Views and attitudes of pregnant women on decision making for LTOP for severe fetal abnormalities

A dissertation submitted to the

Faculty of Health Sciences

University Of KwaZulu-Natal

In partial fulfilment of the requirements

for FCOG (SA) and MMed degree

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DEDICATION

This study is dedicated firstly to the Almighty God, for providing me the strength and courage to complete this dissertation.

To my Mum and Dad for their continuous support and encouragement during my schooling and postgraduate training.

I convey special thanks and gratitude to my wife Zukiswa Bulabula and my children Hlumile, Milisa and Ayema for the pain and endurance over years of my research and training without my presence. To my brother Christian Ndamkou for the brotherly care and continuous support; and to Sylvain Pondja Ndamkou and my grandmother who were laid to rest in my absence.

I also dedicate the work to the entire staff members of the Fetal Unit of IALCH for their enormous support during this study.

Finally, the work of this study is also dedicated to the pregnant women who had to endure the heart rendering information about their pregnancies and helped in the questionnaires.

STATEMENT OF DECLARATION

I, Dr Constant Ndjapa-Ndamkou, hereby declare that the work on which this dissertation is based and which is now being submitted for examination in partial fulfilment for the degree of Masters of Medicine (Obstetrics and Gynaecology) at the University of KwaZulu-Natal is original and is my own unaided work carried out by me under the supervision of Dr L Govender. I also declare that the work of this dissertation has not previously been submitted by me for a degree at this or any other University and the material contained in this dissertation and emanating from other sources have been duly acknowledged.

..... **Date: 30th June 2011**

Dr C Ndjapa-Ndamkou

..... **Date: 30th June 2011**

Dr L Govender
(Supervisor)

Plagiarism:

DECLARATION

I.....**DR C. NDJAPA-NDAMKOU** .....declare that:

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ACKNOWLEDGEMENTS

I, Dr C Ndjapa-Ndamkou would like to extend my gratitude to the following people:

I would like to thank my supervisor, Dr L Govender, for her constant encouragement, motivation and ideas during the preparation of this dissertation.

My sincere gratitude to Prof J. Konje, Head Obstetrics and Gynaecology, Leicester University, UK for his useful comments and support.

Prof J Bagratee, Head of Department of Obstetrics and Gynaecology, University of KZN.

Staff of Department of Obstetrics and Gynaecology at IALCH – without whose assistance, this study would not have been possible.

The patients who participated in this study

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LIST OF ABBREVIATIONS

ENND	Early neonatal death
IALCH	Inkosi Albert Luthuli Central Hospital
LTOP	Late Termination of Pregnancy
SB	Stillbirth
TOP	Termination of Pregnancy
TOPFA	Termination of pregnancy for fetal abnormalities

Abstract

Aim: To study the views and attitudes of pregnant women with a severe fetal anomaly towards late termination of pregnancy (LTOP).

Methods: Data was collected over a 3 month period using a pen and paper semi-structured interview of pregnant women with severe fetal abnormalities (lethal and non-lethal) detected after 24 weeks gestation at a tertiary / quaternary hospital. The interview was conducted during pregnancy and within 2 weeks after delivery. All women had prior counselling about their fetal anomaly by healthcare workers at the Fetal Unit. A variety of demographic and socio-economic characteristics were compared between the women that underwent termination of pregnancy (TOP) and those that continued with their pregnancy. The interview was conducted over approximately 30 minutes in the privacy of a counselling room or side ward. Informed consent was obtained from all participants and the study received ethical approval. The responses were analyzed using a statistical package with descriptive statistics calculated. A p-value of <0.05 was used for statistical significance.

Results: During the study period, 15 pregnant women with severe fetal anomalies were interviewed. Of these, 5 (33%) women requested TOP and 10 (66%) opted to continue with the pregnancy. The mean (range) maternal age for those continuing with the pregnancy was 25 (20-32) years; and in those requesting termination was 31 (22–35) years. The patients who continued with pregnancy were significantly younger than those who decided to terminate (25 vs 31 years; $p<0.05$). The mean (range) parity was 1 (0-3) in the patients who continued with pregnancy and 2(1-3) in the patients who terminated. Eighty five percent of the women were Christians and there was no significant difference in their choices.

Majority of the women indicated that their partners and immediate family members influenced their decision-making. Before delivery, the common reasons for continuing with the pregnancy included: fear of killing an unborn baby, the baby is God's gift and the baby will be well after it is born, let nature take its course and there should be no interference to the pregnancy. All women indicated that they were given sufficient time by the hospital staff to make their own decision about their unborn baby after the options were explained. For those that opted to terminate the pregnancy, the main reasons were the cost implications of raising an abnormal baby; baby will suffer during life and unable to cope with severely handicapped child. Post delivery, most women felt that they made the correct choice after seeing the baby.

Conclusion: Despite the small numbers, this study illustrates that even whilst pregnant with an anomalous fetus, women's views and attitudes towards late TOP for severe fetal anomaly are variable. The younger primigravida are more likely to continue with the pregnancy in the hope that the baby will be born normal. Good support from partners / family after delivery was associated with a more favourable response towards decision-making for LTOP. Follow up larger studies assessing the long-term views and attitudes of women towards late TOP will be important for comparison with initial decision-making process and future prenatal counselling.

1. Introduction

Fetal abnormalities are congenital disorders identified prenatally. A major congenital anomaly affects 2-3% of newborn babies (Boyd et al., 2002). Congenital anomalies are important cause of fetal, neonatal and child mortality and morbidity, accounting for 21% of perinatal and infant deaths in the UK (Macfairlane and Mugford, 2000) and affect about seven percent of babies born worldwide every year (Christianson et al., 2006). However, a relatively smaller percentage of congenital disorders are detected prenatally. Most of the studies assessing women's views and attitudes towards termination of pregnancy for fetal abnormalities are carried out following delivery of a non-viable, albeit normal, fetus. In middle and low-income countries, studies have been sparse. The most likely reason may be the sensitivity of the subject and because many women do not have access to prenatal diagnosis and screening programs.

