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RESEARCH ARTICLE

Ethical Analysis of the Pregnant Women's Decision-Making Process about Congenital Anomalies Detected during the Prenatal Period in Turkey

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Abstract

Objectives: The study has been focused on how the women make sense of what they experience in the decision-making process about continuing or terminating the pregnancy after the prenatal diagnosis. In this process, the expression of the problems experienced by those who lived and their decision-making experiences have been analyzed in terms of medical ethics.

Method: The study was carried out as a qualitative field research in order to achieve the aim of it. During the study, after prenatal diagnosis, in-depth interviews were conducted with women who decided to continue the pregnancy and women who decided to terminate the pregnancy. The data obtained from the in-depth interviews were evaluated by thematic analysis method.

Results: As a result of the evaluation of the data obtained in this study, some important information that can be used as a basis for justification in discussions on terminating the pregnancy after prenatal diagnosis, which is a problem in medical ethics, were obtained. At the same time, it was also observed that the decision on terminating the pregnancy is a personal and difficult decision and the personal factors and a person's world of values play a determinant role in this decision.

Conclusion: In our study, the findings revealed that the moral mindset of individuals was the main determinant in the decision to be made on sensitive and difficult issues, such as the termination of pregnancy.

Keywords: Congenital anomalies, Decision-making process, Ethical analysis, Prenatal diagnosis

Introduction

Congenital Anomalies of the Fetus

Pathological features emerging in the fetus during the prenatal period are called anomalies. These inborn pathologies are also referred to as congenital disorders or congenital malformations. These disorders occur in structural or functional aspects (such as metabolic disorders) of the body during intrauterine life. They can be detected before, during, or after birth (Aksoy, 2001).

According to the data of the World Health Organization (WHO), approximately 303.000 newborns die each year within 4 weeks of birth due to congenital anomalies. Even in European countries where childhood general mortality rates are low, 25% of neonatal deaths occur due to congenital pathologies. Although 50% of the anomalies are not due to a specific cause, there are considered to be conjoined effects of genetic, infectious, nutritional, and environmental factors (WHO, 2010).

Spontaneous abortions and stillbirths may occur due to anomalies (Altin, 2009). Congenital anomalies are a prominent cause of death and disability with an unknown cause among infants and children under the age of 5 years. These anomalies may adversely affect individuals, families, and societies as they may result in life-threatening situations and chronic disabilities. Therefore, detecting anomalies in the fetus is significant concerning child and women's health services and leads to a decision-making process whether to continue or terminate the pregnancy.

Objective

Deciding on the continuation or termination of pregnancy due to anomalies detected during the prenatal period is a personal and difficult experience in which many factors

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are determinant. There are studies investigating various factors that may affect this decision-making process. However, these previous studies focused more on data on how many people made the decision to terminate the pregnancy in which prenatal diagnoses were made. In these data, there is no explanation about what sort of decisions are made in certain situations and on what moral values these decisions are based on. Therefore, performing the ethical analysis of the decision-making process is essential concerning both revealing the moral burden of the issue and preparing the ground for ethical discussions on this topic.

This study focuses on how women with pregnancies to a fetus with anomalies make sense of their experiences in the decision-making process regarding the continuation or termination of pregnancy. The present study aims to analyze how the issues encountered in this process are expressed by the patient and how the decision-making is experienced by them concerning the principles of medical ethics.

Material and Methods

Since this study aims to analyze the moral discourses and the individual experiences of the participants, a qualitative research method was preferred. The study was carried out as a qualitative field research in order to achieve the aim of it. During the study, after prenatal diagnosis, in-depth interviews were conducted with women who decided to continue the pregnancy and women who decided to terminate the pregnancy. The obtained data were then subjected to thematic analysis.

Research Process

The population of this research consisted of women who had an anomaly detected in their fetus using prenatal diagnosis methods during follow-up.

Participants were divided into two groups as those who decided to terminate the pregnancy and those who decided to continue the pregnancy. A critical point in conducting such a study is to gather an informative group of participants that best represents the population from which they are selected and thus enlightens the researcher about the subject under study. Taking this principle into consideration, the snowball sampling method and the method of reaching the person from the source were used for both groups while selecting the participants. Mostly, the person was reached from the source through the specialist physician who made the prenatal diagnosis. Some participants were reached through people who knew their experience.

Main Points

- Performing the ethical analysis of the decision-making process about terminating the pregnancy is essential concerning both revealing the moral burden of the issue and preparing the ground for ethical discussions on this topic.
- The decision on terminating the pregnancy is a personal and difficult decision, and the personal factors and person's world of values play determinant role in this decision.
- In the decision to be made, the age of the woman, whether the pregnancy in question was planned, and the number of living children are effective.
- In the decision to be made, the knowledge and experience of the woman, the opinions of her kinsmen, and the opinion of the healtcare professionals (physician, nurse, midwife etc.) are effective.
- In the decision to be made, the value the woman attributes to the fetus is effective.
- It should be that a standard legal minimum time limit should be given to decision-makers after providing the information.

This study aimed to obtain comprehensive data on personal experience from participants. Thus, in this study, the focus was on the detailed opinions, thoughts, and experiences of the people rather than the superficial information on the research subject. After receiving the approval of the ethics committee, the interviewees we invited agreed to participate, and all signed informed consent forms to confirm participation. Two data collection forms developed by the researcher in the context of this interviews were used. Particular attention was paid to the privacy of the participants as the research subject was sensitive and morally loaded. For this purpose, no one except the researcher and the participant who gave informed consent for this study was included in the interview session. The interviews with the participants were transcribed verbatim by the researcher. Non-verbal expressions, such as pauses during speaking, laughing, and crying, are processed on raw documents to record and reveal the exact meaning of the spoken words in the written text.

