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A REVIEW OF THE ETHICAL AND LEGAL PRINCIPLES USED IN THE DECISION MAKING PROCESS FOR FETICIDES AT SEVEN SITES IN SOUTH AFRICA

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand Johannesburg, in partial fulfillment of the requirements for the degree of Master of Science in Medicine in the branch of Bioethics and Health Law, Steve Biko Centre for Bioethics

Johannesburg, 2009

DECLARATION

I, Bhavna Patel (Student number 8600083X)

declare that this research report titled:

A review of the ethical and legal principles used in the decision making process for feticides at seven sites in South Africa

is submitted for assessment for the MSc Med (Bioethics & Health Law) course is my own unaided work except where I have explicitly indicated otherwise. I have followed the required conventions in referencing the thoughts and ideas of others. It is being submitted for the degree of MSc Med (Bioethics & Health Law) in the University of Witwatersrand, Johannesburg. It has not been submitted before any degree of examination at this or any other university.



Signature 28th day of January, 2009.

This is dedicated to all the health professionals for their dedication and commitment towards providing quality care to patients

ABSTRACT

TITLE: A review of the ethical and legal principles used in the decision making process for feticides at seven sites in South Africa

This study set out to perform an ethical-legal analysis of the current practices across the seven public health centres in South Africa that perform feticide for congenital abnormalities. Ideally, such decisions need to be guided by multidisciplinary discussions with the parent(s) and the parties included in the team, e.g. Obstetricians, Neonatologists, Nursing, Genetics counsellors and Social Workers and following the ethical principles of beneficence and respect for autonomy. Prior to the study, it was unknown as to whether all seven centres were using multidisciplinary groups in the decision-making process and on what basis approvals were being granted for feticide. The objectives of the review were to assess the number of feticides performed, who made the decision to offer the feticide and for what ethical or clinical indications. The results showed that all public health facilities in South Africa differed in the criteria that were used in making the decision to offer feticide. The clinicians varied in terms of who was represented in the team that reviewed the cases of congenital abnormalities. An analysis of the literature, together with a review of the data received on the current practices, guided the development of an

ethical guideline for this service as well as making recommendations as to how the law could be strengthened in order to protect both health workers and patients.

ACKNOWLEDGEMENTS

I would like to acknowledge a number of people who have assisted in shaping my life, both personally and professionally.

- My supervisors, Professors Donna Knapp van Bogaert and Ames Dhai, for their guidance and for having the gift to teach others.
- My mother and late father, who always encouraged me to work hard and succeed.
- My family for their love, support and understanding.
- All the participants of the study for their involvement in the process.

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CHAPTER 1

INTRODUCTION

1.1. INTRODUCTION

Both medical and technological advances have contributed to the ability of health care workers to detect fetal abnormalities antenatally, sometimes raising ethical and legal dilemmas. Most prospective parents are overwhelmed with joy by the news of a pregnancy and value to this life is attached throughout the gestational period. Ultrasound techniques have allowed parents to view this fetus as a living being with arms, legs, a face and a heartbeat. These same ultrasound techniques have also allowed the detection of fetal abnormalities, sometimes early in the pregnancy and sometimes only by the third trimester (Drysdale 2002: 159). The diagnosis of fetal abnormalities pose challenging questions to both the health care workers and the prospective parents about the value of fetal life, the moral status of fetal life and the uncertainty of the outcome of the intervention that is decided upon.

When a fetal abnormality is detected, a decision to terminate the pregnancy is offered to the parents. This could involve termination before the fetus is 12 weeks old or after 12 weeks in the cases where a severe abnormality (or abnormalities) is detected. This is in keeping with the

South African Choice on Termination of Pregnancy Act (1996). Once the fetus is viable, that is after 24 weeks, the termination can be by way of a feticide. The term viable is derived from the French word '*vie*', which means 'capable of living', hence its meaning in this context is 'capable of being born alive' (BMA 2005). As a medical term, feticide is the destruction of a fetus as part of an induced termination where the death is not from natural causes or because of a spontaneous termination (Free Online Dictionary 2008). The procedure usually follows either of these two courses of action: 1) The fetus is given potassium chloride into the heart or 2) the umbilical vessels are occluded by various ultrasound-guided techniques after which labour is induced and the fetus delivered (RCOG 2001).

It is thus important to have an ethical framework outlining how a decision to perform a feticide should be taken and by whom, what the clinician's responsibility is towards the patient and to set ethical principles that need to be considered in order to justify the decisions taken.

1.2. MOTIVATION FOR THE STUDY

Most ultrasound examinations performed antenatally are by individuals whose expertise varies from being self-taught medical practitioners to

those who specialize in obstetric antenatal ultrasound scanning (Pieper 2008: Personal communication). There are currently seven public health facility sites in South Africa that offer feticide for pregnancies complicated by fetal abnormalities. However, no clear guidelines exist on who performs the procedure and on what ethical, clinical or legal criteria such decisions should be taken. Six of these sites are attached to tertiary academic institutions and one site is connected to a non-academic hospital, but there may also be terminations performed elsewhere, including private hospitals. Each of these institutions may be performing the terminations for different indications. Moreover, the decisions for such terminations are made by a number of different health professionals.

Ideally, a multidisciplinary team should consider all factors involved in cases of severe congenital abnormalities. In this way, a patient may be presented with a joint consensus of the benefits and burdens and thus, on her part, she could make an informed decision.

For such reasons, it was felt that further exploration on the practice of feticide was required.

1.3. AIM and OBJECTIVES

1.3.1 AIM

To determine what ethical frameworks and criteria are used to approve the termination of pregnancy in the cases of severe congenital abnormalities in a viable fetus across seven sites in South Africa.

1.3.2 OBJECTIVES

- To determine how many feticides are performed annually and for what reasons.
- To determine who offers the counselling, both pre- and post termination and what options for treatment are presented to the patient.
- To review what ethical and legal criteria are being used as a policy document and who decides whether feticide should be offered to the woman.
- To determine reasons why terminations are refused after feticide is offered for congenital abnormalities.
- To develop an ethical and legal guideline or framework for the management of termination of pregnancy of viable fetuses.
- To inform amendments to the law that will enable clarity on issues that pose ethical dilemmas to both practitioners and patients.

1.4 STRUCTURE OF RESEARCH REPORT

Chapter 2 provides a literature review of the ethical and legal challenges faced when performing feticides for congenital abnormalities. Chapter 3 focuses on the methodology used to achieve the objectives of the study. The study results are reported and interpreted in Chapter 4 and Chapter 5 follows with recommendations. The concluding comments are presented in Chapter 6.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

The termination of any fetus, regardless of gestational age or abnormality poses ethical questions. Key amongst these are: 1) whether or not the fetus has moral status; 2) the dilemma the health professional faces in saving or not saving a potential life; 3) the dilemma of aborting the fetus in order to save the mother's life; 4) the autonomy or non-autonomy of the mother to decide on behalf of the fetus; 5) the interests of the broader society and the plurality of the values held by that society; and 6) the laws that guide these decisions.

In general, the ethics surrounding terminations have to weigh up absolute principles against more pragmatic approaches to the problem. In absolute terms, Kantian ethics, for example, places human dignity above all else. He argues that due to our ability to reason, we should all arrive at the same moral answer when solving ethical dilemmas, thus making this moral truth universalisable, irrespective of the circumstances and consequences (McAdoo n.d.). Thus, on the surface, Kant would argue against any form of termination of pregnancy. This is because of the inherent worth and dignity possessed by all human beings. The

Consequentialist argument on the other hand, makes a judgment based on the overall consequences of the actions to benefit the majority. For example, if the consequence of the birth will bring about misery for the majority of those involved, then the birth should be avoided and it may be considered a right action to abort the fetus. Alternately, if it brings pleasure, a good, or happiness to the greatest number of persons involved, then the consequentialist would reject termination of pregnancy.

In attempting to justify complex circumstances such as a pregnancy resulting from a rape, or in cases where the fetus has a congenital abnormality that will result in its death after birth, or if there is a risk to the health of the mother resulting from the pregnancy, a more pragmatic approach is required. Using the absolute approach does not help to clarify these 'grey' areas, since in reality, they are always compromised by some or other circumstances (McAdoo n.d.). The following discussions focus on the circumstance of having to abort a viable pregnancy that is complicated by a congenital abnormality.

2.2 ETHICAL CONSIDERATIONS

The ethical arguments concerning termination of pregnancy generally revolve around the moral and legal status of the fetus. For some, the basis

of this is religious and for some secular. Various dividing lines have been suggested at which point the fetus is assumed to have a moral status and as such, it should be regarded as having the same rights as a person. According to one secular approach, the fetus is a person when special characteristics are acquired during development, such as the potential to be rational, the potential for intelligence, developing human anatomy and viability (Strong 1992:793). The possession of these differing factors such as the ability to plan for the future, have self awareness and build relationships with others, grounds the different moral rights and evaluations of what it means to be a human being (Gillon 1985: 1734). It is also said that the fetus acquires moral status progressively throughout pregnancy, marked by specific milestones, such as the development of the neural tube, various organs, the maturation of the brain and eventually, the birth (Paintin 2002:371). Others have identified moral status being conferred to the fetus when it possesses one or more intrinsic characteristics that make it independent of the mother and thus similar to a person. However, these characteristics by themselves do not confer personhood; for example, viability is the gestational age at which the fetus can survive outside the uterus, which is at 24 weeks (BMA 2005). This should relate to the biological factors that allow the fetus to survive, but ongoing technological advancements allows survival from an earlier age,

thereby making viability less plausible as a criterion for personhood. There are also no specific biological markers at which it can be said that the fetus develops the potential for rationality or intelligence (Chervenak and McCullough 1993:397). Some philosophers have also argued that personhood depends on being self-conscious and since the fetus is not self aware, they do not have a right to life (Gillon 1985: 1736). Such a position does raise other ethical questions about e.g. the fetus with a congenital abnormality, which due to the handicap, has less of a moral status in terms of its capacity to become a 'person'. It thus remains unclear as to when and if the fetus can become a moral agent in terms of having specific characteristics and ultimately, possessing a right to life.