Pregnant women presenting for a scan expect to be told that their baby is normal. They want to be reassured of the growth and the wellbeing of the unborn baby. When a possible abnormality is suspected, it presents as a shock to the parents. When the abnormality is subsequently confirmed, there may be an assumption that since the parent sought screening in the first place; they intended to proceed to a termination. The burden carried by a mother who knows that her fetus is seriously malformed or will have a short post-delivery survival accompanied by suffering and/or prolonged hospitalization or repeated surgery is significant (Gevers S, 1999). Her autonomous choice may thus be to terminate the pregnancy based on compassion for her abnormal child, self-determination or self-interest (Moodley K, 2008).

In most first world countries TOP with feticide is generally carried out after 22 weeks, even for lethal anomalies (Vadeyar et al., 2005). In South Africa, termination of pregnancy with feticide for severe fetal abnormality is usually performed after 24 weeks; which is the cut- off gestation for clinical viability in most local Fetal Medicine units (personal communication). What constitutes a severe fetal abnormality is based on a consensus opinion by a multidisciplinary team. This also includes both lethal and non-lethal abnormalities.

In South Africa, TOP from 20 weeks onward terminations can only be performed under very limited circumstances. The Choice on Termination of Pregnancy Act 92 of 1996 and the Amendment Act, 2004 is stated below. (Government Gazette 2005 476: 27267).

This act and its amendment allow pregnancy to be terminated under the following circumstances:

A. Upon request of a woman during the first 12 weeks of pregnancy (up to 14 weeks gestational age). A trained midwife and doctor can perform this TOP.

B. After 12 up to, and including 20 weeks, when a medical practitioner after consultation with the

pregnant woman is of opinion that continued pregnancy would pose a risk of injury to the woman's physical or mental health or that there exists substantial risk that the fetus would suffer from severe physical or mental abnormality. Also, TOP is allowed if the pregnancy resulted from rape or incest. Lastly, TOP can be performed if it is decided that the continued pregnancy would significantly affect the social or economic circumstances of the woman.

C. After 20 weeks when the medical practitioner, after consultation with another medical practitioner or a registered midwife, is of opinion that continued pregnancy would endanger the woman's life, would result in severe malformation of the fetus, and would pose a risk of injury to the fetus

When a couple is confronted with a pregnancy in which there is fetal abnormality incompatible with life, they are faced with awkward decision whether to terminate or not (Setubal et al., 2003). Some authors have reported that the decision to terminate may have a negative effect on the couple's relationship, frequently leading to disagreements, projection of rage, anguish and guilt (Benute and Gollop, 2002). Acceptance of the diagnosis of fetal abnormality is very difficult both for women and for partners/husbands as they are faced with interruptions of hope and aspirations. The ultimate intention is to allow the expectant parents after they have received and understood all the pertinent information to form their own assessment on the impact the condition would have on their future child.

1.1 Late termination of pregnancy

A significant aspect of LTOP may be the psychological effect on the pregnant woman herself. It is not unusual to find that termination of pregnancy in the third trimester is often accompanied by a feeling of loss, depression and guilt – especially when the pregnancy has been planned. For example: the typical agony of a pregnant woman who once stated after having LTOP: **'***My brain couldn't move from planning a birth to planning a funeral'* **(**Hunt et al., 2009). The dilemma posed by certain peculiar medical circumstances when the option to have LTOP becomes exceptionally necessary, should always be appraised by all concerned (patients, partner, family and healthcare professionals). To ensure that the post-LTOP emotional and psychological effects are minimized, the women should be provided with appropriate counselling.

The decision of whether to continue or opt for termination in which severe fetal abnormalities have been identified is complex and has been shown to be dependent on many factors. The acceptance rate after an offer of termination varies between studies and may differ due to circumstances of the patients included in the study and the seriousness of the abnormalities detected (Rauch et al., 2005; Stoll et al., 2001; Viljoen et al., 1996). Factors that may influence early termination of pregnancy decision have been investigated

include maternal and pregnancy issues. Maternal factors include maternal age, religious and cultural beliefs, reproductive history, as well as views and attitudes of individuals towards termination of pregnancy. Pregnancy factors include certainty of fetal abnormality diagnosis, severity of the abnormality and whether the abnormality is considered lethal or not. It is often difficult to isolate these factors and influence they have on termination from one another, as many of them are closely linked (Green and Statham, 1996).

There are three main options: to continue with the pregnancy, to terminate the pregnancy, or to consider prenatal intervention. If the decision is to continue with the pregnancy, there should also be a need to an anticipatory management plan for the infant after birth. If the decision is to terminate, there may be a need to go to another hospital or change the obstetrician if termination is not personally acceptable to him or her. The parents should be made aware of these implications, not in an attempt to change their mind, but to inform and prepare them for the process.

1.2 Basic ethical principles

The ethical debate surrounding late TOP and feticide is based on an understanding of the moral status of the fetus (Moodley K. 2008). The HPCSA general ethical guidelines for Reproductive Health states that abortion is very widely considered to be ethically justified when undertaken for medical reasons to protect the life and health of the mother. This guideline is silent regarding LTOP for severe fetal anomaly.

Chervenak et al (2003) have described the basic ethical principles in the management of pregnancies complicated by fetal anomalies. The first ethical principle is that the patient's perspective on health-related and other interests is of paramount importance. The physician needs to respect the patient's own set of values, beliefs and decision-making capacity. The physician's role is to provide adequate information and a recommended management plan, or range of possible plans, for the condition in question. It is vital that the information is provided in a manner that allows the patient to understand it, to be able to reach an informed and voluntary decision. However, it is important to note that the expectant parents' great state of distress, grief or shock may make it very difficult for them grasp and understand information that is provided (Menahem and Grimwade, 2004). What is best for the pregnant woman may differ from what is best for the fetus (for example, where there are physical risks to the woman in continuing the pregnancy). Difficult choices may have to be made and are based on where ethical priorities lie.

1.3 Counselling pregnant women with fetal abnormalities

When a serious fetal abnormality has been confirmed, parents should be adequately counselled about the quality of life for such abnormalities and options should include termination of pregnancy irrespective of the gestational age at diagnosis. For most women this will be a difficult decision and they must be supported in whatever decision they choose. Various factors may play a role in decision - making, and largely depends on the views and attitudes of women towards late termination of pregnancy for severe fetal abnormalities.

