ORIGINAL ARTICLE

INTERNATIONAL JOURNAL OF RESEARCH IN PHARMACEUTICAL SCIENCES

Published by JK Welfare & Pharmascope Foundation Journal Home Page: https://ijrps.com

Patient perspective regarding late termination of pregnancy at a tertiary care hospital

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Article History:

Received on: 02 Sep 2022
Revised on: 25 Oct 2022
Accepted on: 29 Oct 2022

Keywords:

Ultrasound,
Fetal anomaly,
Counselling,
late termination of pregnancy

ABSTRACT

To arrive at an understanding about the view and attitudes of pregnant women regarding late termination of pregnancy after prenatal diagnosis of a severe fetal anomaly. A semi-structured questionnaire based prospective descriptive study was conducted from January 2022 to September 2022 in Obstetrics and Gynecology department of Saveetha Medical College and Hospital, Thandalam. 16 pregnant women with severe fetal anomalies detected after 23 weeks were included. All the women were counselled about the type and lethality of the anomaly including management option. Informed consent was obtained from all the patients and ethical approval was obtained. A total of 16 women with congenital anomalies in fetus detected after 23 weeks of gestation over 8 months of the study period were included in the study. All the participants were properly counselled and given adequate time to make the decision. Among which 11 decided to terminate the pregnancy and 5 continued. All 11 who opted for termination of pregnancy was joint decision by the family. 5 women continued their pregnancy. Reasons to continue the pregnancy were praying that baby will born normal (n=1), hoping that surgery can correct the abnormality (n=3) and wanting to see the baby (n=1). This study shows that women who are pregnant with serious fetal anomalies have a range of opinions and attitudes regarding termination. To compare with initial decision making larger follow-up studies will be necessary to see whether patient's perspective changes over time.

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ISSN: 0975-7538

DOI: https://doi.org/10.26452/ijrps.v13i4.3725

Production and Hosted by

IJRPS | https://ijrps.com

INTRODUCTION

In India termination of pregnancy is legal to be performed at any gestation if medically proved that continuation of pregnancy will result in a severely handicapped child. In spite target scan being a routine antenatal investigation during pregnancy , factors like irregular antenatal check-ups , lack of awareness about anomaly scan , poor accessibility to health facility or expertise and chances of late evolving congenital anomalies lead to late detection of certain lethal or non-lethal anomalies during pregnancy. Detection of severe congenital abnormalities after fetal viability poses a major challenge to women with regard to continuing or termination of pregnancy. This study focuses on the late detection of anomalies and perspective of the patient regarding termination or continuation of the pregnancy.

Aim

To arrive at an understanding about the view and

attitudes of pregnant women regarding late termination of pregnancy after prenatal diagnosis of a severe fetal anomaly.

METHOD

A semi-structured questionnaire based prospective descriptive study was conducted from January 2022 to September 2022 in Obstetrics and Gynecology department of Saveetha Medical College and Hospital, Thandalam. 16 pregnant women with severe fetal anomalies detected after 23 weeks were included. All the women were counselled about the type and lethality of the anomaly including management option. Informed consent was obtained from all the patients and ethical approval was obtained.

RESULTS

A total of 16 women with congenital anomalies in fetus detected after 23 weeks of gestation over 8 months of the study period were included in the study. All the participants were properly counselled and given adequate time to make the decision. Among which 11 decided to terminate the pregnancy and 5 continued. All 11 who opted for termination of pregnancy was joint decision by the family. 5 women continued their pregnancy. Reasons to continue the pregnancy were praying that baby will born normal (n=1), hoping that surgery can correct the abnormality (n=3) and wanting to see the baby (n=1).

On studying the sociodemographic profile (Table 1) of the study population, 3 women were below 20 years of age and all 3 terminated the pregnancy, 5 participants were above 30 years, among which 3 decided to continue the pregnancy and 2 decided to terminate. A majority of 8 participants belonged to age groups between 20-30 years, 6 of them decided to terminate the pregnancy and the rest decided to continue the pregnancy.

9 of the participants were primigravida, 5 were second gravida among which 4 continued the pregnancy and none among the 3 multigravidas continued the pregnancy. Among the 16 participants, 15 were married and 1 was not, and she decided to terminate the pregnancy.

Most of the late detected anomalies were found to be between 23- 28 weeks of gestation, only 2 were detected after that, among which are a diaphragmatic hernia at 30 weeks and an anencephaly in a 32 weeks un-booked patient.

Fetal abnormalities diagnosed

The 5 women who decided to continue their pregnancy had the following abnormalities: severe congenital diaphragmatic hernia (n=2), polycystic renal disease (n=1), corpus callosal agenesis (n=1) and Dandy walker malformation(n=1). The 11 women who accepted termination had the following fetal abnormalities: acrania (n=2), corpus callosum agenesis(n=2), Arnold Chiary syndrome (n=3), renal dysgenesis (n=2), hydrocephalus (n=1) and Holoprosencephaly (n=1).

Pre-delivery interviews Women who decided to terminate their pregnancy

All 11 women stated that they were adequately informed about the nature and lethality of the fetal anomaly and options for management. The mean gestational age when a fetal abnormality was detected was 25 weeks (range 23 - 32 weeks). The mean number of counselling sessions with a health worker before making the decision on late termination was 2 (range 2 - 4). All the patients discussed about condition with their family before taking the decision [1].

