APPROPRIATE ANTENATAL COUNSELING QUESTIONS FOR PREGNANT WOMEN WITH FETAL CONGENITAL ANOMALIES AT SELECTED HOSPITALS IN ADDIS ABABA: CLIENTS' AND COUNSELORS' PERSPECTIVES

Melat Sebsibie[1], Eyob Gelan[2], Birhanu Kebede[3], Dube Jara[4]

ABSTRACT

BACKGROUND: Congenital anomalies, errors in fetal development, can be devastating for expectant parents. Effective counseling on congenital anomalies requires scientific and empathetic methods tailored to sociocultural, educational, and religious aspects of a society. It is crucial to address both counselors' and clients' concerns, yet a standard tool suited to our society's unique needs is lacking. Therefore, this study aims to assess counseling components derived from an internationally validated tool, emphasizing the perspectives of both clients and counselors, with the goal of establishing a standard for counseling pregnant women with fetal congenital anomalies in our setting.

OBJECTIVE: To evaluate clients' and counselors' perspectives on appropriate antenatal counselling questions for pregnant women with fetal congenital anomalies in Ethiopia.

METHODS: A facility based mixed convergent parallel cross-sectional study, conducted in three high volume hospitals in Addis Ababa, Ethiopia. Eight clients for the qualitative and 251 counselors for the quantitative were included in the study. Counselors had graded each question from an internationally validated QUOTE prenatal (The quality of care through the patient's eyes) questionnaire in a 1 to 4 scale based on their judgment as to the relevance of each question in the context of our clients. Clients also had undergone an in-depth interview about the components of the questionnaire to check for its applicability. Descriptive statistics, Cronbach's coefficient alpha reliability analysis and face validity tests were used for quantitative data and thematic analysis was done for the qualitative data and findings were merged.

RESULT: The response rate was 88%, Cronbach's alpha was 0.914 making all of the questions reliable. From the 38 questions, 32 were labeled as valid by the counselors and we identified three themes: (1) Questions from the tool which are asked and got understood by the clients, (2) Questions which are asked but was not clear for the clients and (3) Questions which are not asked to the clients at all. Questions which were valid by the counselors were also well understood by the clients.

CONCLUSION: Most of the counseling questions from QUOTE prenatal questionnaire were found to be appropriate for use in Ethiopian setting by counselors. Additionally, the questions considered important were also well understood by the clients.

KEYWORDS: Antenatal counseling, QUOTE prenatal, congenital anomaly, Ethiopia

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1 department of obstetrics and gynecology, Kidus Petros Hospital, Ethiopia

2 department of obstetrics and gynecology, King Fasil Hospital, Rwanda

3 department of obstetrics and gynecology, Yekatit 12 Hospital Medical College, Ethiopia

4 department of public health, Yekatit 12 Hospital Medical College, Ethiopia

INTRODUCTION

Congenital anomalies, which is an error in fetal development, occurs in 2% to 4% of live births, and affect 7.9 million children worldwide, with a significant proportion detected before birth by routine ultrasound and other screening techniques. Prenatal diagnosis of a congenital anomaly can have significant emotional and psychological consequences for parents of affected babies.[1- 8, 9–12]

Given the psychological stress and uncertainty associated with a prenatal diagnosis, parents should be given prenatal counselling which is an interactive process between a client and a counselor during which information is exchanged and support is provided so that an informed decision can be made and an appropriate action could be undertaken.[1–8]

It should be a two-way communication between a counselor and a client which should be unbiased and respectful of the client's choice, culture, religion and beliefs. Information transfer must be made in a clear and neutral way, using simple language so that it can contribute to the autonomous informed decision making of the client.[1–8]

Full information relevant to their fetus's congenital anomaly, causes, management options, birth outcomes, and short and long-term impacts should be delivered. It should be delivered in an order of flow.[8]

It has to start with the basics of the counseling which is client-counselor relation, then a health education about the anomaly has to be delivered and a support has to be given to reach to the final decision.[8, 10, 13–15]

Counseling on congenital anomaly in Ethiopia is still in its infancy stage because the procedures that counselors employs seems by large what the counselor assumes is better in assisting their clients even if they did not follow specific procedures and the approach is not acknowledging the different cultural diversities of our society. On the client side it is known that Ethiopian patient perceptions regarding causes of congenital anomalies is reported to be on beliefs in supernatural, natural, and societal causes as the reason of the anomaly. This demands a counseling service highly respecting the cultural and religious values of our society.[9, 11]

The lack of guidelines for counseling is set as a significant barrier for counseling service delivery. In most cases, counselors said that they had to set their own standards and they obtained knowledge through trial and error, as well as by consulting other professionals, given the absence of counseling guidelines.[10, 12–14]