Counseling should take place over more than one consultation and may have to be re-visited on each occasion, due to the emotional nature of the situation and the complexity of the information to be conveyed (Malhotra et al., 2010). The first step is providing accurate information about the diagnosis and prognosis in a manner and at a timing that the expectant parents are able to understand. Fetal congenital anomaly necessitate that physicians provide the parents with sufficient information. For any counselling to be credible, the diagnosis must be accurate. The most accurate information possible should be given to the expectant parents, along with a clear explanation of what is still uncertain, unclear or subject to change as the pregnancy progresses. For conditions where there is inadequate or incomplete data as far as their outcome and natural history are concerned, this should be conveyed to the parents.

Several studies highlight the feelings and reactions of women who underwent late-term abortion for fetal malformations (Korenromp et al., 2005; Kersting et al., 2005; Korenromp et al., 2007). These studies have explored this important aspect of LTOP mainly in first world countries. Nearly all the women in these studies have expressed sorrow and pain following LTOP. This has been because they had all looked forward to becoming mothers with pride, joy and anticipation and had already shared the happy news with family and friends and felt emotionally attached to the child they expected. In addition, after termination, most parents will want to know if the prenatal prediction was accurate and what implications are there for future pregnancies.

Very few studies have directly investigated the experiences of women during and after ending a pregnancy for fetal abnormality after viability. In South Africa, the literature is scant on the views and attitudes of patients diagnosed with severe fetal abnormalities towards late termination of pregnancy before and shortly after delivery. In this study, we wish to analyse the views and attitudes of pregnant women towards LTOP for a severe fetal anomaly and in doing so we wish to identify the factors that influence their decision-making. This dissertation describes the experiences of pregnant women following the diagnosis of fetal abnormality and factors that influence the decision-making process.

2. The Study

2.1 Aim

To study the views and attitudes of pregnant women with a severe fetal anomaly towards late termination of pregnancy (LTOP), before and shortly after delivery.

2.2 Objectives

1. To determine the views and attitudes of pregnant women towards late termination of pregnancy for major fetal malformations before and after delivery

2. To determine the factors that influence the decision-making process among pregnant women who have either accepted or declined LTOP for fetal abnormality (ies).

2.3 Method and Materials

2.3.1 Study design

A semi-structured interview was conducted from August 2010 to October 2010 at the Fetal Medicine Unit at Inkosi Albert Luthuli Hospital, (IALCH). This is a tertiary / quaternary hospital in Durban, KwaZulu-Natal. Pregnant women with severe fetal abnormalities detected after 24 weeks gestation were recruited. A Fetal Medicine Specialist saw all women and the decision for a severe fetal abnormality necessitating the option for TOP was based on a consensus opinion by a multidisciplinary team.

All women had prior counseling about their fetal anomaly at the Fetal Unit by two or more of the following: Clinical Geneticist, Obstetrician, a Nurse in the Fetal Medicine Unit, a Nurse Genetic Counsellor, a Clinical Psychologist and / or Social Worker. During recruitment, all women were informed of the nature of the interview, which was voluntary. All women were interviewed within one week of the initial counselling for the fetal anomaly and again within two weeks after delivery. The interviews were conducted in English and with assistance of a nurse interpreter if patient requested translation into their first language. The interview was conducted in the privacy of a counseling room or side ward for approximately 30 minutes per session. For those women that were referred to their local hospital for delivery, arrangements were made for conducting a post delivery telephonic interview at convenient time within 2 weeks of the delivery. A verbal explanation and a written informed consent was

obtained from the participants in the study. The researcher conducted the interview. Data was collected by pen and paper recording of the interview on the semi-structured interview sheet (see Appendix 1A and Appendix 1B). The participants were divided in two main groups – those that accepted and those that declined TOP for severe fetal abnormalities. Further management of the women was according to the unit's standard protocol of management. This included a 6-week follow up visit for postnatal review at the Fetal Unit.

2.3.2 Selection of patients

All women with severe fetal abnormalities detected after 24 weeks seen at the Fetal Unit at IALCH during the 3-month study period.

2.3.3 Inclusion criteria

All women who have been counselled for severe fetal abnormalities beyond 24 weeks gestation. This was irrespective of the decision whether to continue or terminate the pregnancy.

2.3.4 Exclusion criteria

Women having TOP for severe fetal abnormalities less than 24 weeks and those who declined to participate in the interviews.

2.3.5 Statistical analysis

The protocol was discussed with a professional statistician. Data collected for the study were analyzed using descriptive statistics, means (ranges) and percentages. Mann-Whitney rank sum test was used for age comparison. A p value <0.05 was used for statistical significance. The qualitative data was analysed by observed impression and reported in a quantitative form.

2.3.6 Regulatory Approval

The study was approved by the Biomedical Research Ethics Committee of the University of KwaZulu-Natal [BREC No: 145/09]. Hospital permission for the use of data was obtained from hospital management at IALCH and Department of Health, KwaZulu-Natal.

3. Results

Fifteen pregnant women with fetal abnormalities were studied over the three month period from August 2010 to October 2010. The women were divided into two groups; those wishing to continue with pregnancy and those terminating the pregnancy. Five women accepted LTOP and 10 declined. All the pre delivery interviews were conducted at the Fetal Unit counselling room. Seven of the post delivery interviews were conducted in the side room in the postnatal ward and the remaining eight interviews were conducted telephonically at a time convenient to the patient, since these women delivered at their local hospitals.

3.1 Demographic data and social characteristics

Demographic and social characteristics are shown in Table 1. There was no significant difference in terms of race, parity, religion; marital status, financial source, educational level, gestational age at diagnosis. This included the type and even for the lethality of the fetal anomalies. Three women in the declined LTOP group were primigravida, while all 5 women that accepted termination group had at least one other child. Women who chose to continue their pregnancies were significantly younger than those who opted to terminate ($p < 0.05$). Ninety percent of the women that continued pregnancy and 80% that accepted TOP were Black and Christians (p=NS). Of the 4 married women in this cohort, one accepted and 4 declined TOP. Seventy percent women that continued with their pregnancy depended on their partner (30%) or family (40%) for financial income. Nine of 10 women that continued pregnancy received secondary (7) or tertiary (10) education. One woman in each group received no formal education.

