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ARTICLE

Decisional conflict and regret: shared decision-making about pregnancy affected by β-thalassemia major in Southeast of Iran

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Abstract

To study the effect of shared decision-making (SDM) on decisional conflict (DC) scores immediately after consultation and to assess the decisional regret (DR) scores in the first 3 months following women's decision regarding termination of pregnancy. This quasi-experimental study was conducted during August 3rd–February 20th, 2016. We included 80 women whose fetuses were diagnosed with β-thalassemia major (β-TM) through chorionic villi sampling and were referred to the only prenatal diagnosis center at Ali-Asghar Hospital, Zahedan, Iran. While the control group went through the routine procedures, the intervention group received a 90-min counseling session based on SDM. The demographic characteristics form and DC scale were filled out immediately after the consultation session. After 3 months, the women were contacted via telephone call to collect data on their level of DR. The mean DC score was significantly ($P = < 0.0025$) lower in the intervention group (8.47 ± 4.63) compared with the control group (44.10 ± 14.5). Moreover, the mean score of DR was significantly ($P = 0.004$) lower in the intervention group (9.37 ± 15.44) compared with the control group (24.37 ± 23.42). SDM consultation can help women experience significantly lower levels of DC and DR.

Introduction

Beta thalassemia major (β-TM) is the most common single-gene blood disorder, which is inherited as an autosomal-recessive disease. Clinical signs of β-TM present between 6 and 24 months, and these patients need life-long blood transfusion, iron chelation, and splenectomy [1]. Excess iron can accumulate in the liver, heart, and endocrine organs and lead to secondary complications of iron overload. All these complications and treatments impose great emotional and economic burdens on families [2, 3] and high costs on health-care systems [4]. The only curative options for this disease are bone marrow and cord blood transplantation, gene therapy, and stem cell transplantation. However, these approaches can be problematic and need histocompatible donors [1]. In addition, they are cost-intensive [4] and inaccessible for low-income individuals. Therefore, carrier detection, prenatal diagnosis, and counseling should be available for at-risk couples [1].

Setting

Zahedan city is the capital of Sistan and Baluchestan. This province is close to Oman sea, a subtropical, malaria-endemic area. While Sistan and Baluchestan is home to only 3.4% of the Iranian population, annually 25% of new cases of β-TM occur in this province [5, 6]. The previous literature proposed that consanguineous marriage, high rate of population growth (2.7%), and a total fertility rate of 3.7 children per women of reproductive age are associated with high prevalence of β-TM in this province [7]. An initial study in Zahedan Prenatal Diagnosis (PND) center showed that 18.6% of women were positive for β-TM and decided against termination of pregnancy. Additionally, qualitative phase of that study exhibited that women were concerned with cognitive and sociocultural issues, which caused doubt and reluctance to terminate pregnancy to avoid the anticipated regret [8].

Previous articles demonstrated that paternalistic models and poor patient–physician communication (where patients have predominant views about the available options)

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Table 1 Essential elements and content of the session

Essential elements			
1. Explain the problem	Fetus is affected by β-thalassemia (β-TM)		
2. Present options	It is time to think what to do next: pregnancy termination due to β-TM/maintain pregnancy		
3. Elicit couples' knowledge about β-TM	Before going into any decision, they were asked to explain their knowledge of β-TM (try to understand their practical knowledge of β-TM as expressed in their narratives)	1. Check information	1. Consultant provides further information
		2. Check/clarify understanding (whether they are correct and what are the misunderstandings?	2. Answers their questions
			3. If needed, presents evidence
4. Elicit and discuss pros/cons and benefits/risks/costs for child and family (in short and long term)	Use of participant's explanations and narratives to extract:	1. Check information	1. Consultant provides further information
	1. The physical, psychological, financial and social impact of β-TM on baby and her/his family in this special context	2. Check /clarify understanding (Whether they are correct? What are the misunderstandings)?	2. Answers their questions
	2. Identify their uncertainty about whether or not terminate the pregnancy (treatability of disease, faith, etc.)		3. If needed, presents evidence
			4. Helps them to interpret information and deliberate
5. Elicit couples' values/ preferences	Use of participant's explanations and narratives to extract and clarify what, from their point of view, matter most to them?	1. List their more important values and concerns	1. Consultant helps them to forecast what they prefer to happen and how they might feel about short- and long-term outcomes that have relevant consequences*
		2. Help them construct their precise and realistic preferences	
6. Ask about their decisions	They were asked: are you ready to decide?/do you need more time?	Sometimes they explicitly defer for a later time. Consultant checked their reasons, do you have more questions? Are there more things (they have heard or read on the Internet) we should discuss?	1. Providing opportunities to talk about novel therapeutic approaches (stem cell….) for β-TM with an specialist
			2. Show them the fatwa approval of abortion in cases of β-TM
			3. If needed, present other evidence
7. Discuss patient abilities	They were asked: how confident are you that you can make your decision?	Sometimes they asked about abortion procedures (medical /or surgical procedures)	1. Consultant provides further information
			2. Answers their questions
			3. If needed, presents evidence
8. Arrange follow-up to track the outcome	Telephone follow-up after 1 week to track the outcome of decision that was made		

