Supporting women through late termination of pregnancy due to fetal abnormalities in South Africa

Guidelines for healthcare providers

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CONTENTS

Introduction

The decision to terminate a pregnancy due to fetal abnormalities is very difficult.

How can providers support women through the process?

The purpose of this document is to provide practical, implementable guidelines for the support of women faced with the decision to terminate a (usually) wanted pregnancy due to the presence of fetal abnormality. The guidelines are aimed at healthcare personnel involved in the process, including fetal-maternal specialists, obstetrician-gynecologists, clinical geneticists, genetic counselors, maternity ward staff, social workers, counselors, occupational therapists, and psychologists. General practitioners responsible for women's primary healthcare during the months and years after the procedure may also benefit from this document.

We outline the support needed during the decision-making stage, during the actual procedure, and the post-termination of the pregnancy period. These guidelines are based on the core findings of the research conducted by Dr Angie Vorster and supervised by Prof Catriona Ida Macleod[1].The aim is to promote women-focused and supportive procedures and medical care that reduce the likelihood of adverse psychological and social outcomes for the women involved and their families. The information gained from our research allows for nuanced recommendations regarding care in the interests of women who may otherwise experience silencing and stigma.

These guidelines do not provide guidance on the medical or clinical aspects of care. This guidance can be found in the World Health Organization's *Clinical practice handbook for quality abortion care*[2]. The latter document systematically outlines the medical procedures for abortions, including late termination of pregnancy (LTOP).

These guidelines are structured into two major sections: background and recommendations. The topics covered in each are as follows:

[1] Background

a. The legal environment for the provision of late termination of pregnancy (LTOP) in the South African context

b. A brief outline of the fetal conditions for which LTOP may be considered

c. Notes on the induction of fetal cardiac asystole before abortion

d. Brief description of our research

1. Vorster, A. (2022). South African women's experience of the decision, procedure and recovery from 'feticide' and late termination of pregnancy due to the presence of severe fetal abnormality: women's and health service providers' perspectives. Unpublished PhD thesis, Rhodes University, South Africa.Vorster, A., & Macleod, C. I. (2025). Late-term abortions and "feticide" due to fetal abnormality: hearing the silenced voices of women and their healthcare providers. Wits University Press.
2. World Health Organization (2023). *Clinical practice handbook for quality abortion care*. Geneva: World Health Organization. https://www.who.int/publications/i/item/9789240075207

[2] Recommendations

Recommendations for support and care during three phases of the process:

a. The fetal diagnosis and decision-making period

b. Termination of pregnancy and active fetal demise procedures

c. Women's recovery following the procedures

Background

The legal environment

The *Choice on Termination of Pregnancy Act* (Act No. 92 of 1996) (henceforth, CTOP Act) governs the provision of abortion in South Africa. This legislation is considered liberal, as a pregnancy may be terminated upon request in the first 12 weeks of gestation. The Act has contributed to a reduction in abortion-related morbidity and mortality in the country.

According to the CTOP Act, from the 13th up to and including the 20th week of gestation, a medical practitioner, after consultation with the pregnant woman, may perform an abortion if, amongst other things, there exists a substantial risk that the fetus would suffer from a severe physical or mental abnormality. After the 20th week of gestation, a medical practitioner, after consultation with another medical practitioner or a registered midwife, may perform an abortion if the continued pregnancy would result in a severe malformation of the fetus or would pose a risk of injury to the fetus. There is no upper limit for performing a termination of pregnancy imposed by the CTOP Act under these circumstances.

Fetal abnormalities

Fetal conditions are generally categorized into lethal anomalies, severe functional impairments, and multi-system disorders.

Lethal fetal abnormalities are considered incompatible with life, resulting in stillbirth or death shortly after birth. They include:

- anencephaly (an absence of a significant portion of the brain and skull)
- severe forms of holoprosencephaly (failure of the brain to divide properly)
- acrania (absence of the skull, often leading to anencephaly)
- hanatophoric dysplasia (a severe skeletal disorder causing respiratory failure)
- bilateral renal agenesis or Potter syndrome (absence of kidneys)
- hydranencephaly (brain hemispheres are replaced by fluid-filled sacs)
- body stalk anomaly or limb-body wall complex (severe disruption in body wall development)
- triploidy (a chromosomal disorder).