A second approach considers a consequentialist argument that personhood is applicable to mature fetuses because of their similarity to persons and they should therefore be treated as if they were persons in at least the social sense (Strong 1992: 794). An alternate argument states that whether or not the fetus has become mature, it should be treated with the same moral respect as persons are treated at least with regard to avoiding doing anything that may harm the people they are to become (Gillon 1988:3).

It is therefore not permissible to kill a fetus that could harm the person it will become (viz. a potential person). Thereby conferring moral status to the fetus is equivalent to that given to a person (ibid 1988:3).

Vehmas (2002: 52), on the other hand, dismisses the consequentialist arguments and states that prospective parents who decide to procreate should assume a strong responsibility towards their prospective children, whether born with abnormalities or not. Parents assume this responsibility towards this vulnerable and dependent child from the moment they decide to reproduce. He claims that by the time that termination is considered, the fetus is already seen as an existing child. Termination at this stage as a moral duty is highly repulsive to prospective parents, since the fetus with mental retardation could have some prospect of a life worth living and therefore fulfilling the parental responsibility to giving birth to such a child should not be considered to be harmful (ibid: 59).

Strong (1992: 794) suggests that both arguments are sound enough to confer moral standing to a fetus, including the right to life and therefore the fetus is deserving of protection, since viability occurs late in the second trimester. He (ibid: 800) notes that an ethical framework is therefore vital

in dealing with and justifying decisions taken in cases where congenital abnormalities exist.

The principle of beneficence calls for the health care workers to seek a greater balance of benefit over harm (Chervenak et al. 2003: 477). This benefit should extend towards promoting the health of the pregnant woman as well as to the fetus, which in this view, has been conferred moral standing. However, this moral standing is also balanced in the context of the needs of other parties such as the father, other family members or the legal framework that applies to the health care workers.

The principle of respect for autonomy calls for respecting the right of the pregnant woman to make her own decisions, based on her own set of values and beliefs. Part of the notion of respect for persons falls on the health care workers to help her make an informed decision by discussing all options of management such as aggressive management, non-aggressive management, the option of dong nothing, or termination of the pregnancy. The discussion should also include the probability of the diagnosis and the possible outcomes in order for her to make an informed decision (Chervenak and McCullough 1990: 313). The idea of respect for persons does not extend to the fetus. This is because of its insufficiently

developed nervous system. Without this capacity, the fetus has no values or beliefs that are necessary for an individual to have his or her own perspective on his or her best interests. Both the physician and the parents have beneficence-based obligations to the fetus to act in his or her best interests (Chervenak 1985: 442).

In a study by Kramer et al. (1998: 174), it was noted that patients who were offered termination based on a diagnosis of Down syndrome antenatally chose to do so only if the pregnancy was early in gestation and more so in older aged women. Eighty-seven percent (87%) of the women in this study opted for termination, while thirteen percent (13%) decided to continue with the pregnancy. Being autonomous also assumes that the decisions are made rationally and if placed in similar circumstances, the question does arise as to how rational a pregnant woman carrying an abnormal fetus is to make a decision. Regarding termination of the pregnancy, issues arise concerning what sort of counselling is being offered to her both pre and post the termination. In the South African context, the different languages, social beliefs and the vocabulary that people use in counselling further compounds the problem. These issues only deal with the decision to terminate a pregnancy. However, there is a larger aspect of the pregnant woman's life than only having to deal with

the present diagnosis of an abnormal fetus. For example, they also bear the burden of having to disclose the problem of an abnormal fetus to family and friends; face fears of the challenges that may lie ahead if the pregnancy continues as well as come to grips with the uncertainties that accompany the possibility of this happening with a second pregnancy.

Furthermore, the time of the termination is critical, as after 24 weeks, the baby could be born alive, placing an added emotional burden on both the parents and the caregivers (Stratham 2006: 1403). An example such as this emphasises the need for ongoing counselling to be addressed, as well as follow up discussions concerning future pregnancies (Thachuck 2007: 513).

Hollander et al. (2002: 574) have shown that the majority of fetal abnormalities can be diagnosed in the late first and early second trimesters[1] of pregnancy. However, because of different abnormalities presenting at varying gestational ages, the 18-21 week scan[2] cannot be abandoned, as this will still provide some answers before the age of viability.

[1] Between 10 and 16 weeks of pregnancy. The first ultrasound scan is normally done at this stage.
[2] This ultrasound scan at 18-21 weeks of pregnancy specifically looks for features suggestive of congenital abnormalities that may not have been picked up at the first scan.

2.3 LEGAL CONSIDERATIONS

All laws should be based on moral values (Cline 2008). Ideally, legislation on controversial issues like terminations of pregnancy and feticide should only adopted after much public debate about 'pro-life' and 'pro-choice' positions (Gevers 1998: 83). Thus, the plurality of societal values makes the regulation of the practice difficult.

The South African Constitution guarantees the 'right to life' (1996: Clause 11). If one is to assume that this applies to the unborn life, then according to the South African Choice on Termination of Pregnancy Act (1996), for the fetus, this right extends only partially in the second trimester of pregnancy (between 12 weeks and 20 weeks) and considerably in the third trimester (after 20 weeks), thus making assumptions about the moral status of the fetus at that age and conflicting with the constitutional right to life. In other words, the fetus is not a legal person. South African Law does not have any legislature specific to feticides and the South African Choice on Termination of Pregnancy Act (1996) restricts itself to terminations of pregnancy with no reference to feticide.

According to Carstens and Pearmain (2007: 82), the South African Constitution provides that a child is a person under the age of 18 years, but is quiet on the matter of whether an unborn person is a child or not,

even a potential child and therefore does not confer any rights to the fetus. This implies that decisions related to the fetus have to be taken by another rational person on its behalf.

The South African Choice on Termination of Pregnancy Act (Act 92 of 1996) allows terminations up to and including the third trimester, for severe physical or mental abnormalities. Up to 12 weeks, there are no limitations on the reasons for the termination. After the 12th week, the practice requires a joint decision between the pregnant woman and her doctor and the clause stating that social and economic circumstances need to be taken into account, still allows for unrestricted access to terminations. After 20 weeks, the law provides some protection to the fetus in terms of its right to life, but leaves the decision in medical hands, where the medical practitioner is required to confer with another medical practitioner or midwife. What the law does not stipulate is how this decision should be taken and how the law should be balanced against issues of morality, which highlights the lack of guidance when a feticide may be indicated. This balance relates to the need to protect the fetus versus the need to protect the rights of the woman. One of the classic arguments in contemporary ethics involves the fetal versus maternal rights. In brief this argument relates to the conflict that arises when a pregnant woman may refuse treatment that the clinician may consider

beneficial to the fetus. The legal dimension of this conflict in general recognizes that a woman's autonomous choice to refuse a recommended treatment should be respected and that any opposing views should be managed by allowing her to make an informed choice (Nelson 1992: 746). The balance also may be skewed towards the other side where there may be conflict between the patient's autonomous decision and the physician view. Section 10 (1c) of the South African Choice on termination of Pregnancy Act (1996) stipulates that, 'any person who prevents the lawful termination or obstructs access to a facility for the termination of a pregnancy shall be guilty of an offence and liable on conviction to a fine or to imprisonment for a period not exceeding 10 years'.

Thus, health workers may have the right to refuse to perform terminations of pregnancy, but they do not have the right to prevent access to such services. However, this right to refuse care is inferred but not stipulated as a right to conscientious objection in the Act and this could be seen as a shortcoming in the law in terms of protecting the rights of the health worker. Savulescu (2006: 297) believes that the individual's values should have a different role in their public and private lives and that as public servants, doctors should act in the public interests, not their own. On the other hand, while conscientious objection is a human right, we are living in

a complex developing world. The right to conscientious objection is an individual right, not an institutional right and the duty to refer patients to a facility where the service can be provided can become difficult in a setting such as South Africa, hence this right needs to be balanced against the health hazard of unsafe terminations, thereby limiting conscientious objection (van Bogaert 2002: 143).

Legally, there is also confusion regarding the definition of viability of a fetus, thereby leading to confusion about feticides and a blurring of the dividing line between termination of pregnancy and feticide. Viability is considered as having a chance of long-term survival with or without medical help outside of the uterus (Free Online Dictionary 2008). Over the past two decades, survival has improved due to advances in prenatal, perinatal and postnatal healthcare (Seri and Evans 2008: 4). They describe the survivability limit to be at 23 weeks of gestation or at 500g. The South African Society of Obstetricians and Gynaecologists (SASOG) do not offer any guidance on when the fetus is considered to be viable and are silent on the issue of feticide. Internationally, The Royal College of Obstetricians and Gynecologists (RCOG) state that any termination of pregnancy after 21 weeks and six days of gestation should ensure that the fetus is born dead, thus using more than 22 weeks as the age of viability

(RCOG 2001). However, with regard to viability, the RCOG suggests that the management should be in accordance with the British Association of Perinatal Medicine's framework for Practice (RCOG 2001). The British Medical Association of Perinatal Medicine considers infants born between 22 to less than 28 weeks (between 500g and 1000g in weight) of gestation to be viable. They add that an age cut of is difficult to define in terms of viability, since factors such as birth weight, multiple pregnancies and the gender of the fetus also affect the likely outcome. Fetal viability therefore relates to the minimum stage at which the fetus is able to survive (BMA 2005).