So far among the very few, there is one internationally validated and widely used tool since 2011 for counseling of parents having a fetus with congenital anomaly- the quality of care through the patients eyes, QUOTE prenatal questionnaire.[8, 10, 13–15]

Direct use of different counseling tools developed and applied in another set up, like the QUOTE prenatal questionnaire, without customization to the practical livelihood of our society will not be effective in full filling the core values of the counseling. While the capacity to diagnose congenital anomalies is increasing throughout Ethiopia, so far there is no standard tool regarding counseling of pregnant mothers on fetal congenital anomalies which is tailored to our society's educational, cultural, social, religious and economic background in our country.[9,10,12,15]

And this paper will contribute by providing a standard tool for counseling of pregnant ladies with fetal congenital anomaly, which has a scientific ground, taking into consideration of our cultural and religious values and which is assessed from both the counselors' and clients' perspective for its practical applicability. Hence, the aim of the study is to assess clients' and counselors' perspectives on appropriate antenatal counselling questions for pregnant women with fetal congenital anomalies among clients and counselors in Ethiopia.

MATERIALS AND METHODS

Study Design

The study is a facility based mixed convergent parallel cross-sectional study used to assess clients' and counselors' perspectives on appropriate antenatal counselling questions for pregnant women with fetal congenital anomalies among clients and counselors in Ethiopia.

Study Setting and Period

The study was conducted in Addis Ababa, Ethiopia from May 1 to December 31, 2024, in three high volume teaching hospitals (Abebech Gobena MCH center, Black lion referral hospital and St Paul hospital millennium medical college) which are serving as a referral center to all corners of the country. The hospitals are equipped with the different diagnostic modalities, inpatient-outpatient services, different departments and subspecialty units with an average delivery of around 900 per month. All the three of them has been serving as a teaching hospital for undergraduate, post graduate and subspecialty programs, with more than 264 obstetrics and gynecology residents of all levels and more than 82 obstetrics and gynecology specialists, fellows and subspecialists.

Study Population

For quantitative component: The quantitative component of the study was conducted by counselors. Counselors in this study are all obstetrics and gynecology residents, specialists, fellows and subspecialists who are educated representatives of the community who still value the culture, religious value and norm of the society they represent.

For qualitative component: The qualitative component was conducted among pregnant women with fetal congenital anomalies attending antenatal care at selected hospitals. Participants were volunteer clients who had received counseling and completed management, were not in labor or undergoing pregnancy termination, and were not critically ill.

Sampling methods

For the quantitative sample, since the number of counselors is less than the result from the single population formula sample size with P value of 50% which is 384, all counselors were involved and a final of 251 counselors have conducted the research.

For the qualitative study, considering the homogenous nature of the clients and to avoid redundancy, the interview was conducted among eight clients.

Data Collection

The quality of care through the patient's eyes, QUOTE prenatal, questionnaire was used as a self-administered questioner and counselors were grading each question in a 1 to 4 scale based on their judgment as to the relevance of each question in the context of religious, sociocultural, educational and economic background of our clients. From the different listed questions, each question was subjected to the counsellor and he/she was requested to level it as 1= not important, 2= fairly important, 3= important and 4 = very important.

For the qualitative part an in-depth interview were conducted for 15minutes among pregnant mothers with fetal congenital anomalies by a trained female data collectors.

Data processing and analysis

The quantitative data were cleaned and coded using SPSS version 29. Descriptive analysis was done to describe study characteristics. Scale reliability analysis was conducted to assess the reliability of the components of the questions, using Cronbach's coefficient alpha value >0.7 as reliable. Face validity test was used to check the validity of tools. The collected qualitative data were transcribed, themed and narrated. Results were presented using texts, tables and central tendency statistics.

Operational definition

- Counselor's perspective of appropriate counseling question are those questions which are labeled as "important" or "very important" by >75 % of the counselors. (15)
- Client's perspective of appropriate counseling questions are those questions which the client understands and gives clear answers without confusion.[15]
- Reliable and valid questions for quantitative result are those questions which have passed Cronbach's alpha and face validity tests respectively.

Ethical consideration:

Ethical approval is obtained from institutional Review board with IRB number RPO/45/16 on 24/7/24 and participants were provided with the information that their participation was on voluntary basis and an informed consent and consent of publication was obtained from each participant. The information collected from this research project was kept confidential and personal identifiers were avoided.

RESULTS

Quantitative Study

Among 251 counselors who participated in the study, the majority were males (205, 81.7%) and orthodox Christian (143,57%) (Table 1). and Obstetrics and gynecology residents (207,82%). More than two third of the counselors(208,83%) had no previous training in counselling regarding congenital anomaly.