Severe structural abnormalities lead to major disabilities. They include:

- severe form of hypoplastic left heart syndrome (underdevelopment of the left side of the heart)
- severe cases of congenital diaphragmatic hernia (abdominal organs move into the chest)
- severe forms of neural tube defects (e.g., inoperable spina bifida (malformation of the spinal cord and brain)
- severe form of osteogenesis imperfecta type II (brittle bone disease causing fractures in the womb)
- severe hydrocephalus (excessive cerebrospinal fluid causing brain compression)
- significant chromosomal abnormalities (e.g., Trisomy 13/Patau Syndrome, Trisomy 18/Edwards Syndrome) (multiple organ defects and short life expectancy).

Genetic and metabolic disorders are inherited disorders causing progressive deterioration. They include:

- spinal muscular atrophy (progressive muscle weakness)
- Krabbe disease (fatal neurodegenerative disorder)
- Tay-Sachs disease (leads to neurological decline and early death)
- Canavan disease (fatal brain disorder causing progressive disability.

Severe multi-system syndromes include:

- Meckel-Gruber syndrome (a combination of brain malformations, kidney cysts, and polydactyly)
- Walker-Warburg Syndrome (a muscular dystrophy syndrome with severe brain and eye abnormalities)
- severe cases of Lissencephaly (lack of brain folds, causing developmental delays.

Severe non-lethal but significantly disabling conditions include:

- severe limb-body anomalies such as Tetra-Amelia syndrome (absence of all limbs)
- Harlequin Ichthyosis (severe skin disorder causing thickening and scaling)
- severe cases of Beckwith-Wiedemann Syndrome (overgrowth abnormalities and organ enlargement)
  .

Fetal conditions with a **high risk of intrauterine death or stillbirth** include:

- severe fetal growth restriction
- non-immune severe fetal hydrops (abnormal fluid accumulation in the fetus).

Induction of fetal cardiac asystole (IFCA) before abortion

For abortion after 20 weeks' gestation, clinicians may opt for induction of fetal cardiac asystole (IFCA). This avoids signs of life during the abortion. There are various options:

1. injection of potassium chloride into the fetal heart of the umbilical cord
2. injection of digoxin into the amniotic fluid of the fetus
3. injection of lidocaine into the fetal heart or thoracic area.

Each option has its advantages and disadvantages.

1. The first – potassium chloride – is highly effective, leading to immediate asystole, but significant expertise is required to ensure that the injection is precise and safe.
2. The second – digoxin – has a higher failure rate than the first and requires time for fetal absorption. It is easier to administer and does not require ultrasound if the injection is delivered into the amniotic fluid.
3. The third – lidocaine – is effective, with fetal cardiac cessation occurring about five minutes afterward. Injection into the heart is more difficult than into the thoracic area.

While IFCA is the terminology used by the WHO, the term "feticide" has also been used in medical circles. The latter is a morally loaded term, suggesting the "murder" of the fetus. It is also imprecise as it can refer to the death of the fetus following the pregnant person experiencing physical violence.

RECOMMENDATION

Avoid the use of the term feticide in discussing LTOP with women. While it is important to follow the woman in terms of describing the fetus (baby, child, fetus), "feticide" is not a colloquial term and is unlikely to be introduced into the consultation by the woman herself.