The texts were read repeatedly by the researcher. All interviews were evaluated thoroughly by an in-depth thinking process. Each interview was subjected to thematic analysis, and the expressions describing the individual experience were underlined. These statements were compared with descriptions of similar experiences to reveal a pattern. Moving forward, sub-themes were revealed. These subthemes were combined under the themes that indicated the common meanings they contained. In this process, expert support was received concerning qualitative research methods. The determined themes were evaluated with comparative reading and then they were finalized.

Results

Participants of This Study

The study group consisted of 25 women who had a fetal anomaly detected during the prenatal period of a previous pregnancy (Table 1). While 11 out of 25 women who agreed to participate in this study decided to continue the pregnancy, 14 chose to terminate the pregnancy.

Characteristics of Participants

Most of the participants had a second pregnancy, and the number of children was one. Two participants stated that they had spontaneous abortion once, and one participant stated that she had abortion six times. The participant who had six spontaneous abortions had consanguineous marriage, and it was stated by the participant that she had a history of spontaneous abortion in her first-degree relatives.

Table 1
Some Demographic Information of the Participants according to Their Protocol Numbers

No	Age of Woman	Education Status of Woman	Fetal Diagnosis Week	Fetal Diagnosis	Decision
GD.16.01	30	Primary School	17	Anencephaly	Pregnancy continuation
GD.16.02	30	College	8	Risk of infection	Pregnancy continuation
GD.16.03	26	Master Degree	23	Chromosomal disorder	Pregnancy continuation
GD.16.04	39	Primary School	22	Chromosomal disorder	Pregnancy continuation
GD.16.05	32	Primary School	22	Turner syndrome	Pregnancy continuation
GD.16.06	35	Primary School	20	Multiple organ malfunctions	Pregnancy continuation
GD.16.07	39	Master Degree	23	Down syndrome	Pregnancy continuation
GD.16.08	30	Graduated from a Universty	22	Trisomy 18	Pregnancy continuation
GD.16.09	34	Graduated from a Universty	22	Trisomy 13	Pregnancy continuation
GD.16.10	36	Primary School	20	Down syndrome	Pregnancy continuation
GD.17.01	27	Primary School	17	Multiple organ malfunctions	Pregnancy continuation
GS.16.01	28	Master Degree	13	Gastroşizis	Pregnancy termination
GS.16.02	42	Graduated from a Universty	19	Trisomy 13	Pregnancy termination
GS.16.03	29	Primary School	20	Multiple organ malfunctions	Pregnancy termination
GS.16.04	36	Graduated from a Universty	23	Apert syndrome	Pregnancy termination
GS.16.05	32	Graduated from a Universty	22	Chromosomal disorder	Pregnancy termination
GS.16.06	33	Graduated from a Universty	22	Down syndrome	Pregnancy termination
GS.16.07	31	Graduated from a Universty	16	Multiple organ malfunctions	Pregnancy termination
GS.16.08	28	Graduated from a Universty	20	Trisomy 13	Pregnancy termination
GS.16.09	34	Graduated from a Universty	16	Anencephaly	Pregnancy termination

Table 1
Some Demographic Information of the Participants according to Their Protocol Numbers (continued)

No	Age of Woman	Education Status of Woman	Fetal Diagnosis Week	Fetal Diagnosis	Decision
GS.16.10	34	Graduated from a Universty	22	Down syndrome	Pregnancy termination
GS.17.01	35	Primary School	16	Risk of infection	Pregnancy termination
GS.17.02	40	Graduated from a Universty	17	Anencephaly	Pregnancy termination
GS.17.03	36	Graduated from a Universty	20	Multiple organ malfunctions	Pregnancy termination
GS.17.04	34	Graduated from a Universty	22	Down syndrome	Pregnancy termination
Toplam	25	25	25	25	25

Most of the women do not have experience of having a baby with anomaly and/or terminating pregnancy in their immediate vicinity. Only one participant had a child with a disability who was born before, and eight participants stated that they had the knowledge of those who had similar experience because they were nurses.

Most of the women said that their current pregnancy was planned. Three of the five unplanned pregnancies decided to terminate the pregnancy after prenatal diagnosis, and two decided to continue the pregnancy.

Prenatal diagnosis was determined at the earliest 14th gestational week and at the latest 23rd gestational week. Ultrasonography method was mostly used in the diagnosis of prenatal anomaly, and advanced diagnostic tests were also applied for the certainty of the diagnosis. The detected anomaly type is mostly chromosomal anomaly.

Research Questions

In the research, questions that complement each other in terms of meaning load were asked in order to obtain data on the knowledge, emotions, behaviors, and experiences of the participants. In the first question, when, where, and how the participants had the prenatal diagnostic test is questioned. The second question was structured in support of the first question and was prepared to determine who and how told the participants the results of the prenatal diagnosis test. The third question was asked after learning the result of the prenatal diagnosis test to find out whether the test was repeated or not. The purpose of asking these questions is to learn the experiences of the participants regarding prenatal diagnosis methods. The next two questions are information questions to determine what they know about the prenatal diagnosis told to them after the prenatal diagnosis test (Did you have any previous information about the diagnosis you were told (Your family, friends, media, movie, book, etc.)? What do you know/did you know about the medical diagnosis you were told?).

