Factors Influencing Pregnant Women's Use of Patient Decision Aids and Decision Making on Prenatal Screening: A Qualitative Study

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Abstract

Objective: We aimed to identify factors influencing pregnant women's use of patient decision aids (PtDA) and decision making on prenatal screening.

Materials and methods: This qualitative study was conducted between July 2019 and June 2020 in Tehran, Iran. The sample included 26 pregnant women selected by purposive sampling. The participants used a prenatal screening PtDA, then interviewed about factors that would influence their decision making and use of decision aids. The data were analyzed by conventional content analysis.

Results: Three categories were identified for the process of and factors influencing decision making, including the current decision making process, expected decision making process, and factors influencing decision making. Also, five categories were identified as factors affecting the use of PtDAs, including the content of decision aids, the appearance of decision aids, the decision aid platform, the provision of decision aids, and the sub features of decision aids.

Conclusion: To design, develop, and implementation of PtDAs for pregnant women, one should identify the factors affecting pregnant women's decision making and the use of decision aids. This study helped to the identification of these factors, which is the first step towards the use of PtDAs by pregnant women and their participation in decision making.

Keywords: Decision Making; Patient Decision Aid (PtDA); Pregnant Women; Prenatal Screening

Introduction

Pregnancy is one of the most sensitive and important stages of a woman's life, and maternal health directly affects the health and life of the fetus (1-2). Every

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Dr. Leila Nemati-Anaraki Email: nematianaraki.l@iums.ac.ir year, 140 million women in the world become pregnant (3). Pregnant women need to pay special attention to their health and perform screening and diagnostic tests in consultation with their physicians at an appropriate time to ensure the health of the fetus. Screening tests include blood tests and ultrasound and may be performed in the first or second trimester of pregnancy. First trimester

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screening tests include the Nuchal translucency test (NT) and blood test and second trimester screening tests include the triple or quadruple test and ultrasound. The results of these tests can help physicians identify possible birth defects (4). If the fetus is diagnosed with specific genetic conditions such as Down syndrome, pregnant women and their families require information for decision making. Whether or not to act based on the prenatal screening result is one of these difficult decisions.

Providing information to patients helps them make informed decisions about health-related issues and form successful relationships with physicians (5). The World Health Organization (WHO) regards the provision of information to pregnant women and their families for participation in decision making to be an important principle of general care in pregnancy (6).

Health information should be presented in an acceptable format. Patient decision aids (PtDAs) can be employed to inform people and help them understand different treatment options and their associated benefits and harms (7-9). Also by using PtDA, patients can discuss different options with their healthcare providers and choose a preference based on their personal views (10-12). PtDAs improve patients' decision quality (13). They facilitate shared decision making by promoting the patients' knowledge and preparing them for decision making (14-16). The provision of evidence-based information in PtDAs can enable patients to consciously and actively participate in the process of medical care and make them feel clear about their values (17-19).

According to the Health Evidence Network (HEN), the use of PtDAs is beneficial to raising the awareness of the possible outcomes and respecting the patients' values in the decisions. Also, patients who used these tools had fewer decision making conflicts, took an active part in decision making, and were more likely to make decisions (14).

Previous studies have investigated the design and evaluation of the impact of PtDAs on patients and their empowerment in decision making (20-26). This paper is part of a study that designed a framework for developing and implementing decision aids for prenatal screening in Iran. The first step was identifying important factors based on the viewpoints of specialists (like gynecologists and midwives) and pregnant women. To include pregnant women in the decision making process, the present study aimed to identify the factors influencing their use of PtDAs and decision making in prenatal screening. Given the

impact of social and cultural factors, the needs and expectations of Iranian pregnant women in this regard are important and were, therefore, investigated in this study. The identification of these factors helps healthcare systems develop PtDAs for prenatal screening and devise implementation strategies for pregnant women to utilize PtDAs.

Materials and methods

This study was approved by the Ethics Committee of Iran University of Medical Sciences (IR.IUMS.REC NO. 1397-1200). Informed consent was obtained prior to the onset of the interviews, and the participants were reminded of their freedom to withdraw from the interview during recording.