Post-delivery interviews

Table 2 compares answers given by the two groups to questions after delivery of the baby. 6 out of 11 who decided to terminate the pregnancy saw their babies after delivery. Two regretted their decision to continue the pregnancy after seeing their abnormal babies, one of these babies died shortly after delivery, and the other was alive during study period. 72.72% of the women who decided to terminate the pregnancy stated that they had no intention of planning a pregnancy in the next year. The majority of the women said that they had been treated with care and utmost professionalism [2].

DISCUSSION

Detection of a serious anomaly in an expected baby could be a really stressful event for a pregnant woman and her family, counselling plays a major role in making sure the seriousness of the situation is explained to the patient and her family, taking into account their social, cultural and religious beliefs [3], so that they could make the crucial decision with a clear understanding of the condition. It is also important that the parents are given ample time after counselling to decide on what is going to follow regarding the fate of the pregnancy. All of the 3 participants who were below the age of 20 years decided to terminate the pregnancy. Out of 7 multiparous women,6 decided to terminate the pregnancy. Marital status, religion and gestational age at diagnosis were not found to be significantly affecting the decision making of the women [4–6].

Table 1: Comparison of maternal and socio-demographic profile

		Continued the pregnancy (31.25%)	Terminated the pregnancy (68.75%)
Age	<20 years	0	3 (18.75%)
	20-30 years	2(12.62%)	6 (37.5%)
	>30 years	3(18.75%)	2 (12.62%)
Parity	G1	4(25%)	5 (31.25%)
	G2	1 (6.25%)	4 (25%)
	G3 and more	0	2(12.62%)
Marital status	Married	5 (31.25%)	10 (62.5%)
	Unmarried	0	1
Gestational age at diagnosis	23-28 weeks	4(25%)	10 (62.5%)
	28-32 weeks	1 (6.25%)	1 (6.25%)

Table 2: Comparison of post-delivery interview in the two groups

	Continued the pregnancy			Terminated the pregnancy		
	Yes	No	Not sure	Yes	no	Not sure
Have you seen the baby?	5	0	0	6	5	0
Do you think you made the right decision?	5	0	0	10	0	1
Had your family been supportive with the decision?	3	2	0	7	4	0
Are you planning a pregnancy within the next year?	0	5	0	0	8	3
Have you been explained about the possibility of recurrence in your next pregnancy?	5	0	0	11	0	0

Majority of the patient stated that their families were supportive with the decision. Despite the small sample size, this result was consistent with one from a prior study [1]. In this study, all of the patient stated that their decision had not been influenced by the health workers. Following a diagnosis of severe foetal abnormalities, patients who terminated their pregnancy reported difficulty making critical decisions. Some of these patients felt overwhelmed by their circumstances and said they were unable to process certain information that the multidisciplinary team had provided during the counselling sessions. Their notion of being unprepared for decision-making due to the unexpectedness of a serious prenatal abnormality was a notable aspect of their experiences. 6 out of 11 of our patients who terminated their pregnancy saw their new-borns. The major justifications offered for wanting to do this were love for the baby and the conviction that it was God's gift. Features such as anencephaly, hydrocephalus and holoprosencephaly that the patients saw in their new-borns felt convincing to them for having made that decision, this finding was in coherence with study done by Hunt K et al [7].

The calculated rate of late termination of pregnancy in our study came out to be 68.75%, which is very much similar with a reported 60% rate in study done by Breeze et al [8]. Souka et al [9] reported an 86% uptake for LTOP for severe foetal abnormalities, and Gammeltoft and colleagues [10] found that 17 of 30 individuals with foetal malformations (57%) elected to discontinue their pregnancy.

In addition, a five-year analysis by the IALCH's Fetal Medicine Unit reported that 75% of women agreed to have their pregnancies terminated when significant deformities were discovered after 24 weeks [1]. The 11 women in our study who opted for the Late termination had no misgivings about their decisions [2, 11, 12].

CONCLUSION

The lower sample size in this study compared to a prior report from this unit is likely to be responsible for the relatively high acceptance of late termination of pregnancy for severe foetal abnormality.

Our study is unique in the way it included interviews with the women both during their pregnancies and immediately after giving birth to a foetus with a serious anomaly. When our expectant women chose to have their pregnancies terminated late due to a serious foetal defect, their disappointment was both acute and short-lived, especially since the malformations were not foreseen. In our study though Partners and family members played an supportive role in the decision making about the unborn baby; it was clear that it was the mother who eventually made the decision. While the majority of the participants were unsure about preparing for future pregnancies, several of our individuals were apprehensive about doing so. This study shows that women who are pregnant with serious foetal anomalies have a range of opinions and attitudes regarding termination, despite the study's small sample size. To compare with initial decision-making, larger follow-up studies will be necessary to see whether patients' perspective changes over time. In moreover, additional research is needed on how women perceive caring for a child who is seriously handicapped.

Funding Support

The authors declare that they have no funding support for this study.

Conflict of Interest

The authors declare that they have no conflict of interest.

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