In the developing world, viability is placed at 1000g or 26 to 28 weeks (Personal communication with Obstetricians). However, even within the developing world in certain regions, for example South Africa, there are vast disparities in social circumstances and in these situations considerations with regard to gestational age and viability would be largely dependent on whether the woman attended the public or the private sector. Thus, the stipulation of a gestational range presents a grey zone within which survival and outcome are difficult to predict and hence the line between patient autonomy and medical futility becomes blurred (Seri and Evans 2008: 7).

Internationally, a stillbirth is regarded as the death of a fetus weighing more than 500g, which is about 22 weeks of gestation (PEP 2007: 6). In South Africa, all infants weighing 500g or more are potentially viable (that is having a reasonable chance of survival if born alive), but the Department of Home Affairs uses 26 weeks as the gestational age after which all stillbirths have to be registered as a death and be issued a death certificate (Department of Home Affairs: 1999). They do not stipulate a weight. Being viable means having a chance of life and therefore having access to ventilation and intensive care if born alive. However, in the South African setting, because of resource constraints and a high mortality rate, public hospitals use the cut off weight at 1000g to offer ventilation and those less than 1000g are provided with only supportive care (Personal communication with Neonatologists).

It has been shown that the survival of infants born after 24 weeks has improved since the early 1990's, but that there may be a significant risk of disability, ranging from 67% at 23 weeks, 38% at 24 weeks and 20% at 25 weeks of gestation (Rivers et al. cited in: Lee 2004: 17). There may also be difficulties in identifying the exact gestational age since there is a two-week margin of error on either side. Ultrasound scanning also has a 5-day margin of error at 12 weeks and ±12 days at 24 weeks (ibid: 17). Legally,

it is therefore understandable that stipulating a cut off age or weight can be difficult, since this is not an exact science, but the law should reach some consensus on the issue, so that legal acts and guidelines do not contradict one another.

In terms of the South African Termination of Pregnancy Act (1996), there would therefore be confusion for clinicians on what to do between 20 weeks and 26 weeks. To add to the confusion, the terms 'severe malformation' and 'risk to the fetus' can be interpreted differently by different people, leading to terminations for different reasons. The term 'severe' may be interpreted as life threatening to the fetus or resulting in significant disability (FIGO guidelines 2006: 59). In the same way, 'risk' may be a probability in that the fetus has a malformation and hence the possibility that this could be severe in terms of being life threatening. The term 'risk' also includes the possibility that the decision could be wrong since the diagnosis is based on a probability. The vagueness of these terms leaves the decision to terminate entirely at the discretion of the clinician. Problems may arise when some may consider for example a cleft lip to be severe enough to approve termination legally, while others may only recommend the procedure should the diagnosed handicap lead to eventual death. The South African Choice on Termination of Pregnancy

Act (Act 92 of 1996) is typically utilitarian in that it aims for what is perceived to be the best result for all concerned parties based on a presumption of appropriate moral and medical reasons (de Roubaix 2007: 173).

While most of the laws deal with termination of pregnancy, there are no national guidelines on the practice of feticide. The RCOG (1996: 3) developed guidelines to assist Obstetricians and Gynecologists on the interpretation of the law relating to terminations for fetal abnormality. In particular, there is some discussion about the terms 'substantial risk' and 'serious handicap' and the legal role of the medical practitioner is identified. The reason for avoiding any discussion on the ethics of the practice are stated as the College recognising that individual Fellows and Members may have differing beliefs on the topic (ibid: 3). The FIGO guidelines (2006: 58) on the other hand touch briefly on some ethical aspects in the management of the severely malformed fetus and emphasize the need to ensure the autonomy of the mother. However, the guideline does not cover any ethical aspects on the practice of feticide.

International consensus on the issue is also lacking in that terminations after viability are strictly prohibited in some countries and even within

different states of Australia, (de Crespigny and Savulescu 2004: 203),[3] while others, when describing risk use adjectives such as 'significant risk' and 'serious handicap', further raising uncertainty (Mavroforou 2006: 186 ; Gevers 1998: 84).

It is interesting to note that a review of comparative law pertaining to terminations in various countries reveal that there is no law that gives full moral status to the fetus. Neither is there any law that gives the fetus no moral status at all. French and Belgian laws allow for therapeutic terminations if there is a severe abnormality or there is risk to the mother, but they do not specify the limit on the gestational age (Chervenak and McCullough 1990: 311.). The uncertainty in the law may leave the doctors exposed to a lawsuit, for example if there is a poor outcome or a procedure related complication (de Crespigny 2005: 52), thus emphasizing the need for clarity.

The past decade has seen an increase in the number of cases, especially in the United States, where damages are claimed from the physician for negligence resulting in an unwanted child or a child born with a defect.

[3] The article discusses the discrepancies in the laws related to terminations between the different states, with for example in Victoria and New South Wales, only a lethal fetal abnormality that may result in the death of the mother is considered grounds for an termination. The termination is thus performed in good faith and only to preserve the mother's life. In Western Australia, government committees have to approve any terminations after 20 weeks.

Pertaining to this discussion, the concept of 'wrongful birth' needs to be distinguished from 'wrongful pregnancy' and 'wrongful life'. 'Wrongful births' are claims brought about by the parents that they would have avoided conception or terminated the pregnancy had they been properly advised on the risks of the birth defects to the potential child (Carstens and Pearmain 2007: 725). This highlights the need for the physician to ensure that ultrasounds are performed as scheduled and that all possible information is shared with the parents in order for them to make an informed decision concerning whether or not to terminate the pregnancy through feticide.

However, questions remain about who defines this risk or seriousness of fetal abnormalities. Surveys have shown that clinicians differ in their views of which abnormalities are severe enough to offer termination and as a result, many women's lives are changed forever by the attitudes of their doctors to these controversial issues. Ethical and legal aspects of such decisions are seldom covered in medical journals (de Crespigny and Savulescu 2002: 213-214).

The only recorded case in the South African legal literature is in the decision of Friedman v Glicksman (1996(1) SA 1134 (W), where the plaintiff alleged that she had asked for advice on the risks of bearing a

child with an abnormality. The doctor duly performed certain tests and informed her that there was no greater than normal risk. However, the plaintiff claimed that due to the doctor's negligence and breach of his duty of care, a disabled child was born. The judge dismissed the plaintiff's claim based on a 'wrongful life' by stating that

> *'…the South African law cannot recognise that the facts alleged by the plaintiff on behalf of the child are sufficient to sustain a cause of action and that it would be contrary to public policy for courts to have to hold that it would be better for a party not to have the unquantifiable blessings of life rather than to have such life albeit in a marred way' and that this would open the door for disabled children to be entitled to sue their parents for allowing them to be born* (Carstens and Pearmain 2007: 741).

This ruling in itself highlights the need for ethical and legal guidelines of practice that will be considered acceptable, not only by the courts, but also by society as well as noting that legal definitions, particularly relating to feticides, need to be clarified and specified in terms of both ethics and the law.

CHAPTER 3

METHODOLOGY

3.1. RESEARCH METHODOLOGY

3.1.1.Research design

A cross sectional study design was used to determine the objectives as described above. The data included descriptive and analytic components, where clinicians were asked their views on certain treatment methods and an analysis of the number and reasons for terminations was conducted in the form of a clinical audit.

3.1.2 Sample size

Purposive sampling was used and the study population consisted of the seven heads of divisions responsible for feticides within the fetal evaluation clinics at the relevant hospitals. The following hospitals currently perform feticides in South Africa:

- Groote Schuur Hospital
- Johannesburg Hospital
- Tygerberg Hospital
- Chief Albert Luthuli Hospital
- Pretoria Academic Hospital
- Bloemfontein Hospital

- East London (Cecelia Makawane) Hospital – the only non-academic hospital.

3.2. RESEARCH PROCEDURE

3.2.1 Data collection

The measurement tool was a semi-structured questionnaire (Appendix A) that was answered by the heads of the fetal assessment clinics at the above institutions performing feticides. The questionnaire was completed either by the researcher during a telephonic interview or by the participant and then submitted electronically after discussion, depending on their preference. The telephonic interviews took about twenty minutes. Since the cohort was small, telephonic interviews were logistically possible and this reduced the number of non-respondents. Initially, consent was sought from the Head of Department of Obstetrics and Gynaecology at the institutions. The study protocol together with the approval letters from the University of Witwatersrand Human Research Ethics Committee (Medical) and the University of Cape Town Research Ethics Committee was sent to the Heads of Department electronically, asking their permission to interview their respective Head of the Fetal Medicine Unit. The respondents were then contacted electronically to inform them of the study and the questionnaire and the letter of consent from their Heads of

Department was emailed to them before the arranged interview time. Following the telephonic interviews, the respondents were sent the competed interview forms, electronically or by fax for their records.

