of error of 5% using the known population sample size formula (n = Nt2pq/d2 (N-1) + t2pq).

Instrument

The survey used in data collection was prepared by the researchers. The draft survey was revised and finalized based on feedback from three medical ethicists and a perinatologist, subsequently undergoing pilot testing among 18 pregnant women. After this pilot phase, refinements were made to the survey based on the comments made by pilot participants. The first part of the survey included 19 questions, which were aimed at obtaining information about the descriptive characteristics and obstetric history of the participants. The second part included information about six severe congenital anomalies that are common in Türkiye *(anencephaly, spina-bifida, severe hydrocephalus, omphalocele, trisomy 21, severe multiple heart diseases)*[6] as well as questions aimed at evaluating the preference regarding pregnancy in case of an anomaly and the reasons behind this preference **(Supplementary data).**

Data collection

First, permission was obtained from the hospital administration, and this study was approved by the Kocaeli University Ethical Committee of Non-Invasive Clinical Research (Date: August 14, 2020; approval number: 2020/249). The researcher, who is an experienced obstetrics RN, and PhD candidate, collaborated closely with physicians and nurses within the unit. She informed and invited pregnant women who met the inclusion criteria to participate in visiting the unit two days a week. Face-to-face individual interviews were conducted with the pregnant women who gave consent in a room organized in a secluded part of the unit. Given the prevailing circumstances of the fourth wave of the COVID-19 pandemic, precautionary measures, including the use of masks and protective visors, were implemented, and the interview room door' remained ajar throughout the sessions.

During these interviews, the researcher administered the survey questionnaire and recorded the participants' responses. Each participant was initially briefed about a fetal anomaly, and then her questions, if any, were answered in the second part of the survey. Then, the participant was asked what her preference would be about the fate of her pregnancy if it was their pregnancy in the hypothetical scenario of an anomaly diagnosis, alongside the reasons behind such preferences. To maintain impartiality and avoid bias, the researcher refrained from influencing participants' responses, instead allowing them to express their inclinations independently. Furthermore, meticulous attention was devoted to ensuring that each interview concluded within a 30-min timeframe, thereby optimizing participants' time commitment and sustaining focus on the research topic. Starting on September 7, 2020, the data collection endeavor concluded on December 31, 2020, upon reaching a cohort of 351 participants.

Data analysis

The data were analyzed using SPSS, version 23 (IBM Inc., Armonk, NY, USA). Descriptive data are indicated in number, percentage, mean, and standard deviation. The relationship between categorical variables was assessed using Fisher's Chi-square test with Yates' continuity correction. The ratios test was used to compare the preferences concerning fetal anomalies. The statistical significance value was set to be $p<0.05$.

Results

The mean age of the participants was 30.0±4.9 years, and the majority (85.5%) were between the ages of 17 and 35. Regarding educational attainment, 43.3% held bachelor's or postgraduate degree. A significant portion of participants reported neutrality in political views (53.8%), inability to fulfill religious obligations (71.8%), and their beliefs influencing personal decisions (61%) (Table 1).

The majority (66.1%) of participants with an average gestational week of 22.0±6.0 (ranging from 7 to 37 weeks), were at or before the 23rd week of gestation. Notably, 73.5% of the participants reported intention and/or planning regarding their current pregnancy. Furthermore, 23.9% disclosed previous termination of pregnancy, 21.9% had a relative with a disabled child, and 12.5% indicated that their spouse had a disabled child. In addition, 67.2% of participants had undergone PS or diagnostic testing for current pregnancy, with anomaly detected in the fetus of 29.6% (Table 1).

Our paper focused exclusively on the decisions related to the diagnoses of anencephaly and Down syndrome (DS) of participants. The rationale behind selecting these specific conditions was that DS is the most prevalent congenital anomaly in Türkiye, and significant differences exist in life expectancy, anticipated quality of life, and the occurrence of associated sequelae between these two diagnoses. The fetal loss rate during intrauterine life in fetuses diagnosed with anencephaly is 65%, and those who survive birth usually succumb in the first twenty-four hours[7]. Consequently, the ethical issues surrounding these fetal anomalies, as revealed by prenatal testing, are subject to fervent debate. Such discourse often revolves around concerns regarding the judicious allocation of resources, as well as ethical considerations of the best interests of the fetus and their inherent rights. Therefore, these two anomalies indicated by prenatal tests are hotly debated ethical issues in the context of the futile use of resources as well as the best interest of the fetus and fetal rights[8]. In addition, when comparing preferences for continuing or terminating the pregnancy across different cases, a significant difference was found only in cases of anencephaly and DS. This finding was provided insight into the impact of different anomaly diagnoses on women's decisions.

