Views and attitudes of pregnant women regarding late termination of pregnancy for severe fetal abnormalities at a tertiary hospital in KwaZulu-Natal

C Ndjapa-Ndamkou,[1] MB ChB; **L Govender,**[1,2] FCOG (SA); **J Moodley,**[1,3] MD

[1] *Department of Obstetrics and Gynaecology, Nelson R Mandela School of Medicine, University of KwaZulu-Natal, Durban, South Africa*
[2] *Department of Obstetrics and Gynaecology, Lower Umfolozi District War Memorial Hospital, Empangeni, KwaZulu-Natal, South Africa*
[3] *Women's Health Research Unit, Nelson R Mandela School of Medicine, University of KwaZulu-Natal, Durban, South Africa*

***Corresponding author:** L Govender (govenderl18@ukzn.ac.za)*

Aim. To study the views and attitudes of pregnant women with severe fetal anomalies regarding late termination of pregnancy (LTOP).

Methods. Data were collected over a 3-month period using semi-structured interviews of pregnant women with severe fetal anomalies (lethal and non-lethal) detected after 24 weeks' gestation at a single tertiary/quaternary fetal medicine unit in KwaZulu-Natal, South Africa. The interviews were conducted both during pregnancy and within 2 weeks after delivery. The women who underwent LTOP and those who continued with their pregnancies were compared in respect of a variety of demographic and socio-economic characteristics.

Results. During the study period, 15 pregnant women with severe fetal anomalies were interviewed. Of these, 5 (33.3%) requested termination and 10 (66.6%) opted to continue the pregnancy. The women who continued their pregnancies were significantly younger (mean age 25 years, range 20 - 32 years) than those who requested termination (mean age 31 years, range 22 - 35 years) ($p<0.05$). Mean parity was 1 (range 0 - 3) in the patients who continued the pregnancy and 2 (1 - 3) in those who terminated it. The majority of the women were Christians, and there was no significant difference between the groups in their choices. Many women indicated that their partners and immediate family members influenced decision making. All the women said that they were given sufficient time by the hospital staff to make their decision whether to terminate or continue the pregnancy after the options had been explained to them in a non-threatening manner.

Before delivery, the common reasons for continuing with the pregnancy included fear of killing an unborn baby, that a baby is God's gift and the baby will be well after it is born, that nature should be allowed to take its course, and that there should be no interference with the pregnancy. The main reasons for opting for LTOP were the cost implications of raising an abnormal baby, that the baby would suffer during his or her life, and being unable to cope with a severely handicapped child. After delivery and seeing the baby, most women felt that they made the correct choice.

Conclusion. Despite the small numbers from a single academic institution, this study illustrates that even while pregnant with an anomalous fetus, patients' views and attitudes regarding LTOP for severe fetal anomaly were variable. Younger primigravidas were more likely to continue the pregnancy in the hope that the baby would be born normal. Good support from partner and family after delivery was associated with less regret about the decision that had been made. Larger follow-up studies assessing long-term views and attitudes of women regarding LTOP will be important for comparison with the initial decision-making process and for future prenatal counselling.

S Afr J OG 2013;19(2):49-52. DOI:10.7196/SAJOG.645

In South Africa, termination of pregnancy is performed at any period of gestation if it is agreed by consensus decision that continuation of the pregnancy will result in a severely handicapped child. Detection of severe congenital fetal abnormalities after viability poses a major challenge to women with regard to continuing or terminating the pregnancy. The South African literature on the views and attitudes of pregnant women with severe fetal abnormalities regarding late termination of pregnancy (LTOP) is scant. This study from a tertiary hospital in KwaZulu-Natal (KZN) describes women's experiences of the choices faced in the days and weeks after prenatal diagnosis of a severe fetal abnormality.

Aim

We aimed to ascertain the views and attitudes of pregnant women regarding LTOP after prenatal diagnosis of a severe fetal anomaly.

Method

A semi-structured questionnaire-based prospective descriptive study was conducted from August 2010 to October 2010 at the Fetal

Medicine Unit at Inkosi Albert Luthuli Central Hospital (IALCH), KZN, South Africa. At the time of this study, IALCH was the only referral fetal unit for this province in the public sector. Pregnant women with severe or complex fetal abnormalities detected after 24 weeks' gestation were recruited. A fetal medicine specialist (LG) saw all the women, and diagnosis of a severe fetal abnormality necessitating the option of LTOP was based on a consensus opinion by a multidisciplinary team, which included among others a psychologist, social worker, genetics nurse and medical ethicist. The anomalies included both lethal and non-lethal types. All the women received non-directive counselling about the type and lethality of the anomaly, including management options, in a non-threatening manner using simple language, from two or more of the following healthcare workers: fetal medicine specialist, clinical geneticist, obstetrician, midwife nurse, genetic counsellor, clinical psychologist and social worker. Informed consent was obtained from all the participants and the study received ethical approval from the University of KZN. The researcher who administered the questionnaire was not involved in the counselling processes and interviewed the women after they had made their decision. The participants were divided into two groups: those who accepted LTOP, and those who declined and continued their pregnancies. Women were interviewed just before the termination procedure or before delivery (if the pregnancy continued), and again shortly after delivery but before discharge from hospital. The interviews were conducted using the patient's preferred language and in the privacy of a counselling room or side ward. A nurse interpreter assisted when required. The responses were analysed using a statistical package with descriptive statistics calculated. A p-value <0.05 was considered statistically significant.