contribute to non-adherence to physician advice [9]. In dire situations where decision-making is difficult, such as termination of pregnancy, shared decision-making (SDM) with its collaborative process can facilitate the decision-making process. In this method, consultant incorporates accurate information (e.g., diagnosis, course of illness, and moderating factors) and evidence-based information on short- and long-term outcomes of each option. Equally, patients have their own values, preferences, and treatment goals, which are considered in this process [10].

The literature review showed that there is a scarcity of studies on the effect of SDM on decisional conflict (DC) and decisional regret (DR) of women who were deciding about termination of an affected pregnancy with β-TM. Therefore, in this study we sought to achieve two main objectives: (1) to study the effect of SDM on DC scores immediately after consultation; and (2) to determine the impact of SDM on DR score in the first 3 months following women's decision regarding termination of pregnancy.

Materials and Methods

This quasi-experimental study was conducted on 80 women who were referred to the PND center at Ali-Asghar Hospital, Zahedan, Iran, during August 3rd–February 20th, 2016. Ali-Asghar Hospital is the only diagnostic center in Zahedan city (the capital of the Sistan and Baluchestan Province) that provides prenatal screening and diagnosis of β-TM for high-risk couples free of charge for the total population of the province.

The samples included the women whose fetuses were diagnosed with β-TM through chorionic villi sampling (CVS). The women's inclusion criteria were speaking and understanding Farsi, as well as not having history of mental illness or psychiatric antecedents. Those participants who were absent for the consultation session were excluded.

Couples at risk for having a fetus affected with β-TM may refer to PND center themselves or be referred by health-care centers in the province. Once a woman's pregnancy is confirmed with a pregnancy test, she is asked to undergo an ultrasonography to estimate accurate gestational age. This is performed to confirm gestational age and the viability of an intrauterine pregnancy. Then, through the process of booking an online appointment, CVS is performed at the 10–12 weeks from the last menstrual period by a radiologist at Imam Ali Hospital, Zahedan, Iran. Since some couples have to come from distant places, CVS can be performed even at 18 weeks from the last menstrual period. CV samples are then sent to the genetic laboratory at Ali-Asghar Hospital. The CVS results are usually ready 2 days after samples are sent to the laboratory.

Eligible women were randomly allocated to the routine care and SDM groups ($n = 40$ for each group). When the blocks were created by shuffling an equal number of cards for routine care and SDM groups, the women were assigned to the two groups according to the random order of the cards [11]. Due to the nature of the study, it was not possible to blind the researchers and participants, but they did not know in advance to which group the participants would be assigned [11] and participants were blinded to the study hypothesis [12].

Routine procedure

Previous literature and a pilot study performed at Ali-Asghar Hospital displayed the absence of genetic counseling services (by expert genetic counselors or other trained staff) for couples with an affected fetus with β-TM. There is a one-way flow of information from the staff to the couples: "such children should be aborted"; and they are asked to bring the required documentation to introduce to hospital to terminate their pregnancy. Moudi (2016) ascribed that many women are fearful due to possible regret and opt against pregnancy termination [8]. In the control group, the mothers received the routine care, and the demographic characteristics forms and DC scale were completed for them. Three months later, the researcher phoned the participants to collect data on their level of DR.

Intervention

While the control group went through the routine procedures (a paternalistic/or directive genetic counseling approach), review of literature showed that genetic counselors have been tried to move toward a non-directive one. Meanwhile, studies showed that there are particular circumstances in which non-directive genetic counseling approach may be inappropriate [13]. In response to this problem, shared decision-making perspective was considered by scholars. In this new approach, both counselor and women share information. Counselor contributes her/his professional opinion (about genetic nature of disease, risk…) in the decision-making process and the women also express her value and concerns [14].