In anencephalic fetus, many participants (58.7%) reported a preference for continuing the pregnancy, whereas 41.3% favored termination. The primary reasons cited for continuing the pregnancy included scruple (57.8%), sin (46.6%), and the fetus's right to life (21.4%). Predominant reasons for advocating termination encompassed considerations of the fetus's anticipated short lifespan (80.0%) and the desire to spare the fetus from a life fraught with pain and suffering (66.9%) (Table 2). Participants self-identifying as conservatives ($\chi2=9.033$; $p=0.003$), lacking a family history of disabled children ($\chi2=4.604$; $p=0.03$), and undergoing PS ($\chi2=8.344$; $p=0.004$) demonstrated a greater inclination toward continuing the pregnancy in an anencephalic fetus. Preferences for continuing pregnancy exhibited variance based on participants' characteristics. Conservative participants tended to emphasize termination as a sin ($\chi2=4.796$; $p=0.02$), the fetus's right to life ($\chi2=19.532$; $p<0.001$), and predestination ($\chi2=6.375$; $p=0.01$). Similarly, pregnant women who had undergone prenatal screening highlighted considerations of sin ($\chi2=4.755$; $p=0.02$) and predestination ($\chi2=11.606$; $p=0.001$), while those unable to fulfill religious obligations underscored fetal right to life ($\chi2=4.009$; $p=0.04$) and the absence of self-endangerment ($\chi2=4.157$; $p=0.04$).

Table 1: Characteristics of participants (N=351)

	n	%		n	%
Age (mean: 30.0±4.9)			Number of children		
35 and below	300	85.5	None	140	39.9
36 and above	51	14.5	1 and above	211	60.1
Education			Week of pregnancy (mean: 220.0±6.0)		
Primary school	103	29.3	23 and below	232	66.1
High school	96	27.4	24 and above	119	33.9
University	152	43.3			
Birthplace			Prenatal screening/diagnostic test		
Western and coastal regions	245	69.8	Yes	236	67.2
Inner and eastern regions	106	30.2	No	115	32.8
Working status			Fetal anomaly in the prenatal diagnostic test*		
Working	114	32.5	Yes	104	44.1
Not working	237	67.5	No	132	55.9
Social insurance			Assisted reproductive technique		
Have	341	97.2	Used	38	10.8
Have not	10	2.8	Not used	313	89.2
Monthly income			Planned/intended pregnancy		
Sufficient	236	67.2	Yes	258	73.5
Insufficient	115	32.8	No	93	26.5
People living in the house			History of a child with a congenital anomaly		
2	134	38.2	Yes	77	21.9
3	126	35.9	No	274	78.1
4 and above	91	25.9			
Political view			Kinship with the spouse		
Conservative	88	25.1	Yes	44	12.5
Social democrat	74	21.1	No	307	87.5
Not interested in politics	189	53.8			
Religious obligations			Your beliefs influence your decisions		
Fulfillment	99	28.2	Is effective	214	61.0
No fulfillment	252	71.8	Not effective	137	39.0

* Evaluated for pregnant women undergoing prenatal screening/diagnostic testing

Participants who had no history of previous pregnancy termination exhibited a higher inclination toward continuing the pregnancy, citing distrust in the diagnosis (χ2=5.039; *p*=0.02). Similarly, participants below the 24th gestational week expressed a heightened preference for continuing the pregnancy, particularly emphasizing the fetal right to life (χ2=4.290; *p*=0.03). Notably, most of the participants attributing their decision to the belief in destiny were under the age of 36 (*p*=0.04) and held a bachelor's degree (*p*=0.03). Furthermore, participants reporting their spouse or family's opposition to pregnancy termination even if they wanted it were primary school graduates (*p*=0.01), with the majority maintaining close familial ties with their spouses (*p*=0.007).The rationales underpinning the preference for pregnancy termination in an anencephalic fetus also differed according to participant characteristics. Notably, participants self-identifying as social democrats (χ2=8.038; *p*=0.005) and those who underwent PS or diagnostic testing (χ2=7.080; *p*=0.008) reported the likely short lifespan of a fetus as the reason for terminating the pregnancy. Moreover, participants below the age of 36 (χ2=7.170; *p*=0.007), self-identifying as social democrats (χ2=23.804; *p*<0.001), lacking familial ties with their spouses (χ2=8.651; *p*=0.003), and having PS or diagnostic testing (χ2=8.975; *p*=0.003) reported not being forced to live a life that would be full of pain and suffering as their main reason behind their preference to terminate the pregnancy. Furthermore, those who preferred to terminate pregnancy on the grounds that they could not care for a child who needed to receive lifelong treatment were mostly those who reported that their faith was not influential in their personal decisions (χ2=3.880; *p*=0.04) and those whose baby was diagnosed with an anomaly (*p*=0.02).

Table 2: Participants' decisions regarding anencephalic fetus and reasons for the decisions[*]

I would continue the pregnancy (n=206) Because	n	%	I would terminate the pregnancy (n=145) Because	n	%
My conscience would not allow	119	57.8	It would die shortly after birth	116	80.0
Sin	96	46.6	I would not want to force my baby to live a life full of pain and suffering	97	66.9
The baby has the right to life	44	21.4	I cannot take care of a child who needs lifelong treatment	16	11.0
I do not trust the diagnosis/medicine	35	17.0	I cannot put such a heavy responsibility on its siblings after we pass away	7	4.8
This would be my destiny	34	16.5	I cannot economically afford a child who needs constant medical treatment and special care	5	3.4
It would not pose a risk to me	21	10.2	Because it would pose a risk to me	5	3.4
Maybe it would be cured	17	8.3	Government support cannot be deemed adequate	2	1.4
Even if I wanted to terminate the pregnancy, my spouse/family elders would not allow me to	4	1.9	I'm working. To maintain my job ...	1	0.7
			I could not tolerate discrimination against such a child at school, at home, or in society	1	0.7

[*] The participants provided more than one reason

Table 3: Participants' decisions regarding fetus with Down Syndrome and reasons for the decisions[*]

I would continue the pregnancy (N=324) Because	**n**	**%**	I would terminate the pregnancy (N=27) Because	**n**	**%**
Such children can be happy	186	57.4	I cannot tolerate discrimination against the child	12	44.4
The baby has the right to life	154	47.3	I cannot take care of a child who needs lifelong treatment	11	40.7
My conscience would not allow	83	25.6	I cannot put such a heavy responsibility on its siblings after we pass away	10	37.0
Government support is sufficient for the education and care of these children	78	24.1	I cannot economically afford a child who needs constant medical treatment and special care	7	25.9
Maybe it would be cured	74	22.3	I would not want to force it to live a life full of pain and suffering	6	22.2
Sin	54	16.7	I'm working. To maintain my job ...	3	11.1
I don't trust the diagnosis/ medicine	44	13.6	The government support cannot be deemed adequate	2	7.4
This would be my destiny	37	11.4	It would die shortly after the birth	1	3.7
It does not pose a risk to me	20	6.2	Because it would pose a risk to me	1	3.7
Even if I wanted to terminate the pregnancy, my spouse/family elders would not allow me to	4	1.2			

[*] The participants provided more than one reason

In a fetus with DS, 92.4% of participants expressed a preference for continuing the pregnancy, whereas a minority (7.6%) favored termination. Notably, participants below the age of 36 exhibited a greater propensity toward continuing the pregnancy ($\chi2=8.328$; $p=0.004$). Primary rationales cited for choosing to continue the pregnancy included perception of children with DS leading happy lives (57.4%), the fetus's right to life (47.3%), and scruple (25.6%). Conversely, reasons given for preferring termination encompassed concerns regarding potential discrimination against the child (44.4%), inability to provide lifelong care for a child with complex medical needs (40.7%), and reluctance to impose caregiving responsibilities on siblings (37.0%) (Table 3). Participants with a bachelor's degree ($\chi2=6.458$; $p=0.04$), self-identifying as social democrats ($\chi2=5.124$; $p=0.02$), and those whose personal decisions were influenced by their beliefs ($\chi2=12.929$; $p<0.001$) predominantly cited the potential of these children for being happy as their rationale for choosing to continue the pregnancy. Conversely, participants who had not terminated a pregnancy before emphasized the fetus's right to life as the motive for their preference to continue the pregnancy ($\chi^2=3.921$; $p=0.04$). Participants with a primary school education ($\chi2=12.188$; $p=0.002$), unemployed ($\chi2=9.080$; $p=0.003$) and experiencing their first pregnancy ($\chi2=17.675$; $p<0.001$) were more likely to report religious considerations, such as sin, when expressing their preference for continuing the pregnancy. The participants who grounded their preference to continue the pregnancy based on their spouse or family elders not allowing termination were primary school graduates ($\chi2=9.742$; $p=0.01$). Furthermore, participants whose pregnancy was planned grounded their preference for termination rather on the thought that such a child would be exposed to discrimination ($p=0.04$).

A statistically significant difference emerged between the preferences of participants concerning the continuation or termination of pregnancy based on the fetal anomaly diagnosis. Notably, the preference among pregnant women to opt for pregnancy termination in anencephaly was higher than that in DS ($Z=11.25$; $p<0.001$).

Discussion

In the present study, pregnant women exhibited a greater inclination toward continuing pregnancy in the anencephalic fetus. Notably, the preference for pregnancy termination in instances of anencephaly (41.3%) was notably lower than that in previous studies. Meta-analytic studies have reported termination preference rates of 83% and 84% in anencephaly[9,10]. In contrast, in neural tube defect diagnoses, termination rates reached 52.6% in Canada[11], whereas in Türkiye, termination occurred in 67.8% of pregnancies with anencephalic fetuses[12]. The comparatively reduced preference for pregnancy termination observed in the present study may be attributed to the hypothetical nature of the anencephaly scenarios, in contrast to previous studies that involved confirmed anencephaly diagnoses[11,12]. If the babies had been diagnosed with anencephaly or DS, their preferences regarding pregnancy fate might have differed. Indeed, pregnant women in our cohort who had a PS test and/or disabled children in their family had a greater preference to terminate the pregnancy in an anencephalic fetus.

The main finding of the current study was a higher prevalence of pregnancy termination in anencephaly than in DS. Almost all pregnant women chose to continue pregnancy in a fetus with DS, with the predominant justification centered around the potential for these children to lead fulfilling lives and their inherent right to life. This finding underscores the consideration pregnant women given to factors such as the baby's life expectancy and quality of life, as well as the potential suffering associated with their decisions concerning the fate of pregnancy. Research has indicated favorable quality of life outcomes for individuals with DS, as well as their siblings and families. Maternal perceptions often regard DS as a relatively mild disability or even do not perceive it as a disability at all[13]. Furthermore, the inclination to continue pregnancy following a diagnosis of DS may reflect advances in treating individuals with DS and the provision of enhanced educational, social, and financial support for their families. DS is increasingly recognized not as a pathological condition but as a natural variation contributing to human diversity. It has been argued that reducing cases of DS through abortion is a threat to the richness and diversity of the community, and preventing the births of people with this condition is a modern form of eugenics[14]. Further exploration about the experiences of mothers raising children with DS is needed to verify the preference to continue the pregnancy in fetuses with DS in our study.

While a fatal diagnosis, such as anencephaly, is a prominent factor in terminating a pregnancy[15], our study observed a notably lower rate of termination preference in DS than in previous research. The termination rates of pregnancy diagnosed with DS have been reported to be 88% in Europe,[15] 95% in Denmark[16], 86.1% in China[17], and 89% in Uruguay[18]. The proclivity of our participants to continue pregnancy in both diagnoses may be attributed to a desire to avoid the negative psychological ramifications associated with pregnancy termination. Notably, a frequently cited reason for preferring to continue pregnancy was scruple. Although morality and religion occasionally intersect, many pregnant women delineated them as separate constructs, referring to scruple and sin separately. There is ample published evidence that in the case of a fetus with an anomaly, women are faced with a devastating choice, avoiding feeling guilty and taking responsibility for ending the life of the fetus, and that those who have terminated their pregnancy face complex perinatal grief[16,19].

Another significant finding of the present study was that conservative pregnant women predominantly opt to continue pregnancy in anencephalic fetus due to the conviction that terminating a pregnancy is a sin. These findings suggest that conservative Turkish women adhere to the notion that the sanctity of life, bestowed by a higher power, remains inviolable and beyond external intervention. The important effects of religious beliefs on pregnant women's decisions related with the anomalous fetus have been highlighted previously[12,20,21].

In Muslim-majority countries, such as Türkiye, where religious adherence is prevalent, the decision to continue pregnancy for religious reasons is commonplace. Within Islam, pregnancy termination is equated with the cessation of life and is a religious transgression. Studies conducted in countries like England[22] and Ireland[19] have similarly revealed that pregnant women confronted with anencephaly diagnoses often experience intense grief and shock, opting to continue their pregnancies as they perceive abortion as a traumatic event that conflicts with their deeply held religious convictions.

In the current study, particularly among conservative pregnant women, there was a notable emphasis on the fetus's right to life as the primary rationale for preferring to continue pregnancy. This finding aligns with previous research[11,23,24]. Many conservative individuals, guided by the principle of the sanctity of life, reject abortion, and advocate for the protection of fetal life on the grounds of its potential humanity[25]. The concept of the sanctity of life, which is commonly upheld across various religions, likely influenced our participants' inclination to continue pregnancy, driven by concerns about religious disobedience. Some participants expressed the belief that terminating pregnancy would result in spiritual consequences, such as the fear of damnation[26]. Healthcare professionals should discuss with Muslim pregnant women who have undergone screening tests the possibility of terminating the pregnancy in severe anomalies in the fetus[27]. In addition, there exists a critical need for investigations concerning parental responses to the communication strategies employed during the disclosure of severe congenital anomaly diagnoses, as well as the assessment of counselling approaches[23]. For this reason, future qualitative studies conducted with perinatologists, midwives, and pregnant women on termination of pregnancy in case of a diagnosis of severe anomaly in the fetus may help to identify the optimal ways in which to inform parents. The informed and conscientious decision-making of pregnant women and their partners relies heavily on the provision of accurate and comprehensive information regarding these screening tests[28].

The concept of the sanctity of life fails to adequately address circumstances in which the viability of the fetus is compromised[29]. Although the present study revealed a higher prevalence of pregnancy termination preference in anencephaly than in DS, the predominance of moral scruples and religious convictions as grounds for continuing pregnancy in anencephaly implied a potential disregard of the best interests of the child and the burdens endured by both the mother and the fetus. Following the decision to continue pregnancy in severe fetal anomalies, such as anencephaly, parents often advocate for aggressive medical interventions aimed at sustaining the infant's life. This can lead to conflicts, as parents prioritize the quantitative aspect of life, whereas health professionals prioritize the qualitative dimension[30]. In routine clinical practice, the determination of medical treatments and interventions prioritize the patient and this outweighs other factors, with decisions made based on their alignment with these[8]. Given the uncertain prognosis and high mortality rate associated with anencephaly, there is no consensus regarding the recommended medical course of action for affected infants[30]. Considering the irreversible nature of this condition and their inability to engage in typical human activities due to severe neurological deficits, there exists no moral imperative to prolong the life of anencephalic infants through life-sustaining measures, a viewpoint articulated by O'Rourke as morally and ethically untenable[31]. Consequently, the pursuit of medical interventions for anencephalic infants can engender moral distress among healthcare providers, prompting contemplation on the ethical implications of such actions in relation to the infant's welfare. This ethical quandary not only poses challenges for parents but also presents a moral dilemma for the medical team. It is essential to recognize that anencephalic infants deserve to receive appropriate comfort and palliative care during their potentially brief lifespan, just like everyone who is dying[30,31].

Among participants who expressed a willingness to terminate their pregnancy in an anencephalic fetus, a majority cited concerns regarding the baby's anticipated short lifespan and the desire to avoid subjecting the infant to a life fraught with pain and suffering. Previous research has similarly highlighted the premature mortality of anencephalic infants as a primary factor influencing the decision to terminate pregnancy. As the prognosis for the baby's survival diminishes, there is a growing inclination toward considering pregnancy termination. Furthermore, the paramount consideration in the decision to terminate pregnancy is the avoidance of potential pain and suffering for the infant[32]. The inherent purpose of pregnancy is to facilitate the development of the fetus into a functioning individual capable of engaging in human activities[31]. However, termination of pregnancy is not endorsed for fetuses diagnosed with life-compatible diseases or disabilities beyond the 24th week, which is known as the limit of viability [32]. In contrast, anencephalic fetuses, being inherently non-viable, may be subject to pregnancy termination at the discretion of the parents following diagnosis[31]. This course of action, executed in accordance with the autonomous decision-making of parents, serves to safeguard the interests of the fetus and mitigate the futile allocation of medical resources [8].

Our research provided insights into additional factors influencing preferences regarding the outcome of pregnancy in fetal anomalies among Turkish pregnant women. A minority of participants opted to continue pregnancy, citing uncertainties regarding the accuracy of the diagnosis, the absence of immediate health impacts on themselves, and the prospect of a potential future cure for the fetal condition. During the process of parental counselling, it is imperative to elucidate the risks associated with delivering a non-viable infant and the resulting burdens on the infant, mother, and broader family, ensuring that parents comprehend these implications thoroughly[21].

Prevalent considerations encompassing risks and burdens, such as lifelong care requirements for the child, potential health risks to the mother, strain on the affected infant and its siblings, and the risk of societal discrimination, emerged among pregnant women opting for pregnancy termination. Previous studies have similarly highlighted comparable grounds for the continuation or termination of pregnancies[3,16,33,34]. Although the manifestation of distrust in medical interventions is concerning, we underscore the critical importance of providing comprehensive and accurate information. Prenatal screening tests are not definitive diagnostic tests and the distinction between these types of tests should be explained to women and their partners. The substantial caregiving burden endured by parents of infants with anomalies[33], coupled with feelings of guilt surrounding their inability to adequately attend to other children[35], and financial challenges associated with treatment and special education, underscore the necessity for precise and thorough parental counselling following the detection of severe fetal anomalies. In addition to professional guidance, facilitating connections with families raising children with DS or relevant support organizations can offer valuable insights and support to parents facing such decisions[36].

The narratives and experiences of individuals with disabilities and their families serve as valuable resources to bolster the decision-making process of those shaping the trajectory of our future generations[21]. These narratives serve to mitigate unrealistic anticipations and empower individuals to make informed decisions regarding their pregnancies. The persistence of pregnancy, which is potentially driven by economic reliance, societal norms perpetuating female subjugation, or familial opposition, poses a hindrance to pregnant women's autonomy in decision-making concerning their bodies. Prospective research involving pregnant women, and their partners holds promise for elucidating the influence of spousal dynamics on the decision-making process surrounding pregnancy termination.

Strengths and limitations

The study findings have several limitations. First, participants responded to hypothetical scenarios, potentially leading to responses differing from those in real-life situations. Second, despite the implementation of preventive measures, such as mask-wearing, physical distancing, and maintaining an open-door during interviews during pandemic conditions, participants may have experienced heightened stress and unease due to concerns regarding COVID-19 transmission. In addition, the absence of spousal participation in the study may have hindered the disclosure of certain pertinent information on the topic.

Conclusion

The findings revealed a discernible shift in the pregnancy preferences of women within Turkish society, contingent on the diagnosed anomaly of the fetus. Furthermore, the rationales underpinning the choice to continue or terminate pregnancy exhibited either congruencies or disparities contingent on the anomaly. Factors such as personal and religious convictions, the sanctity of the infant's life, skepticism toward medical intervention, optimism regarding potential future treatments, and fatalistic outlooks emerged as recurrent justifications for opting to continue pregnancy in both anencephalic and DS cases. Notably, in the context of DS, the inclination toward continuing pregnancy was accentuated by governmental assistance and the potential for the affected children to experience happiness.

The rationales cited for opting for pregnancy termination in both diagnoses encompassed concerns regarding the compromised quality of life for the infant and the resultant caregiving burdens. Specifically in DS, participants additionally highlighted apprehensions regarding the potential discrimination faced by a disabled child. In essence, the study findings underscored that decisions regarding the outcome of pregnancy were influenced by considerations including the anticipated life expectancy and quality of life of the infant, the ensuing familial caregiving responsibilities, and the availability of governmental support. Given that preferences stemmed not only from religious and cultural factors but also from the perceived risks associated with the diagnosis, it is advisable that prenatal diagnostic counselling be structured to facilitate informed decision-making.

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Competing interests

The authors declared that they have no conflict of interest.

Data availability

Data will be made available upon request.

Contributions of authors

BB and NE conceptualized and designed the study, BB collected the data, BB, RAE and NE performed the analysis and interpretation of data, BB and RAE wrote manuscript. The authors read and approved the final manuscript.

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