3.2.2 Data analysis

The data received was analysed in the following manner:

i) The data received from the institutions was examined and is presented as tables.

ii) The major ethical issues are examined in terms of ethical approaches thought to be relevant to the discussion as well as considering the recommended principles of Beauchamp and Childress in terms of beneficence and autonomy.

iii) Strengths and weaknesses of each approach in this context are identified.

3.3. LIMITATIONS OF THE STUDY

The main limitation of this study is that it only involved the practice of feticides for pregnancies complicated by fetal abnormalities at public institutions, but did not include private hospitals and other reasons why feticides are performed, e.g. maternal risk, etc. thus introducing selection bias. Systematic bias is introduced in that the respondents possibly

answered the questions favourably and not in terms of the current practices at their institutions. This was overcome by ensuring that participants were aware of the confidentiality of the information provided, that they were sent the information prior to the interview and that further assurance of confidentiality was reinforced prior to the telephonic interview. A further limitation is the small sample size and hence we were unable to conduct a formal statistical analysis.

3.4. ETHICAL CONSIDERATIONS

The study was approved by the Human Research Ethics Committees (Medical) of both the University of the Witwatersrand (Ref M080564 - Attached as Appendix B) and the University of Cape Town (Ref 203/2008 - Attached as Appendix C). In addition, all the relevant heads of departments of the seven institutions gave approval for the participants to be contacted (Appendix D).

3.4.1 Beneficence

The study will translate into raising awareness amongst physicians of the complexities of the process of decision-making in this arena, which will result in an overall benefit to the patient. This benefit extends not only to the patient but also to the fetus, who is probably the primary focus of

discussions in pregnancies with congenital abnormalities and the balance of benefits is assessed both in the short and long term.

3.4.2 Informed consent

As this study involved a telephonic interview, consent was verbal. Tacit consent for study participation was assumed if participants responded to the questions asked. They were however sent the study protocol and an information sheet prior to the interview. The views of the participants were respected in terms of their responses to the questionnaire.

3.4.3 Confidentiality

The audit involved the completion of a questionnaire and to maintain confidentiality, no patient names, names of health care workers or institutions were mentioned in the report results. Since the cohort of participants were named and therefore specifically identified people, their identities could not anonymised to the researcher, however, respect for persons and autonomy was not infringed. In addition, they would run the risk of being identified as a group in publications and presentations. The researcher communicated this limitation both verbally and on an information sheet to the participants. All the hard data will be safely kept in the institution for six years if not published or two years in the event of a

publication. At the end of the two or six-year period, all information will be destroyed.

3.5. DEFINITION OF KEY CONCEPTS (Schoeman 2000)

- Fetus – the fetus is the stage of the development of the child that begins eight weeks after fertilization, when the major structures and organs have formed until birth.
- Gestation – This is the period from conception to birth or the time during which the woman carries the developing fetus in her uterus.
- Trimester – The nine months of pregnancy is traditionally divided into three trimesters roughly three months each, during which different phases of development of the fetus take place.
- Congenital abnormalities – This is an anatomical or structural abnormality that is present at birth.
- Feticide – the act that causes the death of the fetus that is not due to natural causes or the spontaneous termination of a pregnancy (FD 2008).
- Gravida – This describes the number of times that a woman has been pregnant, for example, if it is her first pregnancy, then she is Gravida 1, if her second pregnancy, then Gravida 2, and so on.

- Parity – This describes the number of times the patient has delivered a fetus, whether alive or dead, beyond the gestational age of viability. The Parity number is usually seen with the Gravida number, for example, Gravida 2 Parity 1 implies that she is in her second pregnancy and has delivered one live birth.
- Viability – the age at which the fetus is able to survive outside of the uterus (FD 2008). (Experience has shown that in the developed world setting, it is rare for a baby to survive whose weight is less than 500 grams or whose gestational age is less than 24 weeks and these limits are commonly used as the age of viability. However, in the South African public sector, survival is at 1000grams or 28 weeks gestation, prior to which ventilation is not offered) (Personal communication with Obstetricians and Neonatologists).

3.6. CONCLUSION

The research methodology was structured in this way in order to facilitate the responses to be received from the seven institutions within a period of one month allocated to data collection.

CHAPTER 4

RESULTS

4.1 Study participants

All the institutions that were approached responded to the questionnaire. Among these, one indicated that no feticides were being performed at their institution, thus the results are based on the information received from six hospitals. All the respondents are Fetal Medicine Specialists at their hospitals. Data for the study was collected over a period of one month. Three of the institutions opted to be interviewed while of the other three, two responded to the questionnaire electronically and one by way of fax.

The small sample size including only six public hospitals poses a limitation in terms of generalizing the findings of the study, since the practice of feticide may also be occurring at other public hospitals and in private hospitals. However, for the public sector, considering that most cases of suspected abnormalities are being referred to the tertiary institutions according to treatment protocols, guidelines and referral criteria, it is felt that the views presented are representative of the main role-players providing this service and that these findings are an important contribution to the debates on this sensitive topic in Obstetrics. A similar extended review of private facilities would assist in gaining an understanding of the

practice of feticides and could provide additional insight into the ethical and legal challenges and changes that need to take place.

4.2 Responses to questionnaire

In this section, the responses to the six questions in the questionnaire are summarized in tabular form and discussed.

4.2.1. Question 1: Feticide Policies

Do you have a policy document for feticides? If yes, can this be forwarded to be included in the review.

TABLE 1: Feticide policy

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Policy on feticides	No	Yes	No	Yes	No	No

Only two of the institutions indicated that they had a written policy on the practice of feticides. The policies that were forwarded identify a definition of feticide as the procedure to be performed after viability is reached in a fetus with a congenital abnormality. The policies further outline why and how the procedure needs to be performed, who needs to be involved and emphasize the need for extensive counselling. Of note is that both policies touch on the ethical challenges that are faced in making the decision.

'…If these pregnancies are terminated the baby might be born alive and still survive a few hours to days causing many ethical problems on the management.'

However, there were no specific guidelines on how to deal with the ethical issues. One of the policies did mention, '… thorough counseling and documentation by the fetal medicine team..', as well as '..involving the hospital ethics committee'. Both policies cited the involvement of a panel of experts that would discuss the abnormality in order to make the decision to offer feticide. There was recognition of the distress for the family and the importance of compassionate care and psychological support were highlighted. The policy also identified that in addressing some of the ethical challenges, consideration needs to be given to the fact that the fetus would not be able to survive or would have a poor prognosis after birth. It should be noted that although the other institutions did not have a written policy on the practice, the review showed that similar procedures were being followed.

In this type of environment, when there may be so many possibilities to treatment, policies should never be prescriptive, but rather serve as a guide that ensures the treatment of the patient in a caring and

compassionate manner. Debates on the age of viability will remain ongoing, but as a starting point, there needs to be some consensus about this. The review clearly showed that the institutions considered viability to be from 22 weeks, up to 26 weeks. The group thus needs to agree on the gestational age of viability after which a termination of pregnancy should take place by means of feticide. A guideline could thus serve as a framework within which the service is able to function.

Evidence based practice helps to guide some of the decisions that are made regarding feticide and while there may not be an 'official list' of conditions for this procedure, a 'list' develops informally as precedence is set. For smaller institutions, such a guide can be useful in the decision making process.

The guideline would also need to outline the need to confer with other clinicians before a final decision is taken and the need for counseling and psychological support. At this stage, it should not be forgotten, that these situations also affect the caregivers and counseling sessions should be organized for them as well.

4.2.2. Question 2: Number of feticides

How many congenital abnormalities are encountered per year and on average, how many of these are terminated.

TABLE 2: Average annual number of cases presenting to the institution with congenital abnormalities

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Less than 12 weeks	0		5	2		10
12-20 weeks	15		25	10		60
More than 20 weeks	45		100	40		40

TABLE 3: Average annual number of terminations performed for congenital abnormalities

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Less than 12 weeks	0		3	1		10
12-20 weeks	6		10	7		20
More than 20 weeks	23		30	30		10

TABLE 4: Average annual number of feticides

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Number of feticides	6	10	25	6	12	

Some institutions perform six feticides annually, while one facility did up to twenty-five. Of the four institutions that submitted annual estimates of the statistics, it was noted that the number of terminations varied from between 30% up to 75% per institution for fetuses with congenital abnormalities that were diagnosed after 20 weeks gestation.

Of note is the lack of statistics at the institutions, providing only estimates of the number of procedures being performed annually, thus making a comparative analysis difficult. The variations in the percentage of terminations performed could be due to differences in presenting pathology in the different areas, because of diagnostic techniques used or the timing of the ultrasound procedures so that earlier diagnoses are made. Furthermore, the variation could be due to differences in the criteria used as an indication to perform the termination or feticide or due to differing counseling processes, with fewer patients refusing the offer to terminate. With the information requested in the questionnaire and the statistics provided, a definitive deduction on the variation could not be made, except to note the differences.

Variation was also noted in the gestational age after which the termination is done as a feticide, with some institutions quoting 22 weeks and others only after 26 weeks. The South African Choice on Termination of Pregnancy Act (Act 92 of 1996) stipulates that after 20 weeks,

terminations may only be considered in cases of severe congenital malformations, if the woman's life is endangered or if there is risk of injury to the fetus. The term viability is not mentioned or described, hence the differences in the gestational age after which feticides are considered at the different institutions. The need for guidance in the law is recognized. It is accepted that the law cannot account for every eventuality and this applied particularly to the practice of feticide where a decision has to be on a case-by-case basis. However, since there is such variability, the law should provide guidance on the matter.