The intervention group received a 90-min counseling session based on SDM [15], on the same day or morning of the next day. Essential constituents and content of session are demonstrated in Table 1. The counseling sessions were held in a private room in the presence of women (and their husbands) and counselor. The counselor was a postgraduate counseling student trained on SDM. Ten initial sessions were held in the presence of a PhD of Reproductive Health. All the other sessions were audiotaped and transcribed and checked for essential and ideal elements of SDM and

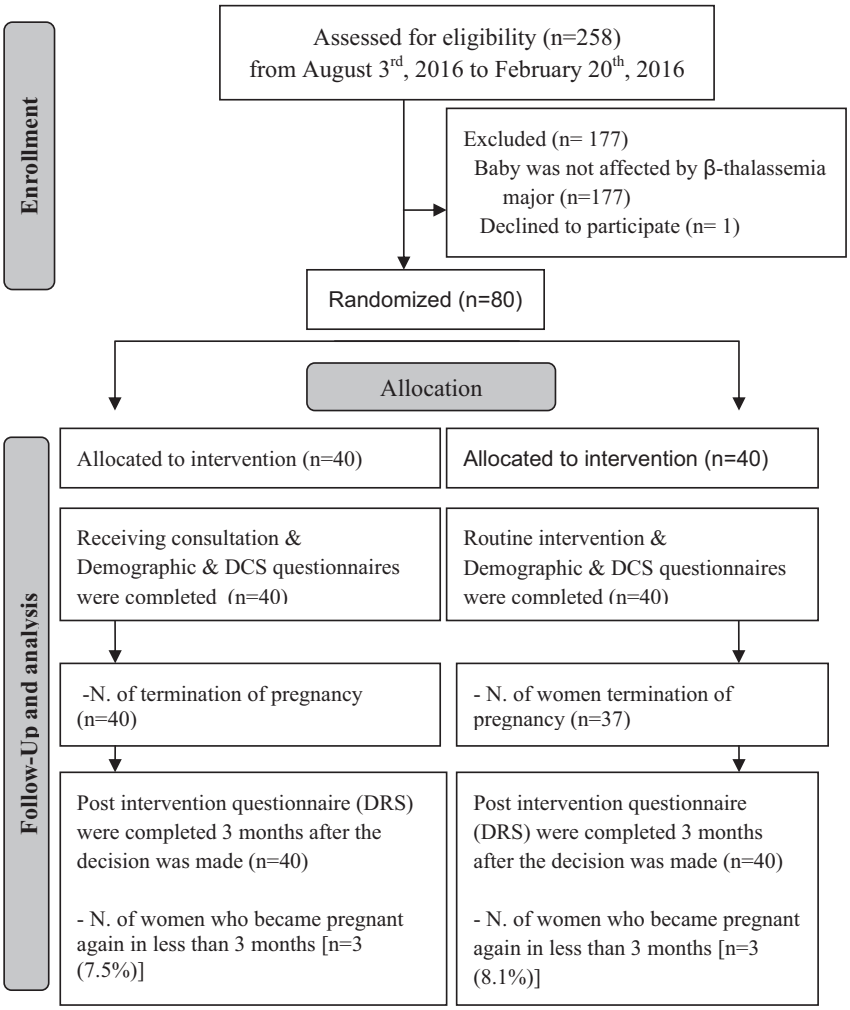

Fig. 1 Flow diagram of study participants

general qualities of consultation [15]. The demographic characteristics form and DC scale were filled out immediately after consultation of all the participants. After 3 months, women were contacted via telephone call to collect data on their level of DR.

Data collection instruments

A demographic characteristics form, decisional conflict scale (DCS), and decisional regret scale (DRS) were applied for data collection.

Decisional conflict scale

O'Conner's DC scale is a 16-item self-report questionnaire. This scale measures uncertainty in choosing options, factors contributing to uncertainty (e.g., feeling uninformed, unclear about personal values, and unsupported in decision-making), and perceived effectiveness of decision-making (e.g., feeling the choice is informed, value-based, and likely to be implemented and expressing satisfaction with the choice) [16]. The participants responded to each item using a 5-point Likert scale ranging from 0 (strongly agree) to 4 (strongly disagree). All the item scores were summed up, divided by 16, and multiplied by 25; total score ranged from 0 to 100. It was stated that "scores lower than 25 are associated with implementing decisions, while scores exceeding 37.5 are associated with decision delay or feeling unsure about implementation" [17].

