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SPECIAL ISSUE ARTICLE

Deliberate delays in offering abortion to pregnant women with fetal anomalies after 24 weeks' gestation at a centre in South Africa

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Abstract

South Africa has an abortion law which codifies the broad themes of reproductive rights set out in the Constitution of South Africa, other laws and national guidelines. Certain wording of the conditions in the Choice Act for abortion after 20 weeks' gestation, are open to interpretation, being 'severe malformation of the fetus' and 'risk of injury to the fetus'. From 24 weeks onwards, abortion is carried out by feticide/induced fetal cardiac asystole ('IFCA') and subsequent induction of labour in South Africa. Some maternal-fetal units have developed guidelines to assist clinicians and patients in decision-making around eligibility for abortion after 20 weeks' gestation, given the broad terms in the law. We consider the guideline used by an institution in the Western Cape for abortion after 23 weeks and 6 days gestation, in terms of its alignment with the law on reproductive rights and its compliance with fair and transparent procedures. We also note its effect on respect for patients and on staff professionalism.

KEYWORDS
feticide, late abortion, reproductive justice, South Africa

1 | INTRODUCTION

There are some legislative limitations to access to abortion in virtually all countries: in a minority it is completely outlawed, whereas in others it accepted for a variety of specific indications, which may vary at different times in pregnancy. It is a highly contested area, in large part because of its close links to both women's rights and to the prescripts of traditional cultures and religions, which may be in conflict. The international legal and policy environment on abortion is in ongoing flux.

This has also been true in South Africa. In the apartheid era, abortion law was highly restrictive, despite a stated aim to control the growth of the Black South African population, which was instead achieved by promoting 'birth control' using for example long-acting injectable contraceptives.[1]

Following a prolonged freedom struggle, South Africa transitioned to a democratic dispensation in the 1990s, with a constitutional framework. In this system, all laws and policies must conform to the values of the Constitution. Its themes of respect for equality, dignity and access to information and the ethical concepts that flow from them, such as autonomy, informed consent, fair treatment and non-discrimination must be reflected in South African laws and policies.

[1]Hodes, R. (2016). The Culture of Illegal Abortion in South Africa. *Journal of Southern African Studies*, *42*(1), 79–93 at 83.

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South Africa is widely considered to possess an enabling legislative and policy environment for reproductive justice i.e. a bundle of rights consisting of access to abortion, contraception, sterilisation, and adequate prenatal and pregnancy care.

The South African Constitution explicitly refers to reproductive health in its Bill of Rights, in the 'autonomy section' at section 12. The Bill of Rights contains the following provisions supporting reproductive choice and promoting reproductive health:

> Section 12(2): 'Everyone has the right to bodily and psychological integrity, which includes the right…
> (a) to make decisions concerning reproduction;
> (b) to security in and control over their body…'

The Choice on Termination of Pregnancy Act 92 of 1996 (Choice Act) repealed the apartheid-era Abortion and Sterilisation Act in South Africa. It recognises that 'the State has the responsibility to provide reproductive health to all, and to provide safe conditions under which the right of choice can be exercised without fear or harm'.[2]

The Choice Act provides for abortion throughout gestation and specifies grounds for abortion that narrow with increasing gestation. Abortion is available upon demand up to 13 weeks. From 13 to 20 weeks, a medical practitioner must be satisfied that there is a risk of injury to the woman's physical or mental health; or a substantial risk that the fetus would suffer from a severe physical or mental abnormality; or the pregnancy resulted from rape or incest; or the continued pregnancy would significantly affect the social or economic circumstances of the woman. After 20 weeks' gestation, there are further restrictions – that a medical practitioner, after consulting with a second medical practitioner or a registered midwife, must be of the opinion that continued pregnancy would: endanger the woman's life, or result in a severe malformation of the fetus, or pose a risk of injury to the fetus.[3]

South Africa has also developed national guidelines and policies in line with its local and international obligations towards attaining sustainable development goals in reproductive health. The National Clinical Guideline on the Implementation of the Choice on Termination of Pregnancy Act, 2020[4] as well as the National Integrated Sexual & Reproductive Health and Rights Policy were developed to comply with South Africa's obligations to its citizens in terms of the Sustainable Development Goals.[5] The National Guideline states that '(the term) termination of pregnancy is used to ensure a clear alignment with the CTOP Act and refers to legal conditions of termination during the *whole* pregnancy' (italics added).