The usefulness of collecting such statistics would need to be considered at the institutional level, especially considering that we are in an environment of increasing litigation. However, this should not be the main impetus for such data collection, but rather that the information could be used as a monitoring tool to articulate where there may be areas of high disease burdens in terms of genetic abnormalities, lack of family planning or low obstetric or neonatal care. Annual reviews of such information would increase the knowledge base and generally help to improve the services.

4.2.3 Question 3: Decision making process to offer feticide

If feticide is offered after 20 weeks:

a. *What are the five main indications for offering feticide*
b. *Who decides that a Termination of Pregnancy (TOP)/feticide can be offered? (if a multidisciplinary team, then please state who is represented on the team)*
c. *Who offers the counseling and list the treatment options offered to the patient?*
d. *What methods are used to perform the feticide?*
e. *On average, what percentage of patients accepts the feticide?*
f. *What are some of the reasons for refusing an indicated TOP*

TABLE 5a: Decision making process to offer feticide – Main indications

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Five main indica-tions	Meningomyelocoele; Hydrocephalus; Congenital infections and brain involvement; Microcephaly; Holoprosencephaly	Trisomy 13 & 18; Severe open spina bifida; Severe brain lesion; Bilateral severe renal disease with pulmonary hypoplasia; Multiple malformations	Severe fetal malformation; Chromosomal abnormalities; Major structural abnormalities such as skeletal dysplasis, CNS or spinal, Amniotic band, Multiple anomolies	Only done after 26 weeks	Trisomy 13 &18; Severe intracranial pathology such as anencephaly or intracranial haemorrhage; Cardiac abnormalities; Dwarfism with skeletal dysplasia	Fetal anomaly non compatible with life; Continuation of the pregnancy is life threatening to the mother.

While the specific indications varied, feticides at all institutions were performed for severe cases of congenital malformation, more commonly Trisomy 13 and 18, severe intracranial pathology, such as hydrocephalus and meningomyelocele or skeletal pathology, such as skeletal dysplasia or spinal abnormalities and if multiple malformations were present. In general, significant consideration is given to the severity of the condition and prognosis after birth. Every case could be individualized and was considered separately.

The indications for the terminations reflect the wide range and variability of the case presentations, thereby justifying the need to view each decision on a case-by-case basis. However, the lack of guidelines poses additional challenges in terms of the ethical dilemmas faced by the clinicians in deciding on an appropriate course of management, for example, if feticide is not performed prior to the termination or the birth, the baby may live for a few hours to days, causing distress not only to the parents, but also to the caregivers if treatment is withheld. Of note is that a diagnosis may have different degrees of severity, the milder of which may be treatable and therefore not considered for feticide.

TABLE 5b: Decision making process to offer feticide – Who decides

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Who decides to offer the TOP	Multidisciplinary team	Multi-disciplinary team	Multi-disciplinary team	Specialist in the specific field of the abnormality is consulted	Multi-disciplinary team	Multi-disciplinary team
Who is represent-ted on the team	At least two Fetal Med specialists; Neonatologists; Midwife; Genetic counsellors	Fetal Med specialists; Paediatrician; Clinical Geneticist; Paediatric subspecialist if needed	Fetal Med specialists; Obstetrician; Paediatrician/ Paed. Surgeon; Midwife; Genetic counsellors; Deputy Head of Department	Specialist in the specific field of the abnormality together with the Geneticist	Two Obstetric consultants and a Geneticist who is also a Paedia-trician	2 Fetal Med specialist; O&G consultant; Nursing sister; Consultant from the speciality where the problem would reside after birth.

All institutions indicated that the decision to offer the patient termination was not taken by one person, but either in consultation with another specialist who is knowledgeable in the field, or by a multidisciplinary team including the Fetal Medicine specialist, a Paediatrician and a Geneticist or genetics counsellor. Only three of the institutions included a midwife in the team. Only after such consultation and agreement on the options available would the patient be counselled and allowed to make an informed decision.

The need for such consultation was verbalized by one of the respondents as the ethical dilemmas faced by an individual having to make such a decision.

> *…the challenges include not having certainty of the diagnosis and outcome; the issues of the autonomy of the patients; the issues of when does the fetus become a patient; if the mother presents to us and asks for an opinion on her fetus, then it becomes a patient; having to do good for the fetus against the mother's autonomy*…

Similar responses were received from other participants during the interview process, although the questionnaire did not specifically ask about the ethical dilemmas, but rather focussed on the process that is being followed at the various institutions.

TABLE 5c: Decision making process to offer feticide – Who counsels

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Who counsels the patient	Genetic counsellors	Fetal Med specialists; Geneticist; Paediatric subspecialist if needed; translator	Fetal Medicine specialist; Geneticist with specialist Paediatrician	Geneticist with Specialist Paediatrician if needed	One Obstetric consultant sometimes with geneticist	Fetal Medicine consultant and genetic counsellor

The counselling of the patient at all institutions is done jointly between the Fetal Medicine, Paediatric and Genetics specialists / counsellors or individually by any one of these health practitioners. The indications, treatment options, outcomes and prognoses are presented to the patient who is then allowed to make an informed decision on whether or not to continue with the pregnancy. The treatment options offered vary with each individual case.

'…options always include non-termination of the pregnancy with either active management of the fetus (that is maximal intervention options prenatally or postnatally, within the context of service limitations and the specific disorder), or entirely an expectant approach (which includes non-intervention to maximize the outcome for the mother, for example, avoiding a caesarean section for an anomaly with a poor outcome) while

not actively terminating the fetus. For abnormalities with a definite lethal outcome, for example anencephaly, termination without feticide would be offered. Alternately, abnormalities with a chance of survival, feticide would be offered before the termination.'

Where there is any doubt of the diagnosis, further confirmatory tests would be done before considering termination or feticide.

The South African Choice on Termination of Pregnancy Act (1996) (Subsections 1c; 4;5 and 6). does not specify who should be included in the team, except to say that the decision should be concurred by two medical practitioners or one medical practitioner and a midwife. The Act does include that the counselling should be encouraged, be non-mandatory and non-directive and that it can be offered by either the medical practitioner or midwife. This is however not mandated in the act.

It is important to note that each member of the team has unique expertise to offer the patient during the counselling process and hence the appropriate specialists need to be included as required. The genetic consultant in particular can advise the patient on the risks related to future pregnancies.

TABLE 5d: Decision making process to offer feticide – Methods used

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
What methods are used to perform the feticide	Potassium Chloride injection into heart; Lignocaine into umbilical vein	IV lignocaine after paralysis with pancuronium bromide; Intracardiac lignocaine if technically possible; Potassium Chloride intracardiac as an alternative	Potassium Chloride into heart	Potassium Chloride injection into heart after cordocen-tesis and administra-tion of sublimaze 100ug.	Dormicum for sedation; Potassium Chloride into heart	Potassium Chloride via Cordocen-tesis

All the institutions indicated that Potassium Chloride was injected into the heart or umbilical vessels of the fetus. It has been reported that the umbilical route is less commonly used compared to the cardiac injection, but a comparative study showed that both methods are effective without compromising maternal safety (Bhide et al 2002: 231). The technique used is determined by the competency of the clinician with the selected procedure. All procedures are performed under ultrasound guidance.

TABLE 5e: Decision making process to offer feticide – Acceptance and reasons for refusal

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
How many patients accept the feticide offer	75%	Statistics not available	60%	100%	A few do reject the offer for feticide	40%
Reasons for refusal	Religious, Cultural, Spiritual beliefs	Moral and religious objection; Social; Denial; Belief in miracles; Pregnancy too far advanced	Social; Religious; Cultural; Belief that condition may improve; Family / Peer pressure; Abandonment by partner; Ability to collect grant	Acceptance of abnormal child; Religious; Prognosis unclear	Religious; Difficulty in making the choice	Family pressure; Failure to understand severity of the condition

The institutions varied from between a 60% to 100% acceptance rate of feticides. Reasons given for refusal include religious beliefs, moral and cultural beliefs, family or peer pressure and in some instances, denial of the condition with the hope of a miracle cure. One institution reported that termination was refused so that patients could collect social or disability grants. All institutions noted that the autonomy of the patient would be respected.

The reasons for the noted discrepancies could be due to the counselling technique used, a language barrier if English or Afrikaans is not the mother tongue or because of socio cultural and religious differences in the various communities that the different institutions serve.

4.2.4 Question 4: Multidisciplinary teams

Do you feel that all institutions should set up a Multidisciplinary Group that decides whether or not feticides should be performed?

TABLE 6: Need for multidisciplinary teams

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Need for Multidisciplinary group	Yes	No	Yes	Yes	Yes	Yes
Who should be represented in the group	Obstetricians; Fetal Medicine specialists; Geneticist; Paediatrician; Nursing; Ethicists initially to discuss indications	It should never be a single person; Parental opinion important	Fetal Medicine specialists; Obstetrician; Midwife; Geneticists; Paediatricians/ Surgeons; Ethicists; Psychologist; Social worker	Fetal Medicine specialists; Geneticists; Paediatricians; Specialist in the field of abnormality; Ethicists; Religious leader	Fetal Medicine specialists; Geneticists; Paediatrician from the subspecialty related to the problem	Obstetricians; Fetal Medicine specialists; Genetic counsellor; Nursing; Specialist from a discipline related to the abnormality

There was consensus among five of the six institutions that a multidisciplinary team was needed to discuss and decide whether or not to offer termination of a viable fetus for congenital abnormalities. However,

the professional categories involved would depend on the individual case, for example, to involve a Paediatric Cardiologist or Surgeon for a congenital heart anomaly. The Fetal Medicine specialist, Paediatrician and genetic consultant were considered to be vital in the team. Other suggestions included a midwife, a social worker, a psychologist, an ethicist and a religious leader. The team would not discuss all cases, since some diagnoses would be straightforward, for example, anencephaly. Three of the institutions suggested that there be some discussion by an ethics committee or that an ethicist be included in the team. One institution felt that a formal multidisciplinary group was not always necessary, since the diagnosis and expected outcome may be clear, however it was agreed that the decision should never be taken by one individual and that some consultation was needed. The patient's legal right to termination for severe abnormalities was recognized in terms of the South African Choice on Termination of Pregnancy Act (1996) and that for viable fetuses, feticide was the only way to ensure a non-live birth of an affected fetus. This institution therefore felt that it was not up to a local committee to decide whether or not they supported the practice. However, discussions need to be held on referral policies in cases of ethical objections.