Moreover, this scale has five subscales (uncertainty, informed, values clarity, support, and effective). Higher scores on the scale or subscales show higher DC, uncertainty, and less effective choice [17]. Cronbach's alpha coefficient of 0.92 confirmed internal consistency of this study.

Decision regret scale

The DRS is a five-item scale measuring regret after healthcare decisions at a particular point in time [18]. The participants responded to each item using a 5-point Likert scale, ranging from 1 (strongly agree) to 5 (strongly disagree)

[19]. Items 2 and 4 were reverse coded; converting the score to 0–100, 1 was subtracted from each item then multiplied by 25. To obtain the final score, the items were summed up and averaged. A score of 0 means no regret, whereas a score of 100 denotes high regret [19, 20]. In the present study, Cronbach's alpha coefficient of 0.94 confirmed internal consistency and a test–retest correlation of 0.99 established the reliability of the scale.

Ethical approval

Permission to conduct this study was obtained from Zahedan University of Medical Sciences (Jun 11, 2016; IR.AUS.REC:1395.119), Zahedan, Iran. Additionally, we received the approval of the directors of Ali-Asghar Hospital and PND Ward. The aim of the study and type of intervention were explained to the participants. The eligible women were enrolled in the present study after having provided written informed consent. It was explained to the women that participation was their choice, and if they were willing to

Table 2 Comparison of women's characteristics between groups

Characteristic		Groups		*P*-value*
		Intervention ($n = 40$)	Control ($n = 40$)	
Age (years)	Mean (SD) Range	27.38 (6.23) 19–42	25.85 (6.7) 17–42	0.2
Gravida	Mean (SD) Range	3.85 (2.03) 1–8	3.00 (1.75) 1–7	0.06
No. of lived health child	Mean (SD) Range	2.10 (1.72) 0–7	1.33 (1.43) 0–5	0.02
No. of lived affected child	Mean (SD) Range	0.65 (0.80) 0–3	0.33 (0.69) 0–3	0.02
Gestational age (weeks)	Mean (SD) Range	14 (1.39) 11–18	13.68 (1.09) 12–18	0.22
No. of abortion (due to affected babies)	Mean (SD) Range	0.13 (0.33) 0–1	0.50 (0.96) 0–3	0.06
History of affected person in family	Mean (SD) Range	0.55 (1.1) 0–5	0.25 (0.49) 0–2	0.20
		N (%)	*N* (%)	*P*-value†
Place of residence				
City		22 (55)	28 (70)	
Village		18 (45)	12 (30)	0.16
Ethnicity				
Baloch		37 (92.5)	37 (92.5)	
Fars		3 (7.5)	3 (7.5)	1
Education				
Illiterate		7 (17.5)	8 (20)	
Primary school		12 (30)	7 (17.5)	
Second school		7 (17.5)	9 (22.5)	
Diploma		10 (25)	11 (27.5)	
University		4 (10)	5 (12.5)	0.67**
Religion				
Shia		5 (12.5)	3 (7.5)	
Sunni		35 (87.5)	37 (92.5)	0.45
Others involvement in decision-making				
Yes		10 (25)	8 (20)	
No		30 (75)	32 (80)	0.59

*Mann–Whitney *U*-test

**Mont-Carlo

†Chi-square

Table 3 Comparison of decisional conflict and regret scores between groups

		Groups		P-value*	P-value**
		Intervention (n = 40)	Control (n = 40)		
Decisional conflict score					
Total score	Mean (SD)	8.47 (4.63)	44.10 (14.5)		
	Range	3.13–20.31	20.31–87.50	< 0.0025	< 0.0025
Subscales					
Uncertainty	Mean (SD)	28.33 (7.01)	40.20 (16.86)		
	Range	8.33–41.67	16.67–83.33	< 0.0025	< 0.0025
Informed	Mean (SD)	7.5 (11.13)	67.29 (20.79)		
	Range	0–33.33	25–100	< 0.0025	< 0.0025
Values clarity	Mean (SD)	6.66 (10.37)	62.5 (21.09)		
	Range	0–25	25–100	< 0.0025	< 0.0025
Support	Mean (SD)	1.66 (5.40)	36.25 (19.29)		
	Range	0–25	0–75	< 0.0025	< 0.0025
Effective decision	Mean (SD)	0.78 (3.52)	15.28 (18.28)		
	Range	0–18.75	0–75	< 0.0025	< 0.0025
Regret score					
Total score	mean (SD)	9.37 (15.44)	24.37(23.42)		
	Range	0–65	0–75	0.001	0.004

*Mann–Whitney *U*-test

**After adjustment, use multiple linear regression for no. of lived health child and no. of lived affected child

withdraw from the study at any time, there was no repercussion for that. Finally, the participants were assured of confidentiality of all the information.