Participants: This study is part of a qualitative study conducted between July 2019 and June 2020 in Tehran. To achieve maximum diversity, sampling was performed with an appropriate distribution of specialized obstetrics and gynecology hospitals in Tehran: the public (middle- and low-income classes) and private sectors (high-income class). Purposive sampling was performed to select the participants and was continued until data saturation. The final sample included 26 pregnant women. Eligibility criteria included: a) Women had to be able to read the prenatal screening PtDA, and b) be at least 20 weeks pregnant or have recently given birth. In these cases, they would have already undergone prenatal screening tests. The pregnant women who expressed ignorance of or disinterest in prenatal screening tests were excluded. The interviewer explained the purpose of the study before starting every interview. At the beginning of each interview, the pregnant women's willingness to participate in the interview was ensured.

Data Collection: The data were collected through semi-structured interviews. The participants used a prenatal screening PtDA and were then interviewed about factors that would influence their decision making and use of PtDAs. The interview guide was designed based on the project's goal and the literature review. All the interview sessions were conducted face-to-face after the participant was familiarized with PtDAs. With the permission of the interviewees, all the interviews were recorded with a voice recorder. At the end of each question, a summary of the interviewer's interpretation of the interviewee's statements was provided to the participant to avoid any misunderstanding. The interviews were conducted in a convenient place

determined by the pregnant women (home, workplace, or clinic) and notes were taken during the interviews. The duration of each interview varied from 20 to 70 minutes.

Data Analysis and Reporting: Data analysis was performed in conjunction with data collection. RZ carried out 26 interviews. RZ is a female PhD student of medical librarianship and information sciences who was trained by LN (a faculty member experienced in conducting qualitative research). The interviews were transcribed verbatim, imported into MAXQDA 10, and coded. The data were analyzed by conventional content analysis as explained by Graneheim and Lundman (27). For this purpose, the texts of the interviews were read several times to gain an in-depth understanding. Then, the codes related to the needs and expectations of pregnant women in decision making and the application of PtDAs were developed. Subsequently, the initial codes were classified as subcategories and categories, and then the categories were collapsed into themes. Discrepancies were discussed until consensus was reached.

Accuracy and Validity of Data: To enhance the accuracy and validity of the data, four criteria (credibility, confirmability, dependability, and transferability) proposed by Guba and Lincoln were taken into account (28). The credibility of the research was enhanced by collecting credible information, having sufficient interaction with the participants, and confirming the information obtained from the interviews. Researchers repeatedly reviewed the data. They also attempted to enhance confirmability by the approval and supplementary comments of faculty members and experts. To improve dependability, the codes were reviewed and modified by assistant professors and advisors through external checks. Furthermore, to improve the transferability of the study, a rich description of the research process was provided so that the study could be evaluated in and applied to the other fields.

Results

A total of 26 pregnant women who had recently performed a screening test were interviewed. Most interviewees (36.36%) aged 31 to 35 years. Also, 73.08% of them were employed, and 50% had a master's degree or higher. Moreover, 53.85% had chosen a public hospital clinic, and the rest had selected private ones. Table 1 presents the details.

Following the data analysis, two themes of "the

process of and factors influencing decision making" and "factors influencing the use of PtDA by pregnant women" were identified. The themes and subthemes are given in Table 2.

Processing and Factors Influencing Decision Making Current decision making process: This category described the current decision making process in pregnancy screening tests taking place in Iran. Most pregnant women said that physicians prescribed screening tests without any explanation, and these tests are performed as a routine procedure. Statements from the participants in this respect included:

Table 1: Demographic characteristics of the participants (n=26)

participants (n=20)		
Characteristics	Items	No. (%)
Age	21-25	4 (15.38)
	26-30	7 (26.92)
	31-35	9 (34/63)
	36-40	6 (23.07)
Type of hospital	Public	14 (53.85)
	Private	12 (46.15)
Academic degree	Under BA/BS	4 (15.38)
	BA/BS	9 (34.62)
	MA/MS	10 (38.46)
	PhD	3 (11.54)
Employment status	Employed	19 (73.08)
	Unamplayed	7 (26 02)

BA: Bachelor of Arts; BS: Bachelor of Science; MA: Master of Arts; MS: Master of Science; PhD: Doctor of Philosophy

"My doctor just ordered a test and an ultrasound. She didn't even talk to me or give me any information, and I didn't know what these tests were." (Participant. 20)

"Doctors are very insistent that you do this screening test. My doctor tells us to do these tests and then come back with the results." (Participant. 12)

Expected decision making process: A number of participants mentioned different expected decision making processes. Different opinions were identified which should be considered in designing PtDAs: the physician making the final decision, pregnant women making the final decision, and participatory decision making.