Only one third of the women knew about the severity of the fetal anomaly prior to being seen at the tertiary unit. The referring doctor and not the Sonographers who performed the initial scan, informed these women. No women indicated that they were told by the health worker(s) to either continue or terminate the pregnancy. All women stated that they were given sufficient time by the health care worker to make their own decision about their unborn baby after the options were explained. Fourteen of the fifteen patients had ultrasound done in their local hospital, which showed features of fetal abnormalities and referred to IALCH for level three scan that confirmed the presence of fetal abnormalities. One patient did not have a scan at the local hospital but presented at IALCH for medical reasons. The ultrasound examination confirmed a fetal abnormality. The majority of the fetal abnormalities had been detected or confirmed in the early third trimester of pregnancy at a mean gestation age of 31 weeks for both groups. The average number of counselling sessions was three. The diagnosis to decision- making time in the accepted and declined groups was a maximum of 4 weeks and 2 weeks respectively.

Table 1. Comparison of demographic and social characteristics

Characteristics	Declined (n=10)	Accepted (n=5)	P - value
Age (yrs) (mean + range)	**25 (20-32)**	**31 (22-35)**	**< 0.05**
Race			
Black	9	4	**NS**
White	1	1	
Parity mean (range)	**1 (0-3)**	**2 (1-3)**	**NS**
Marital status			
Single	7	4	**NS**
Married	3	1	
Religion			
Christian	9	4	**NS**
Other	1	1	
Financial source			
Self	2	1	
Partner	3	1	**NS**
Family	4	2	
Welfare	1	1	
Education Level			
None	1	1	
School	7	3	**NS**
University	2	1	
GA at diagnosis (wks)	**31 (25-36)**	**31 (25-36)**	**NS**
No. counselling sessions	**3 (2-4)**	**3 (2-4)**	**NS**
Time to decision-making(wks)	**1 (1day -2wks)**	**2 (1-4 wks)**	**NS**

3.2 Pre delivery interview

The following responses were given by the women in the study to the open-ended question regarding the reasons for the choices they made for the unborn baby.

3.2.1 Reasons for continuing pregnancy [n=10]:

- guilt of killing an unborn baby (7)
- baby is God's gift, want to see baby (n=7)
- pray that the baby will be born okay (n=6)
- there should be no interference to the pregnancy (n=5)
- baby should die naturally (n=4)
- love the baby and want the baby (n=4)
- surgery will correct/ cure the abnormality (n=3)
- husband refused (n=3)

Majority of the women expressed guilt of killing an unborn baby (n=7), which was a gift from God. Six women did not believe that the baby was abnormal and would pray for a normal baby. Seven patients had further discussions with husbands/partners while three patients did not discuss the problem with any family members. Four of the seven patients who had discussions with husband/partner had further discussions with family as follows; parents (n=1), aunt (n=1), sister (n=1) and mother-in-law (n=1). Three women stated that husband refused the termination. One patient had further discussion with a spiritual leader. It was a joint family decision to continue with their pregnancy in seven women. All women indicated that they were give sufficient time by the hospital staff to make their own decision about their unborn baby after the options were explained.

3.2.2 Reasons for terminating pregnancy [n=5]

- costly to look after abnormal child (n=4)
- baby will suffer if it lives (n=4);
- unable to cope with severely handicapped child (n=3).
- baby will not be normal after treatment (n=3),
- baby has brain damage (n=2),
- family supports the decision because the child will be very abnormal (n=5)

The most important reason for terminating a pregnancy was the cost implications and the suffering that the baby will endure (4). All the women had further discussions with their husbands / partners. In addition, all women had further discussions with one or more other family members as follows; mother (n=3), father–in-law (n=1), and mother-in-law (n=1). All five patients decided in consultation with family members to have termination of pregnancy. None of these women consulted with a spiritualist to assist in their decision-making. All the patients were informed about pros and cons of termination of pregnancy.

3.3 Fetal anomaly and birth outcome

The type of fetal anomaly and birth outcome is shown in Table 2. Intracardiac potassium chloride was used for fetal demise in the women that consented to termination of pregnancy. This was done according to the Fetal Unit protocol. All five women in this group delivered a stillbirth. Four of the ten women that continued with their pregnancy delivered a stillbirth. Of the six babies that were born alive [3 spina bifida + 3 hydrocephalus], one of each were alive at 2 weeks of age. The nature of the fetal anomaly was not significantly different between the groups. The two women whose babies were alive at 2 weeks of age expressed regret in continuing with the pregnancy, even after surgical intervention, citing lack of family support.

Table 2. Fetal anomaly and outcome

Continued (n=10)		Terminated (n=5)	
spina bifida	*3 (2 ENND)*	*achondrogenesis*	*1*
microcephaly	*1 (SB)*	*hydrocephalus*	*2*
achondrogenesis	*1 (SB)*	*holoprosencephaly*	*2*
anencephaly	*1 (SB)*		
hydrops	*1 (SB)*		
hydrocephalus	*3 (2 ENND)*		
2 alive at 1 week [1 spina bifida +1 hydrocephalus]		***all delivered stillbirth***	

SB – stillbirth ENND – early neonatal death

3.4 Delivery characteristics

Table 3 illustrates mode of delivery and fetal outcome between the 2 groups. The delivery details of the ten patients who opted to continue pregnancy irrespective of fetal abnormalities were as follows: Six had caesarean section and four had normal vaginal delivery. There were six live births and four stillbirths.
In the group that decided to terminate pregnancy the delivery details and fetal outcome were as follows: Four delivered by normal vaginal delivery and one by caesarean section. All five were stillbirths. The delivery characteristics were not significantly different between the groups. Four women that continued with the pregnancy delivered a stillbirth at other institutions and only two birth weights were known. Attempts to obtain the birth weights from the labour wards were unsuccessful. The mean birth weights for this group were therefore omitted.