Results

Fifteen pregnant women with severe fetal abnormalities were studied over a 3-month period: 5 accepted LTOP and 10 declined. There were no significant differences between the groups in terms of ethnicity, parity, marital status, gestational age at diagnosis, or type and lethality of the fetal anomalies. The majority of the women were Zulu-speaking black Africans (n=13). The remaining 2 women in the study were white; 1 accepted and the other declined LTOP. Women who chose to continue their pregnancies were significantly younger than those who opted to terminate ($p<0.05$). The demographic and social characteristics of the subjects are set out in Table 1.

None of the women indicated that they had been told by the health worker(s) to either continue or terminate the pregnancy, and all said that they had been given sufficient time by the hospital staff for discussion with their partners/families and to make a decision about their unborn baby after the options had been explained to them. All 5 women who opted for LTOP indicated that this was a joint family decision, and the reasons given were as follows: the cost of looking after an abnormal child (n=4), that the baby will suffer if he or she lives (n=4), being unable to cope with a severely handicapped child (n=3), that the baby will not be normal after treatment (n=3), that the baby has brain damage (n=2), and that the family supports the decision because the child will be very abnormal (n=5). Reasons for continuing the pregnancy (N=10) were feelings of guilt about killing an unborn baby (n=7), belief that a baby is God's gift (n=9), wanting to see the baby (n=9), praying that the baby will be born normal (n=6), feeling that there should be no interference with the pregnancy (n=5), feeling that the baby should die naturally (n=4), loving and wanting the baby (n=4), hoping that surgery will correct or cure the abnormality (n=3), and refusal of termination by the husband/partner (n=3).

Fetal abnormalities diagnosed

The 10 women who decided to continue their pregnancy (that is, who declined LTOP) had the following fetal abnormalities: spinal abnormalities (n=3), severe microcephaly (n=1), achondrogenesis (n=1), acrania (n=1), hydrops/cardiac abnormality/hydrocephalus (n=1) and hydrocephalus alone (n=3). The 5 who accepted termination had the following fetal abnormalities: achondrogenesis (n=1), hydrocephalus (n=2) and holoprosencephaly (n=2).

Pre-delivery interviews

Women who decided to continue their pregnancy

All 10 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 suspected was 28 weeks (range 23 - 34 weeks), and that at confirmation of

Table 1. Comparison of demographic and social characteristics

Characteristics	Continue pregnancy (N=10)	Terminate pregnancy (N=5)	p-value
Age (years), mean (range)	25 (20 - 32)	31 (22 - 35)	<0.05
Ethnic group, n (%)			NS
Black African	9 (90)	4 (80)	
White	1 (10)	1 (20)	
Parity, mean (range)	1 (0 - 3)	2 (1 - 3)	NS
Marital status, n (%)			NS
Single	7 (70)	4 (80)	
Married	3 (30)	1 (20)	
Religion, n (%)			NS
Christian	9 (90)	4 (80)	
Other	1 (10)	1 (20)	
Gestational age at diagnosis (weeks), mean (range)	31 (25 - 36)	31 (25 - 36)	NS

the diagnosis in our unit was 31 weeks (range 25 - 36 weeks). The mean number of counselling sessions with a health worker before making the decision on LTOP was 2 (range 2 - 4). Seven patients who declined LTOP had further discussions with husbands/partners. Of the 3 women who chose not to discuss termination with their partner/family, 1 discussed it with her spiritual leader. Four of the 7 patients who had discussions with their husband/partner had further discussions with other family members, as follows: parents (*n*=1), aunt (*n*=1), sister (*n*=1) and mother-in-law (*n*=1).

Women who decided to terminate their pregnancy

All 5 women in this group indicated that they were adequately informed about the fetal anomaly and options for management. The mean gestational age when a fetal abnormality was suspected was 29 weeks (range 22 - 35 weeks), and that at confirmation of diagnosis in our unit was 32 weeks (range 27 - 35 weeks). The mean number of counselling sessions with a health worker before making the decision on LTOP was 2 (range 2 - 4). All these women had further discussions with their husbands/partners, and with the following other family members: mother (*n*=3), father-in-law (*n*=1) and mother-in-law (*n*=1). None of these women consulted a spiritual leader to assist in making their decision.