With "What did you do after learning the medical diagnosis?" and "What did you do about the continuation or termination of the pregnancy?" questions directed to the participants, it was aimed to obtain information about what they did after receiving a prenatal diagnosis and how they decided to terminate or continue the pregnancy. In order to determine the emotions felt by the participants in the decision-making process, "How did you decide to have this baby?", "How did you feel when you learned that there was a baby with an anomaly?", "What made you feel good-strong, bad and weak in this process?", "What would make you feel better while having this experience?" questions were asked.

In the research, the value-laden answers to these open-ended questions directed to the participants were brought together in terms of their meaning loads, and sub-themes were determined by detailing the main themes. These results present the six contexts: (1) prenatal diagnosis experience; (2) women's ways to cope; (3) continuing the pregnancy; (4) termination of pregnancy; (5) emotional state of the woman; and (6) women's expectations. The themes and sub-themes that fall under the six contexts are presented in Table 2.

Results of the Prenatal Diagnosis Experience of the Participants

It has been determined that women have access to comprehensive information about prenatal diagnosis as a result of both "cognitive level" and "efforts to reach scientific information." All of the participants described what the prenatal diagnosis they were told was and what it meant. Most of the women stated that the decision they made about the continuation and termination of the pregnancy was "a

Table 2
Contexts, Themes and Sub-Themes Identified through Interviews with Participants

Context	Themes			Expression
	Main Theme	**Sub-Theme**	**Sub Theme**	
Prenatal diagnosis experience	Attempt to identify anomaly	Cognitive level		"(...) My wife and I researched the subject as if we were working on the internet every day." GD.16.03
				"(...) I had no knowledge. I researched what this disease could be...." GD.16.04
		Efforts to access scientific knowledge (about diagnosis and treatment)		"The doctor who looked at the ultrasound said. Outside, the doctor said the same thing. I went to the outer center. There was one in .... The radiologist did, too. When he said the same things, I decided to ignore it." GS.16.01
				"(...) I always wanted to confirm the diagnosis. Because the decision I was going to make was very difficult. What if he wasn't sick, would I mean a life?" GS.16.03
	Definition of decision	Having a difficult decision		"(...) At first, they were not sure whether there was an anomaly, they said that it may or may not be corrected." GS.16.05
		Too much emotional burden		"This experience has been quite difficult. Emotional thinking was tiring and wearisome...."GS.16.06
		Effectiveness of familial and religious views		When we were told that you should have it removed, we called our family. We asked my father. My daughter said that if it will affect the mother's health badly, if it can cause the death of the mother, it can be removed, there is no problem in our religion. We also asked a few people with good religious knowledge. They said it's available." GS.17.01
				"(...) I went to the imam to see what would happen. It was said that if he was removed for medical reasons, his parts could be collected and buried, and if he died in the womb, he could be given birth and buried." GD.16.03
		Decision by the physician		"(...) Some said that we will take it directly. It's not like they're leaving a choice, actually. Maybe it is comforting for those who want to say that they should be taken." GS.16.03
	Definition of decision-making process	Having a difficult experience		"(...) It was a difficult experience for us." GS.16.09

Table 2
Contexts, Themes and Sub-Themes Identified through Interviews with Participants (continued)

Context	Themes			Expression
	Main Theme	**Sub-Theme**	**Sub Theme**	
Women's ways to cope	Problem-focused coping	Problem/issue diagnostic effort	Information about the diagnosis of anomaly	"(...) I went to all the doctors I trusted...." GS.16.03
			Informing about the postpartum process	"What happens to him if we're not alive? Who looks after him? These questions clarified our decision-making." GS.16.10
	Emotion-focused coping	Avoiding the problem	Not thinking	"(...) Working and commuting made me feel good. It's not something to be tolerated by staying at home. My work place was busy and there was no time to think." GS.16.03
	Using defense mechanisms	Acceptance		"(...) We are upset. We said from God. We accepted...." GD.16.10
		Fatalistic approach	Submission/ relegation	"(...) I left it to itself. There was a pregnancy that was thought to be impossible. I thought that if I was going to live, it would definitely happen." GD.16.02
		Rasyonalizasyon	Do not think you have been chosen	"(...) We are the chosen people, we are special. That's why it's not possible for everyone...." GD.16.07
			Perceiving the disabled child as a gift of the creator	"(...) This is a gift from Allah. Of course, having such a baby made me even more grateful." GD.16.07
	Using spiritual suggestion methods	Praying	Do not ask for patience	"(...) I just rested. And I prayed." GD.16.06
			Wishing power	"(...) I said give me strength. I said be patient. I said, 'Whatever you give me, show me the cure and ease of the trouble you gave me'." GD.16.07
			Desire to make the right decision	"(...) That is why he is always in my prayers. Oh my God, don't make me mislead, don't make me take the wrong decision, don't give me loads that I can't lift. So I leaned my back on God. In any case, I said that I would accept whatever happens." GD.16.07

Table 2
Contexts, Themes and Sub-Themes Identified through Interviews with Participants (continued)