Table 3. Labour and delivery characteristics

Characteristics	Continued pregnancy (n=10)	Terminated pregnancy (n=5)
Live babies	6	0
Weight (g): mean (range)	2810 (1750-3800)	n/a
Early neonatal deaths	4	0
Stillbirths	4	5
Weight (g): mean (range)	Missing data	2270 (1000-4300)
Labour Spontaneous		
C/S (emergency)	alive (n=2); SB (n=1)	0
NVD	3 SB	3
Labour Induced		
C/S (emergency)	3 alive	1
NVD	1 alive	1

3.5 Post delivery interview

Contraceptive methods were offered to all patients in the postnatal ward before discharge from hospital. Those desiring future fertility were advised to attend their local clinic for continuation of their contraceptive preferences until they were ready for their next pregnancy.

Table 4 illustrates the comparison in answers to the same questions between the groups. This interview was conducted in the postnatal ward within 7 days (7) and telephonically (8) within 2 weeks. All fifteen patients were interviewed post delivery and the responses indicated below:

Table 4. Comparison of post delivery interviews between the groups

	Continued (10)		Terminated (5)	
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?	7	3	5	0
Did any member of your family visit you after delivery?	7	3	4	1
Would you like to see a Social Worker again?	6	4	4	1
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

3.5.1 Continued pregnancy

All the patients saw the baby after delivery. Seven patients agreed that they made the right choice for the baby. Three women regretted their decision to continue with the pregnancy, citing the lack of family support during and after the delivery. This included the two women whose babies were still alive after 2 weeks. Seven patients stated that members of their family visited them since the delivery. Six patients agreed to see the Social Worker again while four patients thought it was not necessary. Eight patients had no plans about falling pregnant in the near future while two patients thought about the option. Seven patients stated that they were cared for in a professional manner and with caring attitude by the nurses and doctors. Only 3 women could recall being explained about their future pregnancies during the counselling sessions. Seven patients coped well with the outcome of the pregnancy; two were stressed with the outcome while one who was so overwhelmed by the sight of the baby and cried uncontrollably.

3.5.2 Terminated Pregnancy

All the patients saw the baby after delivery. All the patients agreed that they made the right choice for the baby. All stated members of the family visited them since the delivery and were very supportive. Four patients agreed to see Social Worker again while one patient thought it was not necessary. Four patients had no plans about falling pregnant in the near future while one patient thought about the option. Four patients recalled the information given during the counselling by the doctor about what might happen in the next pregnancy. Four patients stated that they were cared for in a professional manner and with caring attitude while one patient thought otherwise. One woman was anxious to know what will happen in the next pregnancy.

4. Discussion

Despite the small numbers, this study reflects the variability in the views and attitudes of pregnant women with an anomalous fetus towards late termination of pregnancy for severe fetal anomalies before and shortly after delivery.

Two thirds of women in this study opted to continue with the pregnancy. It was the first pregnancy for three of these women, while all women that opted to terminate the pregnancy had other children. Although it may be difficult to establish with certainty the impact of a severe fetal anomaly of the first pregnancy vs a subsequent pregnancy on the women's views and attitude towards late termination of pregnancy, our small study shows that the younger primigravida are less likely to terminate pregnancy. This finding is contrary to findings in many studies on TOP on demand where, many of the women who seek are abortions are young, in their first pregnancy and lack preparedness for childbearing (Frohock FM., 1983; Gardner RFR., 1975; Russo et al., 1992; Suffla S., 1997; Mdleleni-Bookholane R,. 2007). However, seven of the ten women that opted to continue pregnancy had other children, suggesting that other factors may influence their views and attitudes towards late termination of pregnancy.

Age and parity plays an important role in the decision making for termination of pregnancy. In our study those patients seeking termination were significantly older compared those who opted for continuation of pregnancy. Schechtman et al (2002) reported that older patients were more likely to terminate an affected pregnancy than younger couples suggesting an influence of maternal age on decision-making. Rauch et al (2005) showed no impact of maternal age on the decision regarding termination when abnormalities were diagnosed.

Apart from the age group, there was no significant difference between the groups in terms of their race, parity, religion, educational level, occupation and financial category. Majority of the women in the study were unmarried, Black and Christians. Black patients may be more likely to continue affected pregnancies for traditional and religious beliefs. This was not addressed in our study and may be an important factor for future research. A South African study comparing Muslims patients to other religions found that religious belief was an important factor in the decision about TOP (Viljoen et al., 1996). In addition, black patients may be more inclined to leave the outcome of their pregnancy to fate. Kuppermann et al. (2006) reported that African American women have higher levels of fatalism than women from other ethnic groups do. In addition, they showed that high scores in a fatalism scale were associated with lower willingness to terminate an affected pregnancy (Learman et al., 2005). We were unable to find any publication that looked at the reasons why Black South African women were less likely to terminate an affected pregnancy. In some religions, termination of pregnancy is absolutely forbidden,

for other religious groups late termination is unacceptable (Zlotogora J., 2002). In addition, for some patients, their moral and personal values and beliefs may make it unfavourable to choose termination at a later gestation.

Co-incidentally, the gestational age of confirmation of diagnosis of the severe fetal abnormality and the number of counselling sessions was similar in the groups that continued and terminated pregnancy. The average time taken for decision-making was twice as long in the group that accepted TOP (2 weeks) compared to the group that continued pregnancy (1 week). The factors that influenced the time of diagnosis to decision making was not explored in our study. What was striking from their accounts was their sense of unpreparedness for immediate decision-making. In a study by Davies et al, the psychological outcome was assessed in women undergoing TOP for ultrasound detected fetal anomaly in the first and second trimester. They found that second trimester termination was more stressful compared with first trimester termination (Davies et al., 2005).