The National Guideline also sets out its objectives as being to:

- ensure that patients have access to abortion without undue delay
- ensure that patients seeking abortion can make informed decisions
- increase access to abortion services
- ensure that abortion seekers' human rights are respected, protected and fulfilled.

Despite the enabling legislative and policy environment, there are numerous well-documented barriers to access.[6] Abortion and contraception services are free of charge for all women at public healthcare facilities but only about half of all designated abortion facilities are actually operational,[7] and information on where to obtain abortions is hard to find. Women typically have to visit at least two facilities before they find the correct place to have their abortions at state facilities.[8]

The resistance of health professionals and other workers in the sector also undermines access. This includes widespread conscientious objection which is not currently subject to formal regulation, and hostile behaviour from clinical staff.[9] In addition, the anti-abortion movement has launched several legal attempts to overturn all or part of Choice Act.

It should be noted that neither the Choice Act nor the National Clinical Guideline give further detail about acceptable fetal indications for termination of pregnancy after 20 weeks. The requirements in the Choice Act of 'severe malformation' and 'risk of injury to the fetus' after 20 weeks are not specific about which medical conditions are included and lend themselves to different interpretations. Nor does existing legislation or policy address the role of induced fetal cardiac asystole (IFCA), also known as 'feticide'. However, IFCA needs to be considered if the fetus has reached a gestation that is deemed to be potentially viable (in South Africa, this is taken as 24 weeks). Because IFCA introduces technical and psychological complexity to an abortion procedure, for both the healthcare provider and the patient, it may be reasonable to include it as a consideration in the decision to offer abortion or not.

[2]Preamble to the Choice on Termination of Pregnancy Act 92 of 1996.
[3]Section 2*(c)* of the Choice on Termination of Pregnancy Act.
[4]National Department of Health. (2020). National Clinical Guideline for the Implementation of the Choice on Termination of Pregnancy Act. Retrieved November 30, 2022, from https://www.knowledgehub.org.za/elibrary/national-clinical-guideline-implementation-choice-termination-pregnancy-act-2020
[5]See https://sustainabledevelopment.un.org/memberstates/southafrica and also Lince-Deroche, N., Harries, J., Constant, D., et al. (2018). Doing More for Less: Identifying Opportunities to Expand Public Sector Access to Safe Abortion in South Africa Through Budget Impact Analysis. *Contraception*, *97*(2), 167–176.
[6]Favier, M., Greenberg, J. M. S., & Stevens, M. (2018). Safe Abortion in South Africa: "We have wonderful laws but we don't have people to implement those laws". *International Journal of Gynecology & Obstetrics*, *143*(S4), 38–44.
[7]Trueman, K., & Magwentshu, M. (2013). Abortion in a Progressive Legal Environment: The Need for Vigilance in Protecting and Promoting Access to Safe Abortion Services in South Africa. *American Journal of Public Health*, *103*(3), 2.
[8]Constant, D., Kluge, J., Harries, J., & Grossman, D. (2019). An Analysis of Delays Among Women Accessing Second-Trimester Abortion in the Public Sector in South Africa. *Contraception*, *100*(3), 209–213.
[9]Amnesty International. (2017). Barriers to Safe and Legal Abortion in South Africa. Retrieved November 30, 2022, from https://www.amnesty.org/en/documents/afr53/5423/2017/en/. See also Harries, J., & Constant, D. (2020). Providing Safe Abortion Services: Experiences & Perspectives of Providers in South Africa. *Best Practice & Research Clinical Obstetrics & Gynaecology*, *62*, 79-89. Mosley, E., King, E., Schulz, A. et al. (2017). Abortion Attitudes Among South Africans: Findings from the 2013 Social Attitudes Survey. *Culture, Health & Sexuality*, *19*(8), 918–933.