Context	Themes			Expression
	Main Theme	**Sub-Theme**	**Sub Theme**	
		Visiting the shrine		"(…) Hz. Ibrahim Hz. I wanted to visit Eyüp there too. Everything happens when God says to be. I said maybe the doctors saw it that way. Maybe it'll be fixed until the end. Maybe not, maybe they were wrong. So I said anything is possible." GD.16.07
		Do not be rebellious		"(…) We were a strong and happy family. We could not revolt. We took refuge in Allah. We prayed." SE.16.06
Continuing the pregnancy	Belief system	Not to sin		"(…) He who fears Allah will not do it. I cannot revolt. Sin is already…." GD.16.01
		Obedience to the creator's will		"(…) Why did such a thing happen to us? We tried not to rebel against God. God knows both good and bad…." GD.16.08
	Perception of life	Beginning of life		"(…) It is not whether he was born or not, but because he is still alive in my stomach and because he is our dear child, we decided not to care." SE.16.06
		Purpose of life		"(…) When we say exam, life is a test, after all, we can pass other exams by not accepting this child… Maybe twenty, maybe thirty, maybe fifty years you can live here, so this world has a certain limit. I intend to serve the other world." GD.16.07
		Value of life		"(…) We didn't think about ending it. We couldn't ignore life… We couldn't mean it." GD.16.04
	Cultural factors	Family structure		"(…) My wife works abroad… She didn't want me to mind. He said if you take it off, I will get angry…." GD.17.01
		Value attributed to the fetus		"(…) But alive, you are sick and I cannot say that I do not want you…." GD.16.09
Termination of pregnancy	Trusting scientific knowledge	Precision of scientific diagnosis		"I said we are on the side of science. Caring for such a child requires both opportunity and patience… I have a more scientific approach. Who trusts doctors." GS.16.02
		Difficulty living with anomaly		"Since I live with a disabled child, I know his thing for 6 years and they enjoy what they eat…they can say what they are thirsty for. They say they live like grass. But I would not want them to live like that. But if you gave them a minute or a second they would say they probably would not want to be born like this. I think so…." GD.16.05

Table 2
Contexts, Themes and Sub-Themes Identified through Interviews with Participants (continued)

Context	Themes			Expression
	Main Theme	**Sub-Theme**	**Sub Theme**	
		Maternal health priority		"(…) Maybe even because I will give birth to him, my own health may deteriorate. After all, pregnancy is a tiring process for women's health and body. Maybe even in my ability to conceive again." GS.16.08
	Treatment/ care problem	Need for continual care and treatment		"I think the continuation of pregnancy is unfair to the creature that will be born. Would a child born this way want to be born? I always thought of this question. Even if he was born and lived, everyone will look at him differently. It will take a lot of surgery. It will need constant care. What if something happens to me and my wife, who will take care of her." GS.16.04
		The challenge of the hospital process		"If we continue the pregnancy, after all, she will not be able to live when she is born. Even if he lives, he will have very difficult hospital days, maybe he will have pain that he did not feel while inside me. It's going to be hard to leave him at the hospital and come home. So in the continuation of the pregnancy, everything would be harder and more painful for us than terminating it." GS.17.02
	Cultural factors	Family structure		"I researched the subject from every source I could get information about. I discussed the issue with my family. I tried to decide. I have decided to terminate it." GS.16.05
		Value attributed to the fetus		"(…) He is not a child yet. A cell growing inside of me. It's okay when I'm inside. But after leaving me, I think everything would be difficult for him and for us." GS.16.10
Emotional state of the woman	Feeling bad/ weak	Information failure		"(…) However, not being given enough information, especially not being able to see my wife while I was in the hospital, made me feel very bad. I was inside, they had a hard time outside." GD.16.04
		Physician related		"(…) What made you feel bad and weak was that the doctors didn't say anything because you wouldn't understand, and that they behaved badly and resented it." GD.16.01

Table 2
Contexts, Themes and Sub-Themes Identified through Interviews with Participants (continued)

Context	Themes			Expression
	Main Theme	**Sub-Theme**	**Sub Theme**	
		Hospital related		"(...) The bad thing is that the spouses are not taken. When I learned of the diagnosis, my wife was not there. My wife could not be with me when they took blood from the placenta. Difficult moments and difficult decisions one wants to feel the support of the relatives of the spouse, but here ridiculous rules are not allowed because of egos. You lack humanity." GS.16.01
		Community related		"People's religious thoughts and pressures are upsetting. Words such as sin, will it hurt someone's life were very hurtful. Well, wouldn't it be a sin not to take good care of him." GS.16.04
		Personal deprivations		"Our families were not with us. I wish my mother was with me." GS.16.08
	Feeling good/strong	Related to family and surroundings		"It made me feel good to have strong family ties...." GD.16.04
		Getting psychological support		"It was good to go to the psychologist...." GS.16.02
		Having a plan for the future		"(...) It felt good to know how we wanted to live. My wife wants to specialize and become a lecturer. I am also reading. I want to finish my school and make a job change. We want to be a normal family. We want to raise our children in the best possible way. It would be quite difficult and beyond our wishes to have a child with a disability." GS.17.04
		Study		"(...) It felt good to work all the time...." GD.16.07
		Other children's health		"(...) It made me feel good that my other children were healthy...." GD.16.04
	From pregnancy	Being a mother		"(...) Motherhood was a beautiful thing. It was something that started the moment you felt it in your soul...." GD.16.09
		Having a healthy normal baby		"(...) I wanted a brother to be a companion for my daughter. I want a sibling to call and ask to support each other when we are not alive. But the second baby's illness would be sad for his brother. He wanted so much to have a brother. In the end, going through a birth process knowing that she will die did not feel right for me to my wife." GS.17.02

Table 2
Contexts, Themes and Sub-Themes Identified through Interviews with Participants (continued)