Our study

The main research question focused on in our study was: What are South African women's experiences of IFCA and LTOP due to the presence of severe fetal abnormality, as related by the women themselves and the health service providers who perform the procedure or provide care? Given the paucity of research at the time, we conducted an in-depth grounded theory study to analyze the data. Data collection entailed semi-structured

interviews conducted with 12 women who had undergone IFCA and LTOP procedures between one and five years prior to the interviews, in either the public or private healthcare system in South Africa. Semi-structured interviews were also conducted with 13 healthcare providers. The providers included medical specialists and participants from the fields of clinical psychology, genetic counseling, and nursing who were employed in public or private healthcare in South Africa. Data relevant to public healthcare users and providers were collected from one tertiary (academic) public healthcare hospital, and data regarding private healthcare users and providers were collected from across South Africa.

In the following sections, we use key findings from our study to ground our recommendations for care and support.

Phase 1: Fetal diagnosis and decision-making

Key research findings:

Lelanie (Woman participant):

I don't know because you know at that moment [hearing of fetal diagnosis] you also died. I didn't feel anything. You know people could talk to me. They could do what they want. I didn't register. But I don't know.

Hugh (Clinical geneticist):

I mean the first thing that the mom asks herself after a diagnosis or after an abnormal baby is: "What did I do wrong in pregnancy?"

- Women found the decision to undergo LTOP difficult, conflicted, and amounting to no choice at all.
- The decision-making process was nuanced by women's partners' involvement (or absence), the reactions of the providers during the decision-making process, and the reactions of others in the women's lives.
- Women tried to find explanations for the abnormality, including blaming themselves (behavioral or biological culpability) and supernatural intervention.
- Women used several strategies to protect their well-being: silence, partial disclosure, and re-storying of events (e.g., they had a pregnancy loss or miscarriage).
- Women experienced some healthcare providers as supportive and others as denigrating and coercive.

- Providers said women often reacted with anger, denial, threats, and, sometimes, relief. As above, providers indicated that women blame themselves, often through a lack of understanding.
- Providers saw women as having autonomy to make a choice, whereas women often experienced having no choice available to them.
- Prior to women being presented with the option of LTOP, the possibility is filtered through various institutional committees. Committee decisions are circumscribed by interpretations of the legal parameters as well as individual doctors' personal perceptions of the systemic and medical implications of the decision.
- Providers mostly framed the decision to terminate the pregnancy as "wise."
- Although providers endeavor to present themselves as neutral, uninvolved, ethical, and professional clinicians, their personal perspectives, emotional reactions, and own discomfort with the procedure can affect women's capacity to make fully informed and agentic decisions.

RECOMMENDATIONS

[1] Sensitivity in conveying the fetal diagnosis

- Remain cognizant of the *wantedness of the pregnancy*, irrespective of whether the pregnancy was planned or not.
- Take care in *explaining the fetal diagnosis* and the tests or medical procedures involved in confirming the diagnosis.
- Ensure that the woman *understands causal and prognostic information*; this will assist in reducing her sense of guilt and possible confusion.
- Give *sufficient time* during consultations.
- Structure time, where possible, between disclosing the fetal diagnosis and requiring a decision.

[2] Attentiveness to emotional, cultural, and religious concerns

- Screen for extreme emotional responses and suicidal ideation.
- Include genetic counselors and other mental health professionals, such as psychologists or social workers, from the first phase (not just post-procedural).
- A multi-disciplinary team aids in reducing the responsibility of caring for all aspects of women's experiences.

- Ensure that cultural and religious beliefs are acknowledged and included in the decision-making stage.

[3] Autonomy in decision-making

- Focus attention on the pregnant person as the primary decision-maker.
- Check in with the woman regarding including her partner or family in the decision-making. Follow her lead; do not make assumptions [when women feel empowered to make a decision without coercion, their psychological outcomes are more adaptive than in instances where women did not feel ownership of the first phase].

[4] Controlling the narrative

- Be aware that any re-storying in which women engage (e.g., miscarriage) is a self-protective strategy required in the face of significant stigma and silencing.
- Respect women's narratives and follow their lead in relation to how to story the process.
- Where possible, facilitate women accessing a safe space with other women who have had a similar experience. Peer support can be very beneficial.