Before delivery, the common reasons for continuing with the pregnancy included: fear of killing an unborn baby, the baby is God's gift and the baby will be well after it is born, let nature take its course and there should be no interference to the pregnancy. For those that opted to terminate the pregnancy, the main reasons were the cost implications of raising an abnormal baby; baby will suffer during life; unable to cope with severely handicapped child and difficult to see the baby suffer. This variability in the reasons highlights the awkward decision the pregnant women are confronted with on whether to terminate the pregnancy or not. Some authors have reported that the decision to terminate may have a negative effect on the couple's relationship, frequently leading to disagreements, projection of rage, anguish and guilt (Benute and Gollop, 2002). Acceptance of the diagnosis of fetal abnormality is very difficult both for women and for partners/husbands and family. Interestingly, the responses given in both groups in our study were largely fetus / baby centred and not maternal or family centred. No women considered their personal life or the impact on the community as reasons for the decision- making process. This may be due to the small sample size or the influence of the counselling by the multidisciplinary team prior to the interview.

Most women tend to request for termination after a diagnosis fetal abnormality. This was contrary to our findings and those reported elsewhere. In our study, 10 (66%) of the fifteen women diagnosed with severe fetal anomalies decided to continue with pregnancy. This may be due to small numbers. Apart from the non-interference with the pregnancy, the main reason cited was partner/family refusal for TOP. For four women in our study, this pregnancy was their initiation into motherhood, while others were looking forward to having a second or third child. In earlier studies, Breeze et al (2007) reported 12

(60%) of twenty patients decided to terminate their pregnancy following ultrasound detected fetal abnormalities. Gammeltoft and co-workers reported that 17 (57%) of the 30 patients with fetal anomalies decided to terminate their pregnancy (Gammeltoft et al., 2008). The percentage of women requesting to terminate pregnancy in our study was low (33%) compared to studies done elsewhere (da Costa et al., 2005; Breeze et al., 2007; Gammeltoft et al., 2008). In a previous study carried out in South Africa, Viljoen et al. (1996) reported that 76% of the patients with a detected fetal abnormality opted for termination. Rauch et al. (2005) reported a 33% termination acceptance rate after the detection of a fetal abnormality in the 2nd semester. The difference in acceptance rate for TOP in the above studies may reflect differences in the study group in terms of characteristics of fetal abnormalities detected as well as the different population groups.

The greater proportion of patients deciding to continue with pregnancy in our study raises dilemmas for health care professionals about how best to prepare them for physical experiences and the decisions that they will confront in the immediate repercussions of their decision. Healthcare professionals play a vital role in helping parents cope with ending a pregnancy in these circumstances (Saflund et al., 2004). There are a number of possible reasons for the offer of termination being made so late in gestation at IALCH. Firstly, patients are referred from PHC clinics late in pregnancy resulting in late assessment at a tertiary hospital. In addition, many of the abnormalities such as hydrocephalus and skeletal abnormalities are evident in late gestations (Vaknin et al., 2006).

All our patients saw their baby after delivery in both the groups. The love for the baby and that the baby was God's gift was the main reasons given for wanting to see the baby. In the group that decided to terminate, the last sight of their baby was reason enough for wanting to see the baby. In an earlier study, Hunt et al (2009) reported that most of their patients diagnosed with fetal abnormalities wanted to see their baby after delivery. The reasons given for wanting to see the baby included hoping for visual reassurance that something is "really" wrong. An example being, one woman said: "I wanted to see the lesion on his spine because I wanted to be sure that there had been no mistake while some parents reported pleasure in their baby's appearance". It has been reported that couples terminating a pregnancy for fetal anomalies not only found solace in being able to see the baby but also acknowledge their child and the decision they had made (Korenromp et al., 1992). In addition, seeing the dead baby also provided an opportunity to mourn the loss. Although this is a painful moment, it is fundamental for marking the reality of the loss and is an essential stage in the mourning process.

Most of the women in our study were satisfied with the decision they had taken regarding their baby. In the 10 patients who chose to continue with their pregnancy, the neonatal outcome was variable.

There were six live births and four stillbirths. Four of the six live births resulted in early neonatal death at the time of interview. All women that opted for TOP delivered a stillbirth following intracardiac potassium chloride injection. The two women whose babies were alive at 2 weeks, regretted their decision to continue with their pregnancy citing the lack of support from the partner and family.

Family, friends and partners played a role in women's decisions around either continuing or terminating a pregnancy. Responses ranged from support to being afraid to discuss their intention to terminate the pregnancy. In our study, with respect to the decision-making process, it should be noted that although majority of the women were supported by husbands/partners and family members, the ultimate decision to terminate the pregnancy had been a joint family decision. Some women in our study said that they had encountered people, both in the family and outside, who did not accept their decision for religious reasons. A few women spontaneously related to their own religious beliefs and how this influenced their decisions to seek an abortion, which they depicted as "murder" or "against God's gift". One woman with Christian affiliation even after consultation with family friends sought advice from a spiritual leader. Yet for many women having an abortion was going against "God's will". It was distressing to note that three women had to experience the entire ordeal on their own. They had no husbands/partners or family members at the time of decision making for termination. In addition, they had no visitors after the termination. Was it the fear of being abandoned by family that they may not have informed them about the problem? The question remains unanswered.

In a questionnaire-based study, the attitudes of pregnant women regarding termination of pregnancy for fetal abnormality, the overwhelming majority of the women said they would terminate pregnancy for lethal anomaly and for an anomaly causing mental or physical handicap (Souka et al., 2010). In another study, the psychological impact after second and third trimester TOPFA was compared with women with preterm birth and those with normal birth. After 14 days, 22.4% of women with TOPFA were diagnosed with psychiatric disorder compared to 18.5% women with preterm and 6.2% in normal birth and at 14 months the figures were 16.7%, 7.1% and 0% respectively (Kersting et al., 2009). All our patients were interviewed within 14 days of delivery.

In an earlier study, when patients took the decision to terminate their pregnancies, the women experienced fear, despair, feeling of uselessness and guilt, all of these feelings caused them intense suffering . The killing of the fetus was the most difficult part of the termination (da Costa et al., 2005). More recently, a qualitative study of parents' experiences of decisions after ending a pregnancy for a fetal abnormality revealed distress of facing painful decisions, the sense of being unprepared for these decisions, and receiving no information or forewarning of the choices they would have to make (Hunt et al., 2009). The loss of a much-wanted child through TOPFA is a distressing experience (Jones et al., 2005).