Context	Themes			Expression
	Main Theme	**Sub-Theme**	**Sub Theme**	
Women's expectations	From society	Related to disabled child		"(...) The fact that my child was not considered disabled and the perspective of the people around me made me feel very bad...." GD.16.07
		Regarding the decision		"It would have made us feel better if people weren't biased and empathetic, and avoiding judgmental words about our decision." GD.16.04
	From the health system	Expectations from the physician	Personality characteristics	"(...) It would have felt better if the doctors were more humane." GD.16.06
			Professional responsibility	"Physicians should act more closely. They should be descriptive." GD.16.01
			Code of professional conduct	"(...) It might be good for doctors to be a little more calm with such pregnant women." GS.16.09
		Development of perinatology services		"(...) Perinatology should also be examined after the 20th week. Every time a pregnant woman comes, it should be looked at in detail." GD.16.04
		Improving the rights of disabled patients		"(...) I would like to say that even in those hospitals that guide me, we waste a lot of time. Let them make an appointment, you have this control at this hour. While this will be in three days, in five days, we have been trying to get a disability report for a month and a half. Someone should help us... I ask these from the parliament, from our elders." GD.16.07
		Providing consulting services		"(...) It is really difficult to have such a disabled child under the conditions of our country. There must be people of the Ministry of Family Policy to guide me, your baby will be like this, you have these rights, go here and get informed. Let them say that they support me financially and morally. Nobody helps me, I am always in search. Let it be the authority that declares our rights." GD.16.07

difficult decision," "the emotional burden was high," and "familial and religious views were effective in the decision." Two participants stated that it was comforting that the decision was made by the physician. Participants described the process they experienced as a difficult experience.

It has been observed that women, while making a decision with their spouses, also consider how the decision will affect the lives of their other living children. It has been emphasized that the disabled child will affect the lives of all family members; therefore, it is important to explain to other children and to learn their thoughts on the subject.

Results regarding the Processes of the Participants after Prenatal Diagnosis

After learning the prenatal diagnosis of the participants, the main theme of "problem/issue-focused coping" and the sub-theme of "effort to diagnose the problem/issue" and related sub-themes of the second category expressed as "informing about the diagnosis of anomaly" and "informing about the postpartum period" were determined in the context of "ways to cope."

In the sub-theme of "informing about the diagnosis of anomaly," it was determined that women generally went to the recommended doctors, applied to other health centers, and had paid prenatal tests.

The sub-theme of "informing about the postpartum process" was indicated by the fact that women generally do research on the internet about what can be experienced in the postpartum period and consult their trusted friend/friend physicians.

The participants' efforts to find out what the diagnosis of anomaly is in the decision-making process and how the process after birth will be was evaluated as an important factor determining what the decision would be because women have stated that they usually make decisions by thinking in line with the information they have obtained.

Again, in the context of "women's ways of coping," the main theme of "emotion-focused coping" was determined as "keeping away from the problem" sub-theme and related "not thinking" as the second category sub-theme.

In the context of "women's ways of coping," the main theme of "using defense mechanisms" was generally found in women who decided to continue the pregnancy. Related to this main theme are the sub-themes of "acceptance," "fatalistic approach," and "rationalization"; In the sub-theme of "fatalistic approach," "submissiveness/letting go to the process" and in the "rationalization" sub-theme, "thinking that he was chosen" and "perceiving the disabled child as the gift of the creator" were found in the second category sub-themes.

In the context of "Women's ways of coping," in the main theme of "using spiritual indoctrination methods," sub-themes "praying," "visiting the shrine," and not being rebellious were determined. In their prayers, women generally stated that they wished for patience and strength and wanted to make the right decision.

Factors Affecting the Participants' Decision to Continue the Pregnancy

It has been determined that the belief system, perception of life, and cultural factors mostly affect the decision of women not to terminate the pregnancy after prenatal diagnosis.

It was determined that the participants generally experienced their religious beliefs the same and similar to each other. Although there was no specific question about religious belief among the questions prepared to determine demographic information, all of the participants stated that they had a creative belief. It was determined that the women decided not to terminate the pregnancy due to their belief system, not to sin and to submit to the will of the creator.

Some of the women who did not choose the option of terminating the pregnancy in their decisions stated that they prayed for the fetus to die in the womb before it was born. They did not want the baby, but they did not choose to terminate the pregnancy either. This showed that the belief system was more effective than their wishes in their decisions.

In the in-depth interview of the participants who decided not to terminate the pregnancy, the discourses about the life begins in the mother's womb, the purpose of life is the exam, and the value of life determined the theme of perception of life.

In relation to the main theme of cultural factors in the decision not to terminate the pregnancy, sub-themes of "value attributed to fetus" and "woman's family structure" were determined. It has been determined that women who generally have other children think that the prenatally diagnosed fetus and other child/children have the same moral status, and they take this moral status into consideration when making decisions. It is understood from the testimonies of the women that they do not accept ending the life of the fetus as a right action due to the moral status they attribute to the fetus.

The family structure in which the woman lives has been identified as one of the cultural factors affecting the decision. In families where the woman is not the decision-maker, it has been determined that her husband or family elders are effective in the decision.

Factors Affecting the Participants' Decision Not to Continue the Pregnancy

Most of the women who decided to terminate the pregnancy stated that they accepted the diagnosis of anomaly as certain because they trusted scientific knowledge that it was difficult to lead a life with anomaly and that they thought that maternal health should be a priority.

It has been determined that women prefer to terminate the pregnancy due to treatment and care problems such as the need for continuous treatment and care after the birth of the prenatally diagnosed fetus and the difficult and exhausting hospital process.

It has been determined that most of the women who terminate their pregnancy are the decision-makers, and their spouses and their families are supportive.

It was determined that some of the women who terminated the pregnancy did not give a moral status to the fetus in their statements.