Table 1: Socio demographic characteristics of participants (counselors)

Counselors gender	**Total n** (%)
male	205 (82)
female	46 (18)
Professional level	
year one residents	59 (29)
year two residents	45 (22)
year three residents	48 (23)
year four residents	55 (27)
residents	207 (82)
specialist	15 (6)
fellow	18 (7)
subspecialist	11 (4)
Religion	
orthodox	143 (57)
Muslim	33 (13)
protestant	34 (14)
other	31 (12)
catholic	9 (3.6)
no religion	1 (0.4)
Have you taken any course or a session on counseling	
yes	43 (17)
no	208 (83)
total	251

The QUOTE prenatal questionnaire has two parts – three component questions (client-counselor relationship, provision of health education and decision making support) and detailed questions under the three component questions.

Regarding the counselor's response on the components of the questions, client-counselor relationship, provision of health education and decision making support was valid as important or very important by more than 90% of the counselors (Table 2)

Table 2 Counselors' response on the components of the questioner

client counselor relationship	frequency	percent
not important	0	0
fairly important	12	4.8
important	70	27.9
very important	169	67.3
total	251	100.0
provision of health education		
not important	1	0.4
fairly important	11	4.4
important	66	26.3
very important	173	68.9
total	251	100.0
decision-making support		
not important	4	1.6
fairly important	12	4.8
important	58	23.1
very important	177	70.5
total	251	100.0

Under the content of client – counselor relation, only one questions "asking about previous congenital anomalies" was labeled as not appropriate by the counselors (mentioned as important or very important only by 71.3% of counselors) (Table 3).

From the content of health education, five questions was labeled as not appropriate by the counselors (Table 4) (labeled as important or very important by <75% of the counselors).

Within the content of decision making support all the questions were labeled as appropriate by our counselors (Table 3).

Reliability test

Reliability was assessed for each components of the question separately and for the overall 38 items using Cronbach's alpha (Table 3),

Face validity test

All the questions were assessed by the counselors. Based on this assessment; six questions from the QUOTE Prenatal Questionnaire were excluded from counseling for pregnant women in our setting due to sociocultural and religious considerations. The remaining 32 questions were selected for use by counselors during client counseling

Qualitative Study

Of the eight pregnant women with fetal congenital anomaly, the mean age is 27.5 ± 5 years (21- 35 years).only two of them have first degree, all are married and five of them are orthodox religion followers (Table 3).

Table 3: Socio demographic characteristics of clients

list	age	religion	marital status	occupation	level of education	parity	income (per month)
C1	35	orthodox	married	teacher	1 St degree	3	20000-25000
C2	24	Muslim	married	house wife	grade 5	1	unknown
C3	22	protestant	married	cleaner	grade 7	1	unknown
C4	21	orthodox	married	house wife	grade 12	0	unknown
C5	30	orthodox	married	cleaner	grade 12	2	unknown
C6	29	protestant	married	cashier	1 St degree	1	10203
C7	28	orthodox	married	day laborer	grade 10	2	12000
C8	33	orthodox	married	self employed	10+2	0	30000

We generated three significant themes to illustrate which of the QUOTE prenatal questions can be easily understood by our clients, the themes are discussed, with representative quotes in (table 8A,8B,8C).

From the clients and counselors perspective the final counseling tool for pregnant ladies with fetal congenital anomaly would be seen in Table 4.

Table 4 Final validated counseling tool

	Client–counselor relation
1	Give the client enough time to explain herself properly
2	Put the client at ease or comfortable
3	Take client's concerns seriously
4	Show empathy
5	Use clear and comprehensible language
6	Ask about what the client knows about congenital anomaly before the beginning of the counseling
7	Take adequate time to answer all of client's questions
8	Giving the client the option of (additional) written information or picture aid
9	Add culturally competent educational Film
10	Make it clear that the client can ask anything she wants to know
11	Tell the client that she can always contact you with any questions that she might have
12	Accept client's decisions
13	Give the option of having two or more counselling /discussion sessions instead of only one counselling session
14	Explain client's possible emotional reaction phases
	health education
1	Have an adequate discussion about topics that the client considers to be important
2	Explain about how a birth defect will affect the child in the future
3	Explain how having a child with congenital anomaly would affect the client and the whole family
4	Explain how long the client should take to decide whether or not to terminate the pregnancy with congenital abnormality
5	Explain about how much prenatal tests cost
	decision-making support
1	Ask the client what she knew about the specific congenital anomaly before the start of the session
2	Enquire client's standards, values and views
3	Ask about client's background on religion
4	Ask the client if she wants, her partner/ any one that she prefers, to be with her during the counselling
5	Encourage the client and her partner/ any one that she prefers, to talk together about the anomaly
6	Discuss about how the client or her family would react to a child with a birth defect
7	Ask whether client's family, friends or other people close to her would support her decision
8	Ask "what a healthy child is for her "
9	Ask about which anomalies are acceptable to the client
10	Explain the exact congenital anomaly
11	Explain about the possible causes of the anomaly
12	Explain for clients about all possible options of management for the anomaly
13	Support the client to make decision

The study found that, among the QUOTE Prenatal Counseling questions, counselors excluded eight items as unsuitable for counseling women with fetal congenital anomalies, and the items considered important by counselors were also clearly understood by clients.