The doctors working in these fetal medicine units are thus faced with difficult scenarios and many factors would play a role in influencing their decisions, including their personal perspectives, what their professional guidance is and the institutional structure in terms of support from other health professionals. This assistance helps to guide the clinician in dealing with the conflicts of treating the mother or the fetus, the issues of fetal viability, of sharing the accountability and working within a legal framework, thereby giving support to having multidisciplinary groups where consensus decisions can be taken. In particular, the Fetal Medicine specialist, the Neonatologists or Paediatricians and Genetic specialists needs to be involved. The Royal College of Obstetricians and Gynaecologists guidelines relating to pregnancy termination practices suggest that the team should include Obstetricians, Neonatologists, midwifes and nursing staff (Coward et al. In Lee 2004: 11).

The midwife if possible can offer her views from the perspective of what care would be required as well as the emotional toll this has on both the patient and the staff. Awareness of how such decisions get taken, knowing the details of the cases and being involved in the decision making process would only enhance the compassion in the care offered. Dedicated areas may be reserved for the delivery and mourning purposes, especially when faced with a busy labour ward. In the same way, the social worker or

psychologist being aware of the particular case and knowing the history of the situation could provide valuable assistance with pre and post procedure counselling as well as referring the patient to support groups within their communities.

The role of the ethicist would also be supportive in this team, since all health workers are guided by ethical principles in terms of their behaviour. The ethicist could assist in facilitating the debates on the feasibility of performing the procedure as well as weighing up all available options and supporting what is considered best for all parties concerned in terms of the ethical principles of beneficence and justice. In considering issues of beneficence, it can be ensured that the patient will overall benefit from the procedure. The use of the justice principle during the deliberations will ensure that a fair process is followed for all those involved. At the end of the day, most of the decisions are clinically guided, but some circumstances do also require reviewing social, moral and ethical principles, allowing the ethicist to play a vital role. Ultimately, the third principle of autonomy allows the patient to make an informed decision and this needs to be respected. However, in the environments of resource constraints at such public institutions, the information given to the patient will include services that can be provided and that which cannot. The

ethicists serve an important role to guide the processes of priority setting and this applies to the performance of feticides as well, since if some babies were allowed to be born, the cost of their care to the state as well as their parents would need to be considered and balanced against the available options of care.

4.2.5 Question 5: Legislation

In your view, should the legislation be more prescriptive in terms of risk and disability and what specifically should be changed?

TABLE 7: Changes to the legislation

	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E	Hospital F
Legislation more prescriptive	No	Yes	No	No	No	Yes, as guidelines

Four of the six institutions agreed that the law should not be too prescriptive, since each case had to be considered individually, depending on the weight of the fetus, the type of abnormality and the possible treatment modalities available. One institution specifically requested some change in the legislation in order to regulate the practice of feticides in the private sector.

'…a change is in my mind very much needed since I am aware of unacceptable practices regarding late terminations of pregnancies in this country…… to my knowledge, mainly in the private sector..'

While this may be true, regulations would assist to standardize practices in both the public and private sector. This study has acknowledged the exclusion of the private sector as a limitation and therefore cannot comment on whether or not such practices are taking place. However, there is some agreement that there needs to be some regulation of the practice of feticide. While it is accepted that the law cannot be prescriptive, especially relating to clinical issues such as age of viability, weight of the fetus and gestational age, since these factors have individual variability in the clinical situation. However, the law can provide guidance on these issues through a clause that identifies an age of viability range or definition and secondly to monitor the practice through a reporting mechanism, whereby details such as the gestational age, weight and indication for the feticide are recorded. The law should have a sound ethical basis in terms of moral values, the potential harm to the fetus once born with an abnormality and the right to life based on the probability of survival. It was felt that formal guidelines and legally binding policies would allow for a more ethical approach to the practice. All institutions agreed that ethical practices should be followed.

The legislation has clearly dodged this issue of feticide and speaks only of the conditions for terminations after 20 weeks of gestation. Understandably, the South African Choice on Termination of Pregnancy Act (1996) was not developed for the purposes of feticides and therefore needed to be broad, but because of the emotive nature of the practice, one would expect guidance in the form of regulations. The law is however silent on this matter.

4.2.6 Question 6 – The Scenarios

The respondents were asked to answer the scenario questions in terms of what they would do at their institutions.

4.2.6.a. Scenario 1:

42 year old, Gravida 1 Para 0, at 26 weeks gestation with a diagnosis of Trisomy 21 and a diaphragmatic hernia.

Management options included:

a. Do Nothing
b. Offer termination
c. Offer feticide and then termination
d. Offer pregnancy to continue, but no intensive care or resuscitation will be provided post delivery
e. Offer pregnancy to continue, with full care post delivery

TABLE 8a: Responses to Scenario 1

	Response
Hospital A	Offer pregnancy to continue, but no intensive care or resuscitation will be provided post delivery.
Hospital B	- Offer feticide and then termination - Offer pregnancy to continue, with full care post delivery
Hospital C	Offer feticide and then termination
Hospital D	Offer termination
Hospital E	- Feticide - Neonatal Hospice - Surgery and resuscitation after birth
Hospital F	Offer feticide and then termination

4.2.6.b. Scenario 2:

29 year old, Gravida 1 Para 0, referred from the infertility clinic, at 25 weeks of gestation with triplets. Findings on ultrasound show that baby A has hydrocephalus, while babies B and C are normal.

Management options included:

a. Do Nothing

b. Offer feticide of Baby A

TABLE 8b: Responses to Scenario 2

	Response
Hospital A	Offer feticide of Baby A at 32 weeks
Hospital B	More information is needed since hydrocephaly may have a variable prognosis
Hospital C	Offer feticide of Baby A after 28 weeks
Hospital D	If there is no Polyhydramnios, the Hydrocephalic baby will delay feticide till just before delivery. At 25 weeks, a dead fetus can put the pregnancy at risk.
Hospital E	Offer feticide of Baby A
Hospital F	Offer feticide of Baby A at 32 weeks

4.2.6.c. Scenario 3:

42 year old, Gravida 3 Para 1, at 30 weeks gestation. Ultrasound findings show a cleft lip and palate with a ventricular septal defect of the heart.

Management options included:

a. Do Nothing
b. Offer termination
c. Offer feticide and then termination
d. Offer pregnancy to continue, but no intensive care or resuscitation will be provided post delivery
e. Offer pregnancy to continue, with full care post delivery

TABLE 8c: Responses to Scenario 3

	Response
Hospital A	Offer pregnancy to continue, with full care post delivery.
Hospital B	- Do nothing, just counsel and inform the parents and offer ongoing support - Offer pregnancy to continue, with full care post delivery.
Hospital C	Offer karyotype, if normal then continue with pregnancy at tertiary level. If abnormal, then offer feticide then termination. Important to respect the patient's wishes.
Hospital D	Offer pregnancy to continue, with full care post delivery. Parents should be counselled. Both defects have a good prognosis if there is no genetic abnormality
Hospital E	Offer pregnancy to continue, with full care post delivery. The decision depends on whether the chromosome karyotype is normal. If abnormal, then most likely due to Trisomy 18, in which case feticide would be offered.
Hospital F	Offer pregnancy to continue, with full care post delivery.

4.2.6.d. Scenario 4:

21 year old, Gravida 1 Para 0, at 24 weeks gestation. Ultrasound findings show possible overriding aorta, bilateral polydactly from the heels. Amniocentesis confirms Trisomy 13.

Management options included:

a. Do Nothing
b. Offer termination
c. Offer feticide and then termination
d. Offer pregnancy to continue, but no intensive care or resuscitation will be provided post delivery
e. Offer pregnancy to continue, with full care post delivery

TABLE 8d: Responses to Scenario 4

	Response
Hospital A	Offer termination
Hospital B	- Offer termination - Offer feticide and then termination - Offer pregnancy to continue, but no intensive care or resuscitation will be provided post delivery
Hospital C	Offer feticide and then termination
Hospital D	Offer termination
Hospital E	Offer feticide and then termination
Hospital F	Offer termination

4.2.6.e. Scenario 5:

40 year old, Gravida 4 Para 0, at 32 weeks gestation. Ultrasound findings show hydrocephalus and a meningomyelocele.