Statistical analysis

SPSS 16 was used to perform the statistical analyses. The Kolmogrov–Smirnov test was applied to test the normality of the continuous variables. Mann–Whitney *U*-test was used to compare the data with non-normal distribution. Multiple linear regression was also run to adjust for potentially confounding variables (number of living healthy children and number of living affected children).

Logistic regression was used to estimate the association between DR (the dependent variable) and SDM, controlling for the number of living healthy children, number of living affected children, and DC scores. The dependent variable (DR) was changed to categorical and dichotomous (DRS < 26, DRS ≥ 26) [21]. In line with the previous studies [17, 22, 23], DC was converted into a categorical variable (DCS < 25, 25 ≤ DCS ≤ 37.5, DCS > 37.5), and all other independent variables were considered as linear scales. The forward stepwise likelihood ratio method was adopted in logistic regression to study the effect of each independent variable on DRS. The overall goodness-of-fit model was tested for Likelihood statistics. Two-tailed tests were utilized to compare the variables between the control and intervention groups.

In addition, we performed Chi-square, exact Chi-square, and Fisher's exact tests to analyze the categorical and binary data. Furthermore, Monte Carlo test was employed to test the 2×3 consistency table with dome cells <5. The two-tailed tests were also run to compare the variables between the control and intervention groups. *P*-value <0.05 was considered statistically significant.

Results

From August 3rd to February 20th, 2016, a total of 258 women were assessed for study eligibility (Fig. 1). Eighty women who met our inclusion criteria and were willing to enrol in the study were equally assigned to two groups. The characteristics of the two groups are presented in Table 2. In the control group, three women opted against pregnancy termination; these women were not excluded from follow-up and completed the DR questionnaire. The data showed that in each group three women became pregnant again within 3 months of termination of pregnancy (Fig. 1).

The total DC score was significantly lower in the intervention group (8.47 ± 4.63) compared with the control group (44.10 ± 14.5). The subscale (uncertainty, informed, values clarity, support, and effective) scores were significantly lower in the intervention group compared with the control group after the intervention (Table 3). The data showed that the mean scores of DR scale were significantly lower in the intervention group (9.37 ± 15.44) than in the

Table 4 Reasons for decisional regret 3 months following women's decision-making

Reasons	Example of sentence of women
Sin	"I think I committed a sin; now, I wish I did not have the abortion".
Blame or judgement by others	"I am upset about what people say. They blame me. They tell me I should not have had the abortion. They tell me I have sinned".
Marital unsustainability	"My husband wants to have a second wife. If I did not abort, I would have a child (even if the baby was affected with β-thalassemia), and they had no excuse for this. My husband's family said that I could not bear a child, their son was healthy".
Disease treatability	"If I did not have the abortion, may be his/her disease could be treated….// (bone marrow) transplantation would be performed for him/her; blood (transfusion) would be used to treat his/her disease, like few others in the family
Future infertility	It was my first pregnancy. I think I made a mistake. People say abortion is bad for women's fertility, you become infertile.
Physical deleterious outcome*	"I hurt a lot. Misoprostol tablets were not available, after that, I was taken another pill, but it did not work for several days.

*It was the reason for decisional regret for women in the shared decision-making group

Table 5 Logistic regression results of model predicting decisional regret in the first 3 months following decision-making regarding termination of pregnancy, $n = 80$

Variables	β	SE	Wald	P-value	Exp (β)	95% CI Lower, upper
Decisional conflict score						
DCS < 25						
25 ≤DCS ≤37.5	1.02	0.95	1.14	0.28	2.78	0.42 18.22
DCS > 37.5	2.13	0.64	10.86	0.001	8.45	2.37 30.06

Results are significant at 0.05 probability level

control group (24.37 ± 23.42). Reasons for DR 3 months following women's decision-making are provided in Table 4.

The Likelihood statistics (−2 Log Likelihood = 74.82, Cox and Snell $R^2 = 0.14$, Nagelkerke's $R^2 = 0.22$) were used, as well. The Wald criterion showed that only DCS > 37.5 made a significant contribution to prediction ($P = 0.001$). Exp (β) value indicates that when DCS is >37.5, the odds ratio is 8.45 times as large, and therefore, women are 8.45 times more likely to regret their decision regarding termination of pregnancy after 3 months (Table 5).