Post-delivery interviews

Table 2 compares answers given by the two groups to questions after delivery of the baby. All the women had seen 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 at the time of the interview). These women were among those who were not visited by family members after delivery, but the family members had assisted them in making their decision to continue the pregnancy. All 5 women who had opted for LTOP said that they had made the correct decision. Eighty per cent of the women in each group stated that they had no intention of planning a pregnancy in the next year. Seven of the 10 women who continued their pregnancies demonstrated poor recall about the nature of the fetal anomaly and the chances of recurrence in future pregnancies. Four women who declined and 1 who accepted LTOP felt that they needed further counselling from the social worker before discharge from hospital. The majority of the women said that they had been treated in a caring and compassionate manner by the healthcare workers.

Discussion

Finding out that an expected baby has a serious anomaly is extremely stressful, not only for the pregnant woman but for her family, and counselling needs to take into account the parents' culture, religion, and beliefs[1] in order for them to make an informed decision. Parents also need to be allowed adequate time after counselling to reach an informed decision. Our subjects who opted to continue their pregnancies were significantly younger than those who decided on LTOP. There was no difference between the groups in parity, ethnicity, marital status, type or lethality of fetal anomaly, or gestational age at diagnosis. Religion is known to play an important role in women's decisions whether or not to terminate an abnormal pregnancy.[2-4] The majority of our subjects were Christians (90% of the group who declined LTOP and 80% of those who accepted; $p>0.05$), and religion did not appear to play a significant role in their choices. Although the numbers were small, this finding was similar to that in a previous study in this unit.[5]

The majority of the patients indicated that their decision on LTOP was influenced by family members. No woman said that she had been told by a health worker to either terminate or continue the pregnancy. Patients who had LTOP following diagnosis of severe fetal abnormalities described difficulty of making painful decisions, while some were overwhelmed by the situation and indicated that they had been unable to take in certain information provided by the multidisciplinary team during the counselling sessions. A striking feature of their accounts was their sense of being unprepared for decision making because of the unexpectedness of a severe fetal anomaly.

All our patients in both groups saw their babies after delivery. Love for the baby and the feeling that it was God's gift were the main reasons given for wanting to do this. In the group that had decided to terminate their pregnancies, seeing the stubby limbs or disproportionately big head and facial deformities provided reassurance that something was indeed wrong with the baby, and that the correct decision had been made. Hunt *et al.* reported that most of their patients diagnosed with fetal abnormalities wanted to see the baby after delivery.[6] The reasons given included hoping for visual reassurance that something 'really was wrong' – for example, one woman said 'I wanted to see the lesion on his spine because I wanted to be sure that there had been no mistake.'

Table 2. Comparison of post-delivery interviews in the two groups

	Continue pregnancy (*N*=10) *n*		Terminate pregnancy (*N*=5) *n*	
Questions	**Yes**	**No**	**Yes**	**No**
Have you seen the baby?	10	0	5	0
Do you feel you made the correct choice for your baby?	8	2	5	0
Have any members of your family visited you since you delivered the baby?	7	3	4	1
Would you like to speak to a social worker before you go home?	4	6	1	4
Will you be planning another pregnancy within the next year?	2	8	1	4
Has anyone (doctor/nurse) explained what might happen in your next pregnancy?	3	7	4	1
Were you treated in a professional manner with a caring attitude by the hospital staff?	7	3	4	1

In contrast to our 33% rate of LTOP, Breeze *et al.*[7] reported that 12 of 20 patients (60%) decided to terminate their pregnancy following ultrasound detection of fetal abnormalities, Gammeltoft and co-workers[8] reported that 17 of 30 patients with fetal anomalies (57%) decided on termination, and Souka *et al.*[9] reported an 86% uptake for LTOP for severe fetal anomaly. Furthermore, a 5-year audit from the Fetal Medicine Unit at IALCH showed 75% acceptance of termination for severe fetal anomalies detected after 24 weeks.[5] The low proportion of women requesting LTOP in the current study may be attributable to the small number interviewed over a short period of time.

All 5 of the women in our study who decided on LTOP had no regrets about their decision, while 2 of the 10 who opted to continue their pregnancies regretted the decision after seeing the baby. A woman's choice to continue her pregnancy deszzpite severe fetal anomaly poses a challenge to healthcare professionals, who need to prepare her as well as possible for the physical experiences and decisions that she will face as a result of her decision.