[5] Health service provider self-reflection

- Carefully reflect on your own assumptions regarding women in this position.
- Be mindful of the use of (sometimes inadvertent) blaming or stigmatizing language in conveying the fetal diagnosis (e.g., elderly gravida status) as well as during the decision-making process.
- Actively address your own discomfort and distress regarding late termination of pregnancy and IFCA [your mental health is an important foundation for providing care to pregnant patients].

Phase 2: IFCA and LTOP procedures

Key research findings:

Patricia (Woman participant):

When they put the injection [into her abdomen] to stop the [fetal] heart, it was very difficult. Because I wanted to have that baby, but the situation didn't allow me to. And that night I spent knowing that I carry a dead baby. It was very difficult. The following day they induced labour.

Peter (Fetal specialist):

I had to do the feticide in the ward [not in his rooms] and just about everyone was in tears, and the patient, and the gynae, and the nurse and myself. And it, it just is that way. It is not something that you can just do blindly.

- Women experience the IFCA procedure through embodied stillness, with the moment of fetal demise being of particular significance. Grief reactions were described.
- Women's experience of the IFCA procedure and LTOP is affected by the extent to which they were included in the decision-making around methods of fetal demise as well as delivery.
- The delivery (cesarean section or induction) is constrained by the sector (public or private) within which women receive care. Providers indicated that cesarean section (under general anesthetic) protects the women from trauma, while induction conserves their potential future reproductive capacities.
- Reactions to holding or viewing the fetus varied, including fear, shock, adoration, psychological benefits, performing mothering rituals, and confirming the diagnosis.
- Mistaken readings of the legislation, in many instances, constrained access to the fetal remains.
- Providers may feel distressed when performing IFCA and LTOP.
- Some providers doubt their competence in IFCA procedures.
- Providers may experience stigma.
- Providers use strategies to protect themselves from emotional burden include maintaining a professional stance, clinical distancing, self-care and burnout prevention, accessing support, and reliance upon religion.

RECOMMENDATIONS

[1] Provide complete information regarding the method of fetal demise

- Clearly explain how fetal demise will occur and how the woman will experience this both during the IFCA procedure as well as afterward. If fetal demise will take hours, women need to be clearly informed of this and be prepared for the slowing down of fetal movements.
- Ensure that the woman understands that fetal demise will occur prior to delivery and that they will be delivering a stillborn baby.

[2] Include the pregnant person in delivery method decision-making

- Include the woman, as far as possible, in the decision-making process regarding the method of delivering the stillborn fetus.
- Be cognizant of the multiple issues that impact the psychological well-being of the woman, including having a permanent c-section scar as a reminder of the traumatic loss.
- Listen carefully to the woman's wishes regarding minimizing her own physical and psychological suffering during the delivery process.
- Incorporate the latter into your clinical opinion regarding whether surgical delivery or labor induction would be in the woman's best interests.

[3] Accommodate personal preferences during delivery and in-hospital recovery

- As far as possible, accommodate the pregnant person's preferences regarding privacy (single room, closed curtains around her bed, etc.) and the need for family support during and following delivery.
- Prepare the woman prior to delivery that their baby may have certain physical abnormalities and about the possible physical appearance of the deceased baby (color, possible maceration, etc.).
- Follow the woman's lead regarding whether to view or hold the baby. [Women may want to see physical anomalies themselves to validate the fetal diagnosis; this should be encouraged, but only if they wish to do so.]
- Take photographs of the baby or make hands and footprints; keep these mementos in the patient's file if they do not want immediate access to them. [Women may long for such reminders many months following delivery, although, at the time thereof, they may

feel too overwhelmed and traumatized to view the baby or even photographs.]

[4] Prioritize pain management

- Ensure that women receive adequate and constant pain prevention and relief during delivery and well afterward. [The experience of physical pain is amplified by grief and trauma, and there is no risk to a baby in the administration of medication for pain].