"I think it's better if the doctors make decisions because mothers are not specialists; they are dealing with emotions and cannot make a correct decision. It'd be much better if the doctor made the decision." (Participant. 4)

Table 2: The identified decision making and PtDA features

Theme	Category	Subcategory	No. of people who mentioned the idea
Process of and factors influencing decision making	Current decision making process	Decision making based on the physician's prescription	21
		Acceptance of the decision	7
	Expected decision making process	The physician making the final decision	16
		The pregnant women making the final decision	5
		Participatory decision making	5
	Factors influencing	Individual characteristics	15
	decision making	Level of knowledge	9
Factors influencing the use of PtDA ^a by pregnant women	Content of PtDAs	Comprehensive information	8
		Simple and understandable language	4
		Sharing the experiences of others	12
	Appearance of PtDAs	Using visual images and features	15
		Providing audio information	10
		Providing information in the form of infographics	5
	PtDAs platform	Websites	8
		Applications	13
		In print format(brochures)	5
	Manner of providing the PtDAs	Time of providing the PtDA	6
		The provider	10
	Subfeatures of PtDAs	Decision making by the PtDA	4
		Providing relevant information	6

PtDA: Patient Decision Aid

"I think it's better if the medical staff express the options, provide a full explanation of each items, and leave the decision making to the pregnant mother and her family. Of course, its better if the doctor expresses his/her own option, too." (Participant. 14)

"I think it's better to make the decision jointly." (Participant. 7)

Factors influencing decision making: The individual characteristics of pregnant women also influence their decision making. So decision making is specific to each woman. In this regard, some of the participants' statements were as follows:

"One Person may prefer to make an independent decision. This person asks and accepts another person's decision. But another person may ask different people and then makes his/her decision. For example, I just talked to the physician about the screening. If I'd asked different people had definitely confused me". (Participant. 19)

The level of knowledge is another factor that influences decision making. According to pregnant women, they can decide better if they have enough information:

"They don't usually give specific information to pregnant women unless the woman is curious or already has some information about it. Unfortunately, this is a problem in [healthcare] centers and we can't do anything [about it] except raising our awareness". (Participant. 21)

Factors Influencing the Use of PtDA by Pregnant Women

Content of PtDAs: The content of PtDAs was expressed as an important characteristic of PtDAs and a critical factor affecting their use by pregnant women. Having comprehensive information, using a simple and understandable language, and sharing the experiences of others were mentioned as the content characteristics of PtDAs. The pregnant women stated:

"Some information is usually given in the screening centers, but it's not complete; it's better if it is integrated. It's a good idea that your PtDA includes all of the information comprehensively." (Participant. 14)

"I think your PtDA was very good because, well, all the questions on my mind were expressed in this tool in a language that even an illiterate mother could understand." (Participant. 8)

"It is great to incorporate the experiences of others. It's interesting to know what other people have experienced and what they've done." (Participant. 15)

Appearance of PtDAs: In the words of the pregnant women, the appearance of PtDAs was one of the most important characteristics affecting their use or nonuse. Some statements from the participants were as follows:

"You should use images to give information. What I have seen is very text-oriented, and not everyone has the patience to read long texts." (Participant. 13)

"I think it would be great if you could present infographics next to these texts." (Participant. 23)

PtDA platform: Based on the capacities of novel technologies, many pregnant women mentioned websites and applications as the best platform for PtDAs. However, some participants preferred to use printed materials. Some statements made by the pregnant women included:

"I suggest applications and websites. I think they can be accessed more easily. Almost everyone has a smartphone now." (Participant. 5)

"Apps are better for some people, but the print format is better for others. For example, reading the printed text is a pleasure for some people." (Participant. 6)

Manner of providing the PtDAs: Another factor that influences the use of PtDAs by pregnant women is how PtDAs are provided for them. The provision time and the provider are the two factors affecting the quality and quantity of PtDA use. Some women stated that:

"I think the best time to have this information is before meeting the doctor and before performing these tests because, if we have a question that isn't mentioned in the information you've provided, we'd have the opportunity to consult a doctor." (Participant. 18)

"It is better if doctors would introduce this tool to patients. But if they don't introduce or accept such tools, it's better for a pregnant mother to have access to them before visiting the doctor." (Participant. 9)

Sub-features of PtDAs: Some pregnant women said that adding some features to the PtDAs can encourage them to use the PtDA. The provision of other relevant pregnancy information in prenatal screening PtDAs and the ability of PtDAs in decision making were mentioned in the interviews. Pregnant women stated:

"It would be better if the PtDA made the final decision. I mean, in the last step that summarizes the information, it would be good if the PtDA could suggest a decision." (Participant. 2)

"I don't know if it's necessary, but it's a good idea to provide other information, like,

How much the fetus weighs, and how much the

mother's weight should be. Something like this could be included in the PtDA". (Participant. 11)

Discussion

Herein, factors affecting decision making and the use of PtDAs by pregnant women for prenatal screening were identified. Based on the interviews, the preferred decision making processes differed across women. Some pregnant women preferred the physician to make the final decision, some wished to make their own decisions, and some others chose participatory decision making. Therefore, PtDAs should be able to meet all pregnant women's expectations and assist them in the decision making process. Beach (2019) stated that most women preferred to take an active role in decision making, 28% wanted to make their own decisions, and 71% wished to make their decisions collaboratively with their pregnancy care provider (23). In a qualitative content analysis study, Toledo showed that women preferred shared decision making in using a PtDA for breast cancer screening (24). However, in a research on prostate cancer screening PtDA, most men preferred decision making with their physicians and were surprised about the possibility of a patient's role in decision making (29). Similarly, in our research, some pregnant women were surprised that they could participate in decision making and said that they made decisions based on the physician's prescription. Consequently, PtDAs should help all views in this regard and guide all patients according to their choices.

In the present study, individual characteristics and level of knowledge were identified as factors affecting the decision making of pregnant women. By recognizing pregnant women's characteristics and helping them to identify their values, we can guide them in the decision making process. Moreover, by providing sufficient and reliable information via appropriate tools such as PtDAs, we can raise their health literacy and empower them to make more confident decisions. According to Alden (30), PtDAs can effectively improve patient knowledge and facilitate shared Decision Making. Also Seo (31) and De Oliveira (32) highlighted the impact of health literacy on the decision-making process.

In terms of factors that influence the use of PtDA by pregnant women, the results revealed that pregnant women wish to know more about prenatal screening. According to them, prenatal screening information is dispersed, and the information provided by physicians and health centers is

insufficient. They said the information provided to them in the PtDA was appropriate, useful, and effective. However, in some studies, some pregnant women stated that having this information increases their stress (26, 33, 34), a complaint that was not voiced in the present study. In this study, pregnant women mentioned that they want comprehensive, simple, and understandable information. Also, in the studies by Berry (35), Sebban (36), and Beach (23), content comprehension and completeness were identified as important factors in PtDA information. The necessity of offering simple and understandable information in PtDAs has been reported in other studies as well (36-39).

Also in the current study the appearance of PtDA was identified as an important factor for pregnant women, and they said that figures, audiovisual information, and infographics can promote their use of PtDA. This finding is consistent with the findings of Garvelink (37) and Baptista (29). Furthermore, Fatima (40) mentioned that graphic information such as charts contributes to PtDA information acceptability.

There were various PtDAs platforms that pregnant women wished to use based on their different viewpoints and demands. In other words, the chosen platform varied according to the interests and desires of pregnant women. Thus, we should design prenatal screening PtDAs in different formats, such as websites and in print format, to consider different viewpoints in PtDA implementation. This point has also been mentioned by Portocarrero et al. (26), Beach et al. (23), and Ng et al. (41).

From the viewpoint of pregnant women, the person who provides the PtDA is an important factor. Most pregnant women preferred that their physician should present the PtDA so that they could ask him/her their questions. This result highlights the importance of the supportive role of physicians in pregnant women's decision making, a finding that has been reported before (25, 26, 42). However, physicians may not take the time to present PtDAs to their patients. Thus, in implementation strategies, other healthcare professionals such as midwives can replace physicians. The time of PtDA provision is another factor that, according to pregnant women, influenced their use of PtDAs.

According to pregnant women, the provision of additional information and the PtDAs decision making ability were the other factors that could increase the use of PtDA. Baptista, et al. (29) also mentioned the desire for additional information in

PtDA in their research.

Conclusion

The findings demonstrated pregnant women's views about factors affecting their decision making and use of PtDAs for prenatal screening. Pregnant women need support to make prenatal screening decisions, a support that can be provided by PtDAs. Understanding the viewpoints of pregnant women helps us in the design, development, and implementation of PtDAs. In the future, we plan to identify the views of physicians and policymakers to improve our strategies and assist pregnant women in making prenatal screening decisions.

Conflict of Interests

Authors have no conflict of interests.

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