Results of the Emotional State of the Participants

Women generally stated that they experienced stress, shock, and weariness during the decision-making process, that they felt astonishment, fear, panic, sadness, anxiety, helplessness, and pain, and that they cried constantly because of these feelings.

In the in-depth interviews with women, the main themes of "feeling bad and weak" and "feeling good/strong" came to the fore in the context of "woman's mood."

The sub-themes of the main theme of "feeling bad/weak" were determined as "informational defect," "physician related," "hospital related," "society related," and "personal deprivations."

It was stated that women's feelings of bad/weakness in relation to the physician were mostly due to the physician's negative behaviors and the physician's negative speeches.

It has been determined that women feel bad/weak due to reasons such as the fact that the hospital waiting rooms are mostly the same and the spouse cannot attend the examination or practice.

It was determined that the participants who decided to terminate the pregnancy generally felt bad/weak about the society because of the discourses made about the belief system.

When the participants learned about the anomaly diagnosis, they stated that they experienced personal deprivation due to reasons such as being alone and lack of family support.

The sub-themes of the main theme of "feeling good/strong" were determined as "having a plan for the future," "other children being healthy," "related to family and environment," "receiving professional support." It was determined that the participants generally felt good and strong because of "having strong family ties," "supporting spouses and friends," and "supporting the workplace" in terms of "related to family and environment." Women also stated that they felt good/strong when they received professional support such as meeting with a psychologist.

Results on the Expectations of Women in the Decision-Making Process

In the in-depth interviews with the women, their statements about the expectations of becoming a mother and having a healthy normal baby pointed to the main theme of "women's expectation from pregnancy."

It was determined that the participants generally had expectations from the society about "decision related" and "disabled children." Regarding the disabled child, the participants stated that these children should be accepted in the society and the families of the disabled children should support each other. Regarding the decision, it has been determined that they expect both the society and the close environment/relatives to avoid discourses about belief, not to make negative comments about the decision, to respect the decision, and to support the care of disabled children.

Women are generally more "personal traits" than physicians, such as being good, humane, kind, and sensitive; explaining everything to their patients well, showing "professional responsibility" such as being competent in terms of professional knowledge; they stated that they expect women to respect the autonomy of women, give importance to their privacy, give importance to effective communication time, pay attention to "professional behavior rules" such as being interested and speaking well.

It has been determined that women expect "development of perinatology services," "consulting services," and "improvement of the rights of disabled patients" from the health system.

Discussion

Participants who had an expectation of having a healthy child faced a situation contrary to their expectations after the prenatal diagnosis. After prenatal diagnosis, the family faced possibilities and options, such as having a disabled child/stillbirth/loss of the fetus in the womb or terminating the pregnancy. In the context of these possibilities, they were left to choose between terminating or continuing the pregnancy.

Decision-Maker(s)

In the decision-making process, it is important who the decision-maker is/are and what kind of influence he/she has on the decision. In addition, it is essential to assess whether the pregnant woman is a decision-maker in the choice to continue or terminate the pregnancy.

Most philosophical discussions about the continuation or termination of pregnancy focus on the problem that underlies the relationship between woman and fetus. Our study shows that another important problem arises beyond discussions, such as whether the fetus has an external otherness beyond the pregnant woman, the woman's right to make decisions about her own body, the woman's right to reproduce, and the fetus' right to life. This problem is the inability of the woman to be a decision-maker in her relationship with the fetus and to experience her individual autonomy. If the pregnant woman' decision-making process is at stake, she should definitely be accepted as a decision-maker. However, economic dependence and cultural factors make women dependent on their spouse, family, and the society they live in and make them vulnerable to outside. The woman bound in the society can only experience her autonomy within limits predefined by this dependence (Frederico et al., 2018).

According to previous studies, women are excluded from the decision-making process about the continuation or termination of pregnancy in traditional societies, but on the contrary, they are decision-makers in modern societies

(Sheiner et al., 1998). In traditional societies where women are not usually the decision-makers, the decision to continue the pregnancy is made more frequently than in modern societies (Alsulaiman et al., 2012; Awwad et al., 2008).

In our study, the findings suggest that women consider their spouse and themselves as decision-makers, and the spouse's attitude significantly affects the direction of choice. In addition, women stated that they decided to have a baby together with their husbands, so they requested the necessary arrangements to be made so that their spouses could be with them at all stages of the prenatal process (eg, during the examination or the application of interventional prenatal tests).

Decision-makers can ask their children's opinions or other people close to them due to the significance and sensitivity of the subject to be decided. In our study, the findings showed that women received opinions from their children, parents, relatives, friends, and religious officials during the decision-making process. It was determined that they feel good if the opinions received are in line with the person's decision; otherwise, they feel bad.

Two participants in our study stated that it is more comforting to make the decision by the physician. This finding suggests that sharing the burden and responsibility of decision-making is preferable in the ethical dilemma regarding the value of the potential life of the fetus.

"[…] Some directly stated that they would terminate the pregnancy. In fact, they do not leave much choice to the person. Perhaps their saying 'the pregnancy must be terminated' is a relief for those who actually wish to terminate the pregnancy." GS.16.03

"Actually, the decision to *terminate the pregnancy is not left to us […] It felt good that the choice to terminate the pregnancy was not left to us."* GS.16.01

The physician is in a very effective and unique position on a sensitive issue that the woman should decide on herself (NCB-Nuffield Council on Bioethics, 2014). However, to protect the autonomy of the woman, it is vital that the doctor does not take the role of the decision-maker during his/her counseling. The following statement of one of the participants in our study supports this view.