[5] Accommodate rituals of motherhood

- Where possible, women should be facilitated in enacting some rituals of motherhood should they choose to (examples include bathing the baby, dressing, and holding the baby).
- If possible, assist with a cooling holder/cot to prevent further distress due to degrading remains.
- Handle the remains with care, e.g., ensure that the baby is carefully clothed/covered [This helps women feel that others also respect the loss of their baby and actively display care towards it].
- If the woman has named the baby, it is helpful to acknowledge this and to use that name.

[6] Enable access to fetal remains

- Women are legally allowed to access their fetal remains irrespective of the gestation of the pregnancy. There is no legal requirement that fetal remains should be disposed of as medical waste.
- Respect women's decision in having a private burial or cremation or, if they would prefer, to hand the remains over for state burial.

[7] HSP debriefing and self-care

- Acknowledge the potentially traumatic and upsetting impact the IFCA and LTOP procedure, as well as the hospital care of women, may have on you.
- Engage in group debriefings with all staff involved.
- Explore further psychological support if required. [A provider who is psychologically well (neither burnt out nor vicariously traumatized) is better able to provide empathetic, engaged health care than one who merely moves through these experiences without reflection and support.]

Phase 3: Recovery following the IFCA and pregnancy termination

Key research findings:

Janet (Woman participant):

When they put the injection [into her abdomen] to stop the [fetal] heart, it was very difficult. Because I wanted to have that baby, but the situation didn't allow me to. And that night I spent knowing that I carry a dead baby. It was very difficult. The following day they induced labour. Obviously, it's the guilt feelings, that's what I must say. For me, it would have been, if I don't want to talk about it, it is because I am still too sad. Because I don't want to open up all the old wounds and have all of these memories back and all those things.

Xenia (Clinical psychologist):

For anyone that [burial] is a closure process. So, there are others that just say, "No, I'm going to bury my baby myself" and they do everything in their ability to get that money together to transport that baby and arrange a funeral.

- Women frequently self-silenced, choosing not to share or selectively disclose their experiences with others.
- Interactions with partners were described as difficult, including emotional disconnection, difficulties with communicating, and different approaches to grieving.
- Women experienced a lack of understanding from others.
- Some women spoke about cherishing reminders of their lost baby, including performing cultural or religious rituals to manage the bereavement.
- Trauma responses presented themselves in women who often wanted to avoid reminders (triggers); these may affect follow-up medical appointment attendance.
- Women feared a repetition in subsequent pregnancies, but some longed for the same (replacement) baby.
- Some women felt like they were "going mad."
- Some women indicated that they had grown during the process.
- The research highlighted a lack of continuity of care, with care tapering off after the second phase. This results in providers lacking insight into women's long-term coping and recovery processes.

- Providers emphasized the importance of women burying their babies to achieve some psychological closure.
- The importance of mental health support during this phase was acknowledged, with providers indicating that screening and referrals for psychotherapy would occur at the six-week check-up.
- Concerns regarding maintaining women's reproductive capacity were prominent among providers. Providers saw their role not only as providing biomedical information about risks but also as giving comfort regarding future possibilities of pregnancy.
- Providers felt that other children mitigated negative consequences.
- Institutional support appeared to be restricted to the six-week follow-up appointment and referral for psychological support.
- Women were often reported to have missed the crucial six-week follow-up, and the lack of institutional resources for follow-up was referenced.

Women experience what is called disenfranchised grief

Disenfranchised grief refers to a tension between a person's private sense of grief and denial of the opportunity to grieve publicly. Perinatal grief associated with miscarriage, stillbirth, termination of pregnancy for medical reasons, or death of a baby in the neonatal period falls into this category.

RECOMMENDATIONS

[1] Language matters

- Due to the influence of stigma regarding pregnancy termination, fetal abnormality as well as stillbirth, providers should be mindful of the language they use to describe these. (Women may describe the experience as pregnancy loss or stillbirth with no observable cause)

[2] Partner and family involvement

- Do not assume that women want to include their partners, children, or other family members in follow-up consultations.
- Do not make assumptions regarding the support women may or may not receive from others.