DISCUSSION

Counseling for congenital anomalies in Ethiopia remains underdeveloped, with counselors primarily employing subjective approaches in the absence of standardized procedures and with limited consideration of the country's cultural diversity.

On the client side it is known that Ethiopian patient perceptions regarding causes of congenital anomalies is reported to be on beliefs in supernatural, natural, and societal causes. This demands a counseling service highly respecting the cultural and religious values of our society.[9, 11]

It is highly recommended to establish an objective method for evaluating counseling quality through the use of a validated instrument.

Direct use of different counseling tools developed and applied in another set up, like the QUOTE prenatal questionnaire, without customization to the practical livelihood of our society will not be effective in full filling the core values of the counseling.[10, 12–14]

In our study client counselor relation, health education, decision making support and enquiring client's standards, values and views were chosen to be important and very important by more than 92% of our counselors and all of the clients have mentioned it as very important part of the counseling which is in line with several similar researches.[1, 3, 5, 10, 14–16, 20, 24, 30]

Similar to previous studies, regarding providing clients with written information or pictorial aids, 94.4% of our counselors rated it as important or very important. Additionally, half of our clients reported that pictorial explanations of the anomaly were provided during counseling, which facilitated better understanding.[8, 15, 16, 27]

Consistent with other studies asking about what the client knows about the anomaly before the beginning of the counselling and asking what a healthy child is for the client was labeled as important or very important by 76.1% & 87% of our counselors.[15, 16, 23]

Encouraging the client and her partner to talk together about the anomaly and asking about client's background on religion was valid by 94% & 75% respectively of our counselors similar to previous researches mentioning that clients preferred to get advice about how to discuss the tests with their spouse at home. All of the clients and 98.4% of counselors has chosen the question using clear and comprehensible language to be valid.[3, 5, 8, 14, 16, 21, 30]

Giving the option of having two or more counselling /discussion sessions instead of only one counselling session and adding culturally competent educational film was valid by 88.8% of our counselors and this result is consistent with different research results.[1, 15–17, 26]

Earlier studies have reported similar findings regarding asking clients whether they would like their partner or another preferred person to be present during counseling, as this is an effective way to help relieve stress.[1, 14, 15, 21, 26]

Having an adequate discussion about topics that the client considers to be important, prenatal tests cost and telling the client that she can always contact the counselor with any questions that she might have are mentioned as important or very important by 81% & 93% of the counselors which is reported same by previous works.[1, 14, 15 16, 21, 30]

Putting the client at ease or comfortable was chosen by 97.2% of our counselors as it is also supported by the WHO counseling guide and Midwives' views on appropriate antenatal counselling for congenital anomaly tests.[1, 15]

Explaining about the types and importance of all prenatal screening in general was labeled as important or very important by only 60% of our counselors and all of our clients were not able to

understand the question properly, this is in contrary to the research on midwives' views in Netherland which was rated as important by 98.1% of their counselors and also by a research done in Morocco. This could be explained by the fact that its only very few screening modality that we have as a country and mentioning those which won't be available will not be as such important to the client.[6, 15, 16]

Asking about previous congenital anomalies and asking about client's family history of birth defects was valued only by 71.3% and 60.5% respectively of our counselors in contrast to the Netherland's study which was 89.7% for both and this could potentially be explained by the fact that our clients usually considers that most of the congenital anomalies are because of supernatural power and religious related so they tend not to reveal to anyone else. And another explanation could be even the definition of healthy child is different for different client and the question could be a vague one and sometimes the clients won't even remember it properly. [1, 8, 9, 16, 25, 26]

Explaining which anomalies would be identified with prenatal screening and explaining why the client may or may not be eligible for certain prenatal tests was valued as important or very important only by 56.% and 57.8% respectively of our counselors as opposed to 96.7% and 86.7% respectively in the midwives views research. the other question of explaining about how often congenital anomalies occur in pregnant women of clients age which is valued by 60.2% of counselors in our case was in contrary of 70% by the above study, this could be taking our clients educational background into consideration and explaining the congenital anomaly types and the screening types may not match to our clients educational background.[6, 15, 22]

CONCLUSIONS

This study indicated that most of the counseling questions were found to be appropriate for use in Ethiopian setting except for questions about the previous history of congenital anomaly, various perinatal screening tests, eligibility criteria and family history of congenital anomalies which are deemed less important by our counselors and clients. Additionally the questions considered important by counselors were also well understood by the clients.

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Availability of data

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Corresponding author

Melat Sebsibie

E mail- melatseb@yahoo.com

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