"[…] The doctor who said that we need to terminate the pregnancy made us very upset. We just asked them to tell us the information we did not know. The doctor should not have told us to terminate the pregnancy without even knowing our decision, our thoughts [….]" GD.16.06

This statement of the participant shows the ethical gravity of the physician–patient relationship based on mutual participation. According to Yalim (1995), the main reason for the physician–patient relationship to evolve into a relationship based on mutual participation is the change in the basis of trust. Rather than believing that "the doctor will do what is best for him" (the Hippocratic element of trust), patients today rely on the physician they believe will provide him/her with the information he/she needs to decide the best choice (the trust element based on informed consent). Therefore, in our study, it was assessed that it is ethically necessary for physicians to adopt an approach based on mutual agreement on a sensitive issue, such as the termination of pregnancy.

Factors Affecting the Decision

In the decision-making process, it was assessed whether the pregnancy was planned, or not, and the number of living children were major factors determining the choice to be made. Field studies on the subject show that the decision to terminate the pregnancy is made more frequently in unplanned pregnancies (AGI-The Alan Guttmacher Institute, 1999; Maral et al., 2007; Ribera et al., 2007; Demirci, 2015; Chae et al., 2017). In our study, it was seen that the participants who made the decision to terminate the pregnancy had more living children compared to the other group.

Having experience with the subject to be decided is a central factor in the decision-making process. In the study of Schechtman et al. (2002), women with a history of a pregnancy with a fetus that had an anomaly had a higher tendency to terminate the pregnancy. In our study, the participants who were nurses generally stated that they had the knowledge of what people experienced in similar situations, and most of them made the decision to terminate the pregnancy.

"[…] Being a healthcare worker and predicting what we would experience made us feel better because we had no difficulty in making our decision.[….]" GS.17.03

Studies on the subject generally show that socio-cultural elements, economic factors, and belief systems are effective in the decision to continue or terminate the pregnancy (Altin, 2009; Ekinci, 2014).

However, our study has shown that the emotional bond between the woman and the fetus and the value the woman gives to the fetus are also effective in the decision to be made. One of our participants stated that she made the decision to terminate the pregnancy without waiting for the result of the genetic test not to be more emotionally attached to the fetus. The statement of this participant is as follows:

"[…] Dr. [….] recommended that we wait for the genetic screening result. However, if I had waited for three more weeks, the fetuses would be 16-17 weeks old. Therefore, I would be more emotionally attached to them." GS.16.01

In our study, some of the women stated that they empathize with the fetus while making decisions. They stated that they thought whether the fetus would want a life with disabilities and whether it would want the surgeries required for their postpartum health. In addition, some of the participants stated that they did not find it moral to refuse the pregnancy

after the diagnosis of the pathology while they wanted the baby while the fetus was known as healthy. With these statements, the participants reveal that they give a moral position to the fetus and try to make the final decision by making a moral assessment. In addition, these discourses can be read as women prioritize the fetus more than themselves when making the decision. This approach of women is explained by the "self-sacrifice model" in McDonagh's work. In this perspective, which is defined as the "self-sacrifice model of motherhood," the mother's rights, such as reproduction and career planning, are of secondary importance, and termination of pregnancy is considered a matter of moral conscience (Mcdonagh, 2002). At this point, mother and fetus are considered as two separate and equal individuals. In the opposite model defined as the "self-defense model motherhood," it is stated that motherhood is not in the governing area of the state and the state cannot interfere with the reproductive preferences of women. In this model, it is argued that the rights of women over their own body, their reproductive rights, and other rights, such as future planning, have a certain priority. At this point, while the mother is accepted as an individual, a moral position at the mother's level is not recognized for the fetus.

In the decision-making process, it is necessary that the person has detailed information about the subject to decide. In the quantitative study of Altin (2009), the relationship between the degree of understanding the congenital anomaly and whether to accept the option to terminate the pregnancy was assessed. As a result of this assessment, the findings showed that as the understanding of the congenital anomaly increased, the number of people who accepted to terminate the pregnancy also increased. Again, in another study conducted by Schechtman et al., it was determined that there is a lack of information in families who do not agree to terminate the pregnancy. In our study, the findings showed that women were trying to obtain information about the nature of the prenatal diagnosis from the physicians who followed the pregnancy, and more specifically about the congenital anomaly and its treatment. It was determined that most of the participants made efforts to better comprehend the diagnosis by researching the subject on the internet, consulting with the physicians they trust, going to recommended physicians, and having advanced and expensive prenatal diagnostic tests.

The Period of Providing Information and Making the Decision

In our study, it was assessed that the sufficiency and quality of information are crucial for people to make decisions on important and sensitive issues. In many countries, there is an obligation to inform women adequately. However, the quality of information content may vary.

In our country, there is no standard guide for informing women about the termination of pregnancy. The information provided by the medical board to the woman and her spouse about the termination of pregnancy is usually limited to the duration of the interview.

Allowing a certain amount of time to make decisions on such sensitive and important matters is critical in terms of reassessing and reasoning the choice to be made. In some countries, a legal minimum time limit for making decisions about termination of pregnancy has been defined. The minimum time that must pass until the termination of pregnancy after the physician providing the necessary information with an interview is 3 days in countries such as Germany, Portugal, and Spain; 6 days in the Netherlands and Belgium, 7 days in Italy, and 24 hours in the USA (Ozel et al., 2017). However, in our country, a woman who is informed about the termination of pregnancy is not required to wait for a certain time for the final decision (Turkey Ministry of Health, 2014). In our study, the necessity and importance of this waiting period were expressed as follows by one participant:

"[…] The doctor said, 'if the pregnancy is not terminated, we will lose the mother.' This word was spoken towards noon. It was also told us to 'make a quick decision.' He said we should have made our decision by the afternoon. Time has not been given. Maybe, I will not have a baby again after this termination." GS.17.01

It is also critical what information women utilize in their decision-making processes. In our study, the findings suggest that belief systems, perception of life, and cultural factors had an effect on the decisions of women who did not choose to terminate their pregnancy.