In our study, five patients were depressed, and needed referral to a psychologist. According to Bryar SH, (1997), the grief felt when a pregnancy is terminated for fetal abnormality is thought to be as intense as for those who experience spontaneous perinatal loss.

Regarding the plans for another pregnancy, although our women were afraid of going through the same ordeal again, only two women affirmed that they would like to have another baby in the next year.

Most of the women stated that the multidisciplinary health care received both during the decision-making process, termination and after the procedure were seen as an effective support mechanism to help them overcome their difficulties. The ongoing counselling and seeing the baby after delivery provided much relief for the painful decision making process they endured. Contrary to another study, women in our study referred to the feelings of rightness of their decision to terminate their pregnancy, even in the midst of all suffering, following confirmation that the fetus was not normal (Dallaire et al., 1995).

5. Limitation of study

Our study has been limited by a small number of pregnant patients interviewed. This study forms part of an ongoing larger study to assess the views and attitudes of the family members and other stakeholders such as the community members and various categories of health care workers towards late TOP and the factors that play a role in the decision-making.

6. Conclusion and Recommendations

Despite the small number of women that were interviewed, this study is unique in the sense that the interview was conducted while the women were pregnant with a severely abnormal fetus that has already attained viability, ie: capable of ex-utero survival. Most studies reported in the literature revolved around the womens' views and attitudes following abortion of unintended pregnancies. Even in the latter scenario, a literature search revealed no studies in which the interview was conducted during pregnancy. Nonetheless, this study, like many others, illustrated that woman's views and attitudes towards late TOP are variable. While many studies have shown that younger patients may opt to terminate an unintended pregnancy, the decision appears reversed in the later gestation when the fetus has attained viability, even for a severe fetal anomaly. The role of partners and family members seem to have an impact on the views and attitudes of pregnant women towards the decision-making for their abnormal unborn baby. A larger study assessing the roles of the family members, as well as other stakeholders such as the community members and various categories of health care workers is ongoing at this unit.

Follow up studies assessing the long-term views and attitudes of pregnant women towards late TOP will be important for comparison with initial decision-making process. There is also a need for larger studies comparing views and experiences of women having a spontaneous perinatal death vs iatrogenic intrauterine fetal demise by intracardiac potassium chloride for a severe or complex fetal anomaly. Furthermore, evaluating the views and attitudes of women caring for severely handicapped children will help improve our counselling women when complex fetal anomalies are detected prenatally.

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8. Appendices

Appendix 1 A: PRE-TERMINATION INTERVIEW:

PATIENTS' QUESTIONNAIRE

STUDY TITLE: VIEWS AND ATTITUDES OF PREGNANT WOMEN ON DECISION - MAKING FOR LTOP FOR SEVERE FETAL ABNORMALITIES.

PATIENT/STUDY NO		HOSPITAL NO		AGE (Yrs)		PARITY	

PRE-TERMINATION INTERVIEW:

Marital status: single/married

Religion: Christian /other

Financial source: self/partner/family/welfare

Education: none/school/university

Gestation at 1st scan at IALCH

Gestation at first scan in wks (local)

Gestation at 1st scan at IALCH

Current gestation (weeks)

Provincial diagnosis

Did you know about your baby's abnormality before coming to this hospital? YES | NO

If yes – who informed you?

Which person(s) informed you about the abnormality at this hospital?

How many times were you counselled on the likely outcome for this baby?

Did you understand the problems that your baby is likely to have if it lives? YES | NO

The time to make your decision was: TOO LONG | JUST RIGHT | TOO SHORT

What do you consider as just the right amount of time to make a decision?

What is your decision about this pregnancy? CONTINUE | TERMINATE

Give at least 3 reasons for this choice:

Have you discussed your decision with any of the following?

Partner/Local Doctor/Other Family Member(s)-Specify/Religious Leader

Did a health worker tell you to terminate or continue with this pregnancy?

YES	NO

Did any member of your family influence your decision? If so, which one(s)

Partner	**Your Parent(s)**	**Partner's Parent(s)**	**Religious Leader**	**Other:**

If you have chosen to terminate your pregnancy, did you understand the method of termination explained to you by the doctor?

YES	NO

Do you feel that you made the correct choice for this baby?

YES	NO

Give reasons for you answer:

Appendix 1B: POST-TERMINATION INTERVIEW

Have you seen the baby?	YES / NO
Do you feel you made the correct choice for your baby?	YES / NO

Give at least three reasons for your answer

Did any member of your family visit you in hospital after delivery?	YES / NO
Would you like to speak to a Social worker again?	YES / NO
Will you be planning for another pregnancy within the next year?	YES / NO
Has anyone (Doctor or Nurse) explained what may happen in your next pregnancy?	YES / NO
Do you feel that the hospital staff treated you any differently compared to the women that delivered normal babies?	YES / NO

Delivery outcome

Labour	INDUCED	SPONTANEOUS	Perinatal outcome	Alive	Stillbirth	ENND

Mode of Delivery	NVD	C/S	Birth weight (kg):	

Is there anything you want to ask about this pregnancy?

Appendix 2: Postgraduate Approval Letter

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

RESEARCH OFFICE
Biomedical Research Ethics Administration
Westville Campus, Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/ResearchEthics/BiomedicalResearchEthics.aspx

30 May 2011

Dr C Ndjapa- Ndamkou
9 Drostdy
19 Silverton Road Musgrave
Durban
4001

Dear Dr Ndjapa-Ndamkou

PROTOCOL: Views and Attitudes of Pregnant Women on decision making for late termination of pregnancy for several fetal abnormalities: Dr C Ndjapa-Ndamkou. : BE145/09.

PROTOCOL AMENDMENT RATIFICATION

Further to our letter to you dated 15 April 2011 this letter serves to notify you that at a full sitting of the Biomedical Research Ethics Committee Meeting held on 10 May 2011, the Committee RATIFIED the sub-committee's decision to approve Protocol Amendment for the change in study title.