- Encourage women to reach out to other women they trust, particularly those who have experienced pregnancy loss.

[3] Follow-up appointments

- Acknowledge that women may want to miss their follow-up appointments to avoid reminders of the trauma.
- Navigate discussions regarding causal factors and the likelihood of future pregnancy complications with sensitivity.
- Follow-up appointments should include psychological support and screening for depression and post-traumatic stress disorder. These should occur at six months and one year post-hospital discharge.
- Support groups (in person or online) should be offered to women where possible.

[4] Sick leave and work

- Discuss the amount of sick leave (which would have been maternity leave had they not undergone the LTOP) women require. [Many women prefer to return to work after six weeks in order to return to normality and be distracted from their grief. Others may require extensive leave to recover physically and psychologically.]

[5] Trauma and grief (disenfranchised grief)

- Advise women of the possibility that they may develop complicated grief reactions and may experience symptoms of post-traumatic stress disorder.
- Empower women to identify the symptoms, normalizing them as common reactions. Common symptoms include avoidance of reminders, feeling suicidal, existential conflicts, intense sadness and grief, recurrent thoughts about their loss, recurrent images of the baby or certain aspects of the experience, anxiety, difficulty sleeping, fatigue, poor concentration, forgetfulness, emotional numbness, and intense guilt.
- Provide the woman with contact details for suitable psychological support.
- In all sessions (from phase 1): (a) be non-judgmental, (b) use compassionate language, following the woman's lead in describing the procedure, and (c) acknowledge the loss of both the wanted infant and the future women envisioned.

Conclusion

The diagnosis of fetal abnormality, the decision-making process, the IFCA and LTOP procedures, and the recovery afterward are all underpinned by immensely sensitive and nuanced interactions between the woman and her health service providers. These guidelines have provided some recommendations for healthcare providers involved in this process.

Recommendations for the Department of Health include:

- Design sensitivity training programs for healthcare providers that address women-centered approaches to IFCA and LTOP, as well as acknowledge the detrimental impact of abortion stigma and disenfranchised grief on women undergoing the procedure.
- Address the lack of access to, and availability of, psychological services, particularly for patients using public health care services.
- Address the lack of genetic counselors and clinical geneticists employed in the public healthcare system.
- Ensure that all healthcare providers involved in the procedure and who care for women undergoing the procedure receive routine psychological debriefing and access to psychological support services.
- Ensure that healthcare providers who perform IFCA are adequately trained to do so in order to protect both the patient and the provider from the implications of adverse outcomes and failed or repeated procedures.

Other guidelines include:

- *South African society for ultrasound in obstetrics and gynaecology clinical guidelines.* These are aimed at the multidisciplinary clinical team or hospital committee in deciding on the conditions under which IFCA and LTOP can be offered: www.sasuog.org.za/downloads/SASUOG%20Position%20statement%20on%20late%20TOP%20for%20fetal%20anomalies.pdf
- *National clinical guideline for implementation of the choice on termination of pregnancy act*. This document by the South African Department of Health covers most aspects of comprehensive abortion care but does not include reference to the IFCA procedure or support during this process:www.health.gov.za/wp-content/uploads/2023/04/Termination-Pregnancy-Guideline_Final_2021.pdf

Various hospitals have developed guidelines for fetal conditions that fall within the stipulations of the CTOP Act and the procedures for offering IFCA and LTOP. However, as argued by Kleinsmidt and colleagues[1], these guidelines are not necessarily in line with the CTOP Act or the National Department of Health guidelines. They refer to one such guideline, a Western Cape Provincial Department of Health circular issued in 2019 called the Guideline for the Management of Feticides. The document is no longer available on the Western Cape Provincial website.

1 Kleinsmidt, A., Malope, M., & Urban, M. (2023). Deliberate delays in offering abortion to pregnant women with fetal anomalies after 24 weeks' gestation at a centre in South Africa. *Developing World Bioethics*, 23(2), 109–121. https://doi.org/10.1111/dewb.12387

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