Management options included:

a. Do Nothing
b. Offer termination
c. Offer feticide and then termination
d. Offer pregnancy to continue, but no intensive care or resuscitation will be provided post delivery
e. Offer pregnancy to continue, with full care post delivery

TABLE 8e: Responses to Scenario 5

	Response
Hospital A	Offer feticide and then termination
Hospital B	Much more information needed to reach a decision
Hospital C	Offer feticide and then termination
Hospital D	Offer feticide and then termination
Hospital E	Offer feticide and then termination
Hospital F	Offer feticide and then termination

In the five scenarios that were presented, each institution answered differently, with some suggesting more than one option for a particular scenario. It is recognized that with every case, there may be other factors to consider and that the respondent's interpretation of the question guided the responses. It was however expected that the scenarios were clear-cut

enough for a consensus on the decisions, but this was not found. In some cases, respondents did mention that the final management decision would depend on certain other interventions, such as karyotype testing for the fetus presenting with a cleft lip and ventricular septal defect. Again, this identifies with the need to view each case individually, since individual physicians' perceptions differ. Given these complexities in the time and gestational age at which the diagnosis is made, sometimes facing the uncertainty of the diagnosis and the different presentations that may be involved, it seems that having a list of conditions where a feticide should be performed is not possible. Any guideline would thus have to broadly encompass a range of situations that may arise, but at the same time provide a framework for clinicians to work within.

Ail the institutions mentioned that extensive counselling was important and that the suggested options would be discussed with the patient that an informed decision could be made. Decisions would also be guided by the available resources to provide the care, for example, the length of time for prolonged ventilation or rehabilitative care that would be needed. Some institutions may consider themselves to be more conservative in their decisions, while others may be more liberal. An ethical guideline could thus serve as a framework within which the service is able to function, since there is a common goal to do what is considered best for the patient.

Using the ethical principles for this purpose will provide guidance along the pathway to a decision (Rainbow 2002).

CHAPTER 5

RECOMMENDATIONS

This review deals with the challenges facing clinicians when congenital abnormalities are diagnosed during pregnancy and attempts to address these by providing the clinician with an ethical guideline. Chervenak (2003:474) identifies the two basic ethical principles of beneficence and respect for autonomy that should inform the duty of the clinician in terms of the obligation to promote and protect the health related interests of the patient. The ethical principle of beneficence obligates the clinician to seek the greater balance of clinical benefit over harm for the patient, while respect for autonomy allows the patient to make decisions on her own health-related and other interests.

Given the plurality of values among patient populations as well as among different clinicians, ethical behaviours will differ. It is generally understood that laws and directives may be general in nature and that they cannot deal with every situation that a clinician may face (World Medical Association Medical Ethics Manual 2005: 21). According to the manual (ibid: 26-31), ethical issues can be approached rationally or non-rationally. The Non- rational approaches include:

- Obedience – where the rules are followed irrespective of whether or not they are right.
- Imitation – where the behaviour follows that of a role model, usually someone in a senior position.
- Feeling or desire – where the behaviour depends on what one feels is the right thing to do.
- Intuition – where the behaviour is determined by the immediate perception of the right way to act.
- Habit – where one follows previous practices.

The rational approaches include:

- Deontology – where doing the right thing means treating all individuals equally.
- Consequentialism – where the decision is based on an analysis of the likely outcome, with the choice being the one that produces the best outcome.
- Virtue ethics – where the behaviour is reflected in the character of the decision makers and clinicians with good virtues will make good decisions.

The manual further suggests that the best way to make a rational ethical decision is to use a combination of these principles (ibid: 30-31).

The following steps are proposed as a guide to ethical decision-making and will be used in the development of an ethical guideline for feticides.

1. Determine whether the issue at hand is an ethical one.

2. Consult authoritative sources such as medical association codes of ethics and policies and respected colleagues to see how physicians generally deal with such issues

3. Consider alternative solutions in light of the principles and values they uphold and their likely consequences.

4. Discuss your proposed solution with those whom it will affect.

5. Make your decision and act on it, with sensitivity to others affected.

6. Evaluate your decision and be prepared to act differently in future.

These steps are used to structure the following proposed ethical guideline on the management of a diagnosis of congenital abnormalities that may require a feticide.

5.1 Ethical guideline for feticide

The guideline (attached as Appendix E) could be applicable to both public and private facilities throughout South Africa that offer feticide and can be used as an ethical basis for the decision making process.

The introduction offers some discussion on the ethical principles that need to be considered when faced with the diagnosis of a fetal abnormality. These include informed consent, respect for autonomy and beneficence-based obligations to the fetus. In addition, the framework around which the discussions need to be held is outlined. The guideline then offers a checklist of pertinent questions, based on the WMA (2005: 31) guide to ethical decision making that should be considered before a final decision is made. The importance of involving a multidisciplinary team; of appropriate and informed counselling sessions with the patient; of ensuring that the diagnosis is confirmed and that the prognosis is presented as an evidence-based outcome is highlighted in the guideline.

While this guideline serves as an ethical framework, it should be regarded as the minimum standard and broadened at each institutional level to outline the clinical procedure and what the responsibilities of the health professionals are. In addition, the guideline can be tailored towards other clinical challenges being faced by health professionals in the work environment.

5.2 Legal changes:

Changes to the law cannot happen based on a single recommendation and further consultative processes need to take place before this can be

envisaged. In addition, the law will need to stipulate and be prescriptive of its application to both the public and private sectors.

In general, the following need to be given consideration.

5..2.1 Age of viability

The legislation on terminations of pregnancy needs to be tightened to include age of viability and how the decisions for terminations should be conducted post viability. As a general rule, the age of viability is at 24 weeks gestation. The South African Choice on Termination of Pregnancy Act (Act 92 of 1996) needs to either extend the period from 13 weeks to 24 weeks, to include the generally accepted age of viability, instead of the current 13 weeks to 20 weeks, or it needs to stipulate what should be done between 20 and 24 weeks, when the fetus becomes viable. Alternately, the weight limit should be stated as a range that may be considered acceptable for viability. This would provide clinicians with some guidance from a clinical basis and assist in legally regulating a practice that currently is open to varying interpretations. This does not imply that current practice is unethical, but the results of this study do show some variability in the age at which feticides are performed. As stated earlier in the report, this study did not review services in the private sector, adding a further dimension of variability.

5.2.2 Consultation

Of importance is the need to stipulate that consultation with certain role-players, for example the Fetal Medicine specialist, another Obstetrician and a Paediatrician have to concur before a decision is taken. Furthermore, it needs to be stipulated that in cases of congenital abnormalities, genetics consultants have to review the case and offer advice to the patient on future pregnancies. The ethical framework of beneficence based obligations to the fetus need to be included in this section of the law or presented as a guideline.

5.2.3 Monitoring and evaluation

Once stipulated, the law should also have a process of monitoring the enacted legislation by requesting written reports on each feticide performed and the indications thereof. This could assist in monitoring that the legislation is being adhered to as well as serve to assess the indications for the feticides. For this process to provide benefit, the necessary administrative functions would need to be in place.

5.2.4 Case histories and incidentation

There should not be a ‘list’ of diagnoses, but rather to allow the clinicians to review and take decisions on case histories. However, once reported,

the legislation should stipulate an annual national audit in order to ensure that the identified diagnoses are warranted for the performance of feticides.

CHAPTER 6

CONCLUSION

Using an ethical framework is essential in the decision making process on the outcome of pregnancies complicated by fetal abnormalities. This review has highlighted that at the six public institutions that participated in this study, it was noted that there were discrepancies in the way in which the practice of feticide is performed. The review also concludes that this is mainly due to a lack of clear ethical guidelines and legal direction.

Of note was that the age of viability should be an important determining factor. There was a strong view that the decision needs to be taken by a multidisciplinary group of specialists who through their expertise and use of evidence based practice can assist in reaching a more ethically acceptable decision.

As an objective of this study was to develop an ethical guideline, this together with the legal recommendations for change will assist the clinician in balancing his responsibility to the patient in terms of her autonomy and his beneficence based obligation to her and to the fetus as a patient with moral standing.

This will only serve as a guide in that the final outcome or decision should be made on a case-by-case basis and will depend on the type of anomaly, the prognosis and the reliability of the diagnosis that is made

APPENDICES

Appendix A

QUESTIONNAIRE

Name of Hospital:

_____

1. Do you have a policy document for feticides? ☐ Yes ☐ No

(If yes, can this be forwarded to me to be included in the review?)

2. How many congenital abnormalities are encountered per year and how many of these are terminated (or on average):

- Less than 12 weeks _____ Terminated: _____
- 12-20 weeks _____ Terminated: _____
- 20 + weeks _____ Terminated: _____

Feticide : _____

(If possible, please provide stats from your institution for at least the last three years)

3. If feticide is offered after 20 weeks:

- What are the 5 main indications for offering feticide

_____

_____

_____

_____

_____

Who decides that a TOP/feticide can be offered? (if a multidisciplinary team, then please state who is represented on the team)

_____

_____

_____

_____

_____

Who offers the counselling and list the treatment options offered to the patient?

_____

_____

_____

_____

_____

What methods are used to perform the feticide?

_____

_____

_____

_____

On average, what percentage of patients accepts the feticide?

_____

What are some of the reasons for refusing an indicated TOP?

_____

_____

_____

_____

4. Do you feel that all institutions should set up a Multidisciplinary Group that decides whether or not feticides should be performed? Yes ☐ No ☐

If yes, then who should be represented on in this group?

_____

_____

_____

_____

If No, then provide reasons.

_____

_____

_____

_____

5. In your view, should the legislation be more prescriptive in terms of risk and disability and what specifically should be changed?

_____

_____

_____

_____

_____

6. Please answer the following questions in terms of what **you** would do at **your** institution.

Scenarios: Please indicate what treatment protocol will be followed in the following clinical situations.