Discussion

The present study revealed that women who had positive CVS results for β-TM and took part in a SDM consultation session could decide whether or not terminate their pregnancy with less conflict. Moreover, these groups of women experienced less regret in the first 3 months following their decision regarding termination of pregnancy.

The results of the present study demonstrated that, even in disadvantaged areas such as Sistan and Baluchestan Province, women who participated in SDM consultation reported significantly lower DC scores. Hamilton (2016) noted, a good medical decision is characterized by a good decisional process and outcomes [24]. In the present study, we employed couples' narratives (explaining the life stories of a child affected with β-TM) to involve women (and their husbands) in the decision-making process, encourage mutual exchange of information and opinions (i.e., preferences) about the health situation, discuss the risks and benefits of the available options, and elicit personal goals and preferences (e.g., ideas, concerns, and outcome expectations) to determine and choose an option that is in line with their values [9, 24–27].

The present study also showed that, in the control group, three women (7.5%) with DC score range from 40.63 to 43.75 chose not to terminate their pregnancy. In fact, DC is an expression of internal uncertainty or conflict about which medical option to choose when choices involve risk, loss, and regret or challenge personal life values [23, 28–30]. Consistent with the previous studies, the present study exhibited that DC raises the chances that patiments (or clients) change their mind, delay their decision, and make decisions with unfavorable outcomes [21, 28]. In congruence with the O'Conner (2010) results, we found that DC scores >37.5 increase the chance of decisional delay or hesitation about implementation of the decision [17].

Creyer (1999) proposed that regret involves the belief that the original decision was wrong at the time it was made [31]. In agreement with previous studies [23, 32], the

present data indicated that women who took part in the SDM obtained significantly lower scores of regret 3 months after decision-making. There are two reasons that may justify the lower scores of regret in the present study. First, the nature of SDM facilitates a good decisional process addressing the individual patients' predicaments and preferences [33] and engages individuals in a deliberate discussion to make a realistic [34] and defensible decision at the time. Second, a wide range of support techniques that could be influential [15, 27] are employed in this method of consultation (present evidence, e.g., artifacts), especially in the present study (services and approval from the most important family members). In the present study, 38 (95%) of women participated in the SDM consultation session with their husband or husband and another influential family member (e.g., mother-in-law). In congruence with the previous studies [35], we observed that these persons play an active role in supporting women to implement their decision.

In the control group, three women opted against pregnancy termination. According to Hamilton (2016), it is highly essential to be aware that outcome of a good medical decision is hinged upon social context and interpersonal relationship. In fact, patient/client is under pressure to balance the abortion (due to probability of a genetic problem) against moral dilemma and socio-cultural opposition to abortion [21, 25, 36]. Such situations sometimes predispose patient/client towards making hasty decisions (e.g., not abortion) that provide immediate relief [37]. Creyer (1999) stated that individuals who obtained negative outcomes or feedbacks are more risk-averse than those who received positive outcomes or feedbacks.

Additionally, despite a good decisional process, patient can experience post-DR because of negative outcomes [24, 38]. In the SDM group, a few women reported regret because of adverse emotional or physical experiences during abortion procedure. The current study, along with previous studies, confirmed that post-DR undermines the intention to repeat the same choice again. Our findings substantiated the results of a previous qualitative study on a similar population, [8] as some regretful women mentioned: "even if the fetus was affected with β-TM in the next pregnancy, I would not go for abortion again".

This study has several limitations. First, due to time constraints it was not possible to consider a larger sample size. Second, we were not able to study the level of regret over time and effect of regret score on reproductive behaviors (e.g., decision on termination of pregnancy in subsequent pregnancies with positive CVS). Third, because of some limitations, we were not able to measure DC score before the intervention and select only women with DC (DC ≥ 25). Finally, low DR scores may be biased since the participants may not have wanted to upset the researcher by reporting high level of regret [20].

It can be inferred from the present study that SDM helps consultants involve women/couples in a deliberate discussion to make a realistic and defensible decision at the time. As decisions are made in an evolving socio-cultural context, in line with Elwyn (2010), we propose the use of couple's narratives as they can forecast future emotions and elicit preferences. Moreover, using SDM, consultants can determine couples' information level, misunderstandings, and myths about β-TM (e.g., treatment with donkey or camel milk).

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Compliance with ethical standards

Conflict of interest The authors declare no competing interest in this study.

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