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TOP after 20 weeks for fetal indications is provided at a limited number of expert centres, by a multidisciplinary team. The team is typically led by a fetal medicine specialist who does ultrasound assessments and invasive procedures, and it includes genetics health professionals (medical geneticists and genetic counsellors) who provide the bulk of counselling and discuss the option of genetic testing and options regarding continuation of pregnancy. Decisions about whether the findings warrant the offer of abortion are usually made by the multidisciplinary team. To address the above-mentioned gaps in national legislation and guidelines, teams have in some cases developed their own guidelines, which are approved at institutional or organizational level.

Most severe fetal anomalies are detected in the second or even third trimester, in the context of a wanted pregnancy.[10] For the woman or couple, the decision on abortion is thus a difficult and painful choice whether to terminate the pregnancy or to continue in the expectation of severe disability of the child, potential suffering and a high burden of care.[11] Following non-directive counselling for the woman, a period of time is often required to come to terms with the finding and to make decisions. Women's decisions vary with the anomaly and its implications. They are not very well documented in the South African public health sector setting, but there is evidence that uptake of prenatal testing and abortion for Down syndrome is quite low, whereas for spina bifida as many as 70-80% of women choose to terminate a pregnancy after non-directive counselling.[12]

In summary, while the South African Constitution upholds the importance of both reproductive rights and autonomy of decision-making, national legislation and guidelines do not give detail on the acceptable fetal indications and methods for abortion after 20 weeks' gestation. The development of guidelines within some hospitals and health professional organizations has attempted to address the gap. However, it cannot be taken for granted that guidelines initiated by medical specialists will give due regard to either the ethos of the South African Constitution or the lived experience of women in their care, especially in the context of widespread resistance to abortion amongst health professionals. This calls for the development of broader policy at national or provincial level. We discuss the implementation of a provincial policy on abortion for fetal indications by the Western Cape Health Department and show how, rather than being a solution, it is an example of medical resistance to abortion.

[10]British Pregnancy Advisory Service. (2015). Termination of Pregnancy for Fetal Anomaly. Retrieved October 5, 2022, from https://www.bpas.org/get-involved/campaigns/briefings/fetal-anomaly/

[11]For a family's perspective, see Doward, L. (2021, November 14). The Agony of Choosing Termination for My Baby who had Foetal Anomaly. *The Guardian*. Retrieved November 30, 2022, from https://www.theguardian.com/lifeandstyle/2021/nov/14/choosing-termination-baby-foetal-anomaly

[12]Krzesinski, E., Geerts, L., & Urban, M. (2019). Neural Tube Defect Diagnosis and Outcomes at a Tertiary South African Hospital with Intensive Case Ascertainment. *South African Medical Journal*, *109*(9), 698–703.

2 | CASE SCENARIO

Shortly before the COVID-19 pandemic, the Western Cape Provincial Department of Health issued an official "Guideline for the Management of Feticides" (Circular H146/2019; henceforth called "The Circular").[13] This was sent to the chief executive officers of tertiary hospitals and other facilities in the province, with the expressed purpose "to assist clinicians to perform their duties within the constraints of the law".

The document provides that all cases in which IFCA for fetal indications is under consideration should be submitted to a hospital committee, to be established for the purpose. It outlines a specific process to be followed:

- The health provider should inform the woman/couple of the findings but <u>not</u> the management options available.[14]
- The case should be reviewed by a committee of at least seven members including the medical manager of Obstetrics and Gynaecology, the heads of fetal medicine and nursing, other health professionals (a social worker and specialists in fetal medicine, genetics and neonatology), and if necessary an ethicist, within 48 hours.
- The committee considers the case history and its implications for "prospective disability arising from ongoing pregnancy", any institutional barriers preventing intervention before 24 weeks, and a psychosocial assessment of the client and her immediate support structure.
- The committee makes a decision regarding the offer of IFCA based on "(near) certainty of diagnosis and (near) certainty of outcome" with currently "available standard of care and taking all the specifics of the case into account". It is to be offered if the outcome is expected to include one or more of the following:early death
  - o severe and irreversible deficit in development capacity, "resulting in inability to achieve a reasonable level of self-awareness or…functioning within society or…meaningful interpersonal relationships"
  - o "unbearable pain and suffering…with… a very poor quality of life"
  - o "unreasonable burden of care on the part of the parents or society"
- If IFCA is authorised this will be offered to the woman, through a prescribed informed consent process that requires both a medical geneticist and fetal medicine specialist to be present. Alternatively, if the woman previously requested IFCA but this is declined, the alternative options and the possibility of referral to another tertiary centre will be given.
- Ongoing care and support will be offered.