1. 42 year old, G1 P0, at 26 weeks gestation with a diagnosis of Trisomy 21 and a diaphragmatic hernia.

- ☐ Do nothing
- ☐ Offer termination
- ☐ Offer feticide and then termination
- ☐ Offer pregnancy to continue, but no ICU/resuscitation care will be provided post delivery
- ☐ Offer pregnancy to continue, with full care post delivery

Other options

_____

_____

2. 29 year old, G1P0 patient referred from the infertility clinic, at 25 weeks gestation with triplets. Findings on ultrasound show that baby A has hydrocephalus, while babies B & C are normal.

- ☐ Do nothing
- ☐ Offer feticide of baby A

Other options

_____

_____

_____

3. 42 year old G3P1, at 30 weeks gestation. Ultrasound findings show a cleft lip and palate with a ventricular septal defect of the heart.

☐ Do nothing

☐ Offer termination

☐ Offer feticide and then termination

☐ Offer pregnancy to continue, but no ICU/resuscitation care will be provided post delivery

☐ Offer pregnancy to continue, with full care post delivery

Other options

_____

_____

4. 21 year old G1 P0, at 24 weeks. Ultrasound findings show possible overriding aorta, bilateral polydactyl from the heels. Amniocentesis confirms Trisomy 13.

- ☐ Do nothing
- ☐ Offer termination
- ☐ Offer feticide and then termination
- ☐ Offer pregnancy to continue, but no ICU/resuscitation care will be provided post delivery
- ☐ Offer pregnancy to continue, with full care post delivery

Other options

_____

_____

5. 40 year old G4 P0, at 32 weeks. Ultrasound findings show hydrocephalus and a meningomyelocoele.

- ☐ Do nothing
- ☐ Offer termination
- ☐ Offer feticide and then termination
- ☐ Offer pregnancy to continue, but no ICU/resuscitation care will be provided post delivery

☐ Offer pregnancy to continue, with full care post delivery

Other options

_____

_____

_____

_____

Thank you for completing this questionnaire.

Appendix B

Ethical approval from the University of the Witwatersrand

Appendix C

Ethics approval from the University of Cape Town

Appendix D

Approval letters from Heads of Departments.

Appendix E

ETHICAL GUIDELINES FOR FETICIDES

NOTE: This guideline serves to assist clinicians in developing institutional specific guidelines or policies for the practice of feticides in pregnancies complicated by fetal abnormalities.

INTRODUCTION

Feticides are performed for pregnancies complicated by fetal abnormalities when the gestational age has reached viability or above 24 weeks. These guidelines serve as an ethical framework or checklist to assist clinicians in making the decision on whether or not to suggest feticide as a treatment option to the patient. The most important part of the management of these patients includes obtaining an informed consent from the patient after explaining all the treatment options, thereby basing this entire framework on the ethical principle of respect for autonomy. There needs to be some emphasis on the limited access to terminations during the third trimester and that services function under resource constraints, hence not all treatments options are possible. There also needs to be consideration given to the health status of the mother if the pregnancy continues and the effect of prolonging the life of the fetus on her psychological well-being.

Management alternatives can be broadly categorized as:

- Offer pregnancy to continue
- Offer induction of labour in order to terminate the pregnancy
- Offer feticide, then termination
- Offer pregnancy to continue, but only hospice care will be provided after delivery
- Offer pregnancy to continue, and full care will be provided after delivery.

According to Chervenak and McCullough (1990:313), the approach to obstetric ethics incorporates beneficence based obligation to the third trimester fetus, which lies on a continuum from no beneficence based obligations through minimal beneficence based obligations to more than minimal beneficence based obligations. Anencephaly and triploidy are conditions that can be diagnosed with certainty and the outcome in these cases will be death or short term survival and the absence of cognitive development capacity. Recommending that the pregnancy be allowed to continue is a justified option since this will not increase the already unavoidable risk of death and absence of cognitive development. There is therefore no beneficence based obligation to propose any intervention that would prolong the life of the fetus. Offering termination or feticide and then

termination is also justified, since the death of the fetus is unavoidable and is already a certainty. Chervenak (1990: 314) justifies this decision by saying that : 'Preventing a future that holds no benefit for the patient does not harm the patient. Thus beneficence based obligations to a fetus with a lethal anomaly are not violated by terminating the pregnancy.'

With conditions where there is either minimal beneficence based obligation to the fetus, for example in fetuses with renal agenesis, where there is a high probability of death as an outcome, feticide or termination could be recommended, or the pregnancy could be allowed to continue with no treatment after delivery to be offered to the neonate, since this would be futile intervention. In this group, consideration would also be given to cases where there is a high probability of neurodevelopmental deficit.

Any fetus with a prognosis of expected survival following intervention and some deficit in neurodevelopment justifies more than minimal beneficence based obligation to the fetus, with the intervention offering benefit. An example of this includes a fetus with a diagnosis of diaphragmatic hernia or a ventricular septal defect that may be repaired surgically post delivery. The decision would be guided by the severity of the problem and knowledge of the probability of any severe physical or mental handicap.

While these obligations act as a guide to recommending the best possible treatment to the patient, all possibilities need to be discussed with her and her final decision should be respected. Thus, the beneficence based obligations to the fetus need to balanced against the beneficence based obligations and autonomy of the pregnant woman (Chervenak and others 2003: 476). Consideration should also be given to the health risks to the mother if the pregnancy continues and balancing the rights of the mother against those of the fetus. At all times during and after the pregnancy, there needs to be an ongoing dialogue with the patient.

GUIDELINE

5.1.1: Determine whether the issue at hand is an ethical one.

This would involve clearly stating when the circumstance becomes a problem in terms of identifying the gestational age of viability and having specific criteria by which the management of the pregnancy should include the performance of a feticide. Ideally, an early diagnosis will be less complicated in terms of ethical decision making than a diagnosis that is only made post viability. Obstetric practices such as early ultrasound and referral procedures need to be in place in order to ensure this.

5.1.1.1. Assessment of the problem

- Is the gestational age less than or above 24 weeks
- If below 24 weeks, then the fetus is pre-viable and the management should be according the South African Choice on Termination of Pregnancy Act (Act 92 of 1996)
- If above 24 weeks, then consideration needs to be given to the following criteria in order to decide if a feticide is indicated or not.
  - Is there certainty of the diagnosis
  - Is there certainty of death as an outcome of this anomaly
  - Is there certainty of a significantly compromised neurodevelopmental outcome of this anomaly.
  - What is the variability in terms of the probabilities for each of the above. If there is a lack of certainty, then the decision should be based on a high index of probability with care that can be provided within the resource constraints.
  - Would the continuation of this pregnancy place the mothers health at risk

5.1.2. Consult authoritative sources such as medical association codes of ethics and policies and respected colleagues to see how physicians generally deal with such issues.

5.1.2.1 Confirm the diagnosis.

- Has a confirmatory ultrasound been done.

- Has an amniocentesis and karyotyping, if necessary, confirmed the diagnosis.

5.1.2.2 Verify the problem

- Has a second specialist concurred with the diagnosis.

5.1.2.3 Consult with other specialists who are knowledgeable on the condition.

5.1.2.4 Review the literature for evidence based practice on feticides and the outcomes for similar conditions.

Facts that are relevant to the problem need to be identified, scrutinized and confirmed as reliable. This includes ensuring that all confirmations have been conducted in the form of ultrasound testing and further testing as deemed necessary by utilizing antepartum and intrapartum diagnostic modalities as available. At this stage, the facts have to outweigh the opinions. Besides the relevance of the facts, an 'environmental' scan is required, which could include maternal health risk, previous history, family history, exposure to hazardous substances, among others.

5.1.3. Consider alternative solutions in light of the principles and values they uphold and their likely consequences.

- Should the pregnancy be allowed to continue
- Should the pregnancy be terminated through induction of labour
- Should feticide be offered, and then terminated
- Should the pregnancy continue but no treatment offered after birth
- Should the pregnancy continue with full treatment offered after birth

5.1.3.1 List all the options

The multidisciplinary team including the Fetal Medicine specialist, the second Obstetrician, the Neonatologist / Paediatrician, the Geneticist and Midwife meet to discuss the options, benefits and possible outcomes based on sharing expertise and evidence based practice. Consideration should also be given to the human and financial costs related to the decision.

Based on the assessment, an outcome has to be articulated as the best possible resolution given the diagnosis, the circumstances and the resources available.

5.1.4. Discuss your proposed solution with those whom it will affect.

- Joint decision on the best available option of treatment
- Present options to patient
- Respect for patients' autonomy.

5.1.5. Make your decision and act on it, with sensitivity to others affected.

- Offer extensive ongoing counselling, including genetic counselling to the patient.

Each option is considered in terms of the institutional, provincial or national guideline or any relevant legal framework if available. The decision should also be able to withstand and be justifiable under public scrutiny. It should be consistent with the plurality of the values of the professionals, the organization and the community. The decision should satisfy the ethical principles of truth telling, of do no harm, adherence to justice and beneficence. The needs of the vulnerable and powerless fetus need to be considered. The final decision needs to be compatible with the most compelling principle identified in order to justify the chosen course of action, since it will set a precedent for later decisions. Adequate consultation should be satisfied and in the case of feticides, respecting the autonomy of the patient.

5.1.6. Evaluate your decision and be prepared to act differently in future.

The decision and outcome should be evaluated and followed up in order to learn and share from the experience.

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