One-third of the women in our study (4 who continued their pregnancy and 1 who terminated) asked to see the social worker before discharge from hospital. These women needed further counselling and reassurance about their decisions after being faced with the reality of the situation. In contrast to findings reported by others,[10-12] all the women in our study who opted for LTOP felt that they had made the right decision, even though it was a painful one, after confirmation that the fetus was severely malformed or would suffer severe morbidity should it survive.

Conclusion

The relatively low uptake of LTOP for severe fetal anomaly in this study compared with a previous report from this unit is probably due to the small sample size. Interviews conducted both while the women were pregnant with a fetus with a severe anomaly and shortly after delivery make our study a distinctive one. The immediate and short-term reactions of our pregnant women when they opted for LTOP for a severe fetal anomaly included disappointment, especially because the anomalies were not anticipated. Partners and family members played an important role in the initial decision making about the unborn baby; however, it was disturbing to note that 4 women lacked family support when they needed it, especially immediately after the delivery. We found that many of our subjects were cautious about planning future pregnancies.

Despite the small numbers, this study illustrates that women who are pregnant with severe fetal anomalies have varying views and attitudes regarding termination. However, larger follow-up studies to assess whether views and attitudes change in the longer term will be important for comparison with initial decision making. There is also a need for larger studies comparing views and experiences of women who have a spontaneous perinatal death compared with iatrogenic fetal death for a severe or complex fetal anomaly. Furthermore, follow-up studies of women's views on caring for a severely handicapped child are required.

1. Gagnon A, Wilson RD, Allen VM, et al. Evaluation of prenatally diagnosed structural congenital anomalies. J Obstet Gynaecol Can 2009;31(9):875-889.
2. Sasongko TH, Abd Razak Salmi AR, Zilfalil BA, Albar MA, Hussin ZAM. Permissibility of prenatal diagnosis and abortion for fetuses with severe genetic disorder: Type 1 spinal muscular atrophy. Ann Saudi Med 2010;30(6):427-431. [http://dx.doi.org/10.4103/0256-4947.72259]
3. Ahmed S, Green JM, Hewison J. Attitudes towards prenatal diagnosis and termination of pregnancy for thalassaemia in pregnant Pakistani women in the North of England. Prenat Diagn 2006;26(3):248-257. [http://dx.doi.org/10.1002/pd.1391]
4. Ahmed S, Hewison J, Green JM, Cuckle HS, Hirst J, Thornton JG. Decisions about testing and termination of pregnancy for different fetal conditions: A qualitative study of European white and Pakistani mothers of affected children. J Genet Couns 2008;17(6):560-572. [http://dx.doi.org/10.1007/s10897-008-9176-x]
5. Govender L, Moodley J. Late termination of pregnancy by intracardiac potassium chloride injection: 5 years' experience at a tertiary referral centre. S Afr Med J 2013;103(1):47-51. [http://dx.doi.org/10.7196/SAMJ.6006]
6. Hunt K, France E, Ziebland S, Field K, Wyke S. My brain couldn't move from planning a birth to planning a funeral: A qualitative study of parents' experiences of decision making after ending a pregnancy for fetal abnormality. Int J Nurs Stud 2009;46(8):1111-1121. [http://dx.doi.org/10.1016/j.ijnurstu.2008.12.004]
7. Breeze ACG, Lees CC, Kumar A, et al. Palliative care for prenatally diagnosed lethal fetal abnormality. Arch Dis Child Fetal Neonatal Ed 2007;92(1):F56-F58. [http://dx.doi.org/10.1136/adc.2005.092122]
8. Gammeltoft T, Hang TM, Hiep NT, Hanh NTT. Late term abortion for fetal anomaly: Vietnamese women's experience. Reprod Health Matters 2008;16(31):46-56. [http://dx.doi.org/10.1016/S0968-8080(08)31373-1]
9. Souka AP, Michalitsi VD, Skentou H, et al. Attitudes of pregnant women regarding termination of pregnancy for fetal abnormality. Prenat Diagn 2010;30(10):977-980. [http://dx.doi.org/10.1002/pd.2600]
10. Dallaire L, Lortie G, De Rochers M, et al. Parental reaction and adaptability to prenatal diagnosis of fetal defect or genetic disease leading to pregnancy interruption. Prenat Diagn 1995;15(3):249-259. [http://dx.doi.org/10.1002/pd.1970150308]
11. David HP. Psychosocial studies of abortion in the United States. In: David HP, Friedman HL, Van der Tak J, et al., eds. Abortion in Psychosocial Perspective: Trends in Transnational Research. New York: Henry P David, 1978:97.
12. Mourik MCA, Connor JM, Ferguson-Smith MA. The psychosocial sequelae of a second trimester termination of pregnancy for fetal abnormality. Prenat Diagn 1992;12(3):189-204. [http://dx.doi.org/10.1002/pd.1970120308]