[13]Circular H146/2019 is appended to the end of this article.

[14]As opposed to the provisions of the National Health Act 61 of 2003 which requires patients to be informed of their treatment options, benefits and risks and mandates patient participation in decisions affecting their health and treatment as soon as possible.

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- The hospital through the provincial health department will indemnify staff regarding any legal action that may arise.

In the Western Cape province there are two tertiary level units that provide prenatal diagnosis. The *status quo ante* was that each unit had its own process for offering abortion after 20 weeks, including abortion with IFCA. The criteria for offering abortion with IFCA differed somewhat between units and were similar to that proposed in the Circular, but the process was simpler. The offer of abortion was based on a collective decision within each unit, which included input from other medical disciplines if required. One unit also had a guideline that had been ratified by their hospital board. This standardised the criteria for the offer of abortion as far as possible and provided for referral to the Hospital Ethics Committee in cases where there was a lack of consensus in the team. This facilitated expeditious healthcare, in contrast to the cumbersome process outlined above.

The latter unit lodged a complaint about the Circular, due to concerns about its content, the fact that there had been no meaningful consultation through provincial structures, and that it conflicted with its existing guidelines. Thereafter it then emerged that neither unit had been involved in drafting the guideline. After a subsequent meeting of all the role players, the Circular was withdrawn at provincial level but remains in force at the other institution.

Closer inspection of the lengthy founding statements of the Circular shows several that conflict with South African law. These include that:

> "ending the pregnancy and ending fetal life are distinctly different interventions....Hence feticide beyond viability requires separate explicit consideration"

> "the 'right to life' (1996: clause 11) can be applied to the fetus and is inferred by the Choice on Termination of Pregnancy Act…"

> "The provisions of the Act insofar as they have reference solely to the interests of the fetus are … only applicable up to the point of viability…"

> "[T]he Constitutional law of South Africa does provide for human rights and constitutional values, among these human dignity and human worth. These values can by inference be held to be applicable to the human fetus, since such a fetus is also part of humanity. These values allow an interpretation that *can be argued to support the existence of fetal rights*." (italics added)

> "[B]ringing competing principles of beneficence and autonomy into reflective equilibrium will require both the physician and the parents to consider their beneficence-based obligations to the fetus and to act in his or her best interests."

3 | DISCUSSION

The emphasis on reproductive justice in South African law is deliberate, considering the role of the law in the past in enforcing racial injustice and inequalities which persist today, including in the country's health sector. The importance of reproductive justice in South African law is a recognition of the socio-economic effects of the lack of reproductive choice on women in society, especially impoverished women who inevitably rely on the state system for health services.[15] Where the Choice Act is silent on the exact meaning of a requirement for access to abortion, in our view, decades of disadvantage and the need to promote women's rights in a constitutional democracy justify a broad interpretation of women's rights to abortion. This is especially so when the decisions have profound long-term effects for women and their families, and are made by health workers whose social context is far removed from those of the patients.[16]

Although the implementation of a formal process for case review prior to offering an abortion for fetal indications appears reasonable, the case scenario raised procedural, practical, ethical and legal issues that, in our view, invalidate it, but also raised concerns regarding the motive for introducing a review committee.

3.1 | Singling out IFCA procedures

The terms of reference of the proposed review board were incorrect in singling out the procedure of IFCA. The Choice Act provides a single set of criteria for abortions after 20 weeks gestation, and the National Guideline emphasizes that abortion is possible throughout gestation, by implication