Yours sincerely

Mrs A Marimuthu
Senior Administrator: Biomedical Research Ethics

Appendix 3: BREC approval letter

UNIVERSITY OF
KWAZULU-NATAL

18 March 2011

Dr L Govender
Department of Obstetrics and Gynaecology
Nelson R Mandela School of Medicine

Dear Dr Govender

PROTOCOL: "Views and attitudes of pregnant women on decision making for late termination of pregnancy for severe fetal abnormalities." Student: C Ndjapa-Ndamkou, student number: 207527892. (Obstetrics and Gynaecology)

Your request for approval of protocol amendment dated 22 February 2011, has been noted and executively approved.

This decision will be ratified at a full sitting of the Committee scheduled for 12 April 2011.

Yours sincerely

Professor M Adhikari
Dean's Assistant: MMed Programmes
Postgraduate Education and Research Committee

CC. Dr C Ndjapa-Ndamkou

Postgraduate Education Administration,
Medical School Campus

Postal Address: Private Bag 7, Congella, 4013, South Africa

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Appendix 4

PATIENT INFORMATION DOCUMENT

Study title:: Views and attitudes of pregnant women on decision making for late termination of pregnancy for severe fetal abnormalities

Good day. My name is Dr Ndjapa Ndamkou. I am doing research towards a Masters degree (MMed) through the University of KwaZulu-Natal. Research is just a process to learn the answer to a question. My research is based on views and attitudes of pregnant women on decision making for late termination of pregnancy for severe fetal abnormalities

My research therefore involves pregnant women like you in whom the scan has shown severe fetal abnormality (ies) in the baby and you are over 6 months pregnant.

In this research, I want to know what are your views about termination of pregnancy at this late stage. I want to establish what are the reasons that make you to decide whether or not you would like to terminate this pregnancy and compare these reasons with your responses after the birth of your baby.

INTRODUCTION:

There is currently no information in the 'books' about the views and attitudes of pregnant women whose baby is not normal and their decisions whether or not to stop the pregnancy for severe fetal abnormality (ies) in the late stage of pregnancy in our province.

I intend to evaluate the views and attitudes of our patients towards the practice of late termination of pregnancy for severe fetal abnormality (ies).

You have been informed that your baby has not grown normally and this abnormal growth will cause problems at birth and/or later in your baby's development such as mental problems, problems with learning, walking and/or talking. Your baby will therefore not be like the other normal children. Most often, these abnormalities occurred by chance and we do not find a reason.

You were informed by the doctor at the clinic that the abnormality found in your baby was been discussed with a team of experts and it was agreed that your baby will be severely "handicapped" should it live. To avoid the suffering that this abnormal child will go through, you were given the option to "stop" or continue the pregnancy even at this late stage.

Invitation to participate: We are asking you to participate in this research study because you have a baby with a severe abnormality and you are over 6 months pregnant. Your management of this pregnancy will not be affected by your participation in this study.

What is involved in the study - We will require about 20 to 30 minutes of your time to answer questions about yourself and the reasons for your decisions. These questions will be asked by myself before your baby is born (after you made your decision whether or not to terminate this

pregnancy) and shortly after the birth of your baby (before you go home from the hospital).
Your medical treatment will not be affected whether you participate in the study or not and if you do participate – whether you accept or decline the termination.

Risks: You will be referred to a Psychologist and Social Worker for supportive counseling during and after the pregnancy. Should any complication arise, you will be managed like any patient with a similar complication.

Potential Benefits: If we identify any psychological, social or behavioral problems during the interview or the follow up visits you will be referred for further counseling. There will be no direct benefits to you by participating in the study.

Alternative: Should you not want to be part of the study and if we identify your pregnancy as "low risk", you will continue your antenatal care and delivery at your hospital. Should we identify any problems and depending on the seriousness of the problem, we may admit you at this hospital (IALCH) and take over your care.

Participation is entirely voluntary: Your refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled to.

Confidentiality: Every effort will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed.

Contact details of researcher - for further information or if you have any queries at any time regarding this research you may contact me:

Dr C. NDJAPA – NDAMKOU
Obstetrics & Gynaecology
IALCH / NRMSM
Cell: +2783 321 1620 **Fax: +2731 201 4057**

Contact details of BREC Administrator or Chair – for reporting of complaints/ problems:
Biomedical Research Ethics, Research Office, UKZN, Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 4769 / 260 1074
Fax: +27 (0) 31 260 4609
Administrator: Ms D Ramnarain Email: BREC@ukzn.ac.za

Appendix 5

INFORMED CONSENT DOCUMENT

Consent to Participate in Research

Dear ……. Category / KZ……

Good day. My name is DR C.Ndjapa Ndamkou. I am doing research towards a Masters degree (MMed) through the University of KwaZulu-Natal. Research is just a process to learn the answer to a question. My research is based on views and attitudes of pregnant women on decision making for late termination of pregnancy for severe fetal abnormality (ies).

My research involves pregnant women in whom the scan has shown severe fetal abnormality (ies) in the baby presenting after 6 months. In this research, I want to know what are your views about terminating pregnancy at this late stage. I also want to establish what are the possible reasons why women choose whether or not to terminate pregnancy at an advanced stage

You have been informed about the study and the reason for your enrolment by me: DR C. NDJAPA-NDAMKOU

Your participation in this study is entirely voluntary; your refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled to. You may withdraw at any time of the interview.

If you agree to participate you will be given a copy of this document to sign and an information sheet which is a written summary of the research.

Contact me Dr C. NDJAPA – NDAMKOU on my cell phone: 0833211620 at anytime if you have questions about the research

You may contact the Biomedical Research Ethics Office, Telephone 031 260 4769 / 260 1074 or Email: BREC@ukzn.ac.za

The research study, including the above information, has been described to me orally. I understand what my involvement in the study means and I voluntarily agree to participate. I have been given an opportunity to ask questions that I might have about participation in the study

…… …… RHTP (Where applicable)

Signature of Participant DATE

…… …… (Where Applicable)

Signature of Witness DATE

…… …….. (Where Applicable)

Signature of Translator DATE