It has been observed that women who choose to continue pregnancy based on the belief systems have the motivations of believing a creator, submission to the creator's will, and fear of sinning. Similarly, in field studies on the subject, religion has been reported to be a major factor in decision-making (Sagi et al., 2001; Korenromp et al., 2009; Çavlin et al., 2012).

In our study, the participants who did not choose to terminate the pregnancy stated that they found the life precious, the life already began in the womb, and the life was a test by the God (based on their belief systems). Moving forward from these discourses, it was considered that the participants thought that life began in the intrauterine period and that they gave the fetus a moral status equal to a healthy child or even an adult. Therefore, it was considered that they did not prefer to terminate the pregnancy because they believed that terminating life in the womb was a great sin and that they did not want to be punished by God. Some of the participants stated that they prayed for the baby to die in the womb before it was born. Although they did not want to have a disabled baby, these participants did not choose to terminate the pregnancy. It seems that the beliefs of the participants are more leading and determinant than their personal wishes in their mindsets.

It has been determined that the scientific and medical certainty of the diagnosis, the difficulties of the life of a child with a congenital anomaly, the need for continuous treatment/care, and the problems that would be caused by hospital treatments are effective in the decisions of women who decide to terminate their pregnancy. In the study of

Altin (2009), it was reported that consideration of the health problems that the baby would suffer throughout his/her life significantly affects the decision-making process. Similarly, the postpartum care and treatment process, which varies according to the type of congenital anomaly, was one of the main problems that women brood about in our study. The following sentences expressed by one of the participants based on her experiences expressed the difficulty of this process:

by one of the participants based on her experiences expressed the difficulty of this process:

"[…] Since I have lived with a disabled child for six years, I know everything about him. However, they can neither enjoy what they eat nor say they are thirsty. [….] They'd probably say that they wouldn't want to be born like this if you gave them a minute or a second. I think so. […] We can provide care now, but what will we do in the future?" GD.16.05

Some of the participants who were observed to make decisions based on scientific knowledge in our study stated that they did not want to continue the pregnancy by putting their own health at risk because they thought that nature would definitely terminate the life of the fetus, even if they did not do it themselves. It was seen that these participants, who did not attribute a moral status to the fetus, prioritized their own health. These perspectives of the participants coincided with the views expressed in discussions on the basis of the right to decide on the woman's own body (Nuttall, 1997; Dolen, 2012; Sert, 2013). However, in opposition to these debates, there are intellectual grounds based on the value of the fetus in intrauterine life and its right to life (Drake et al., 1994; Norup, 1998; Beckwith, 2007; Rimon-Zarfaty & Jotkowitz, 2012; Brown et al., 2014).

Participants generally stated that they experienced stress, shock, and weariness during the decision-making process. Moreover, they felt confusion, fear, panic, misery, anxiety, helplessness, and pain, and they repeatedly cried because of these feelings. It was observed that they used coping strategies to alleviate this emotional burden. The women who decided to terminate the pregnancy generally preferred to stay away from the problem by not thinking about the process. The women who decided to continue pregnancy generally used defense mechanisms (acceptance, fatalistic approach, rationalization) and spiritual suggestion methods. Among these methods of suggestion, it was determined that they most frequently preferred to pray, visit shrines, and not to be rebellious.

The findings obtained in this study suggest that women accepted their husbands and themselves as decision-makers in the decision to be made about the termination or continuation of pregnancy. In the decision to be made, the age of the woman, whether the pregnancy in question was planned, the number of living children, the knowledge and experience of the woman about the subject to be decided, the opinions of her kinsmen, the opinion of the physician, and the value the woman attributes to the fetus were effective. At the same time, in our study, it has been seen that proper provision of information and the quality of information to be provided are of utmost importance for people to make decisions on such vital and sensitive issues. Thus, a standard guide should be developed for decision-makers regarding prenatal diagnosis and the post-pregnancy processes, particularly about the termination of pregnancy. It is deemed necessary that a standard legal minimum time limit should be given to decision-makers after providing the information.

In our study, the findings revealed that the moral mindset of individuals was the main determinant in the decision to be made on sensitive and difficult issues, such as the termination of pregnancy. Further studies to be conducted on these issues should be qualitative in structure.

Limitations of the Study

The interviews were recorded on a voice recorder with the consent of the volunteers. Some interviewees did not want the audio recording to be taken. Notes were taken during the interview as the information to be given by the participant was considered important in any case. It was thought that there might be data loss during note-taking on paper.

At the time of the interview, the spouses of the women were not included in the study due to reasons such as not being able to get permission from the places where they work or not wanting to participate in the interview.

No participant was included in the study specifically for the anomaly detected in the prenatal diagnosis. Therefore, the decision-making processes about termination or continuation of pregnancy were not analyzed specifically for the anomaly.

Only those who decided to terminate the pregnancy due to fetal anomaly were included in the study. Those who decided to terminate the pregnancy for other reasons were not included in the study.

Ethics Committee Approval: This study was approved by the local ethics committee of Gülhane Military Medical Academy Medical Hospital. Ref. No 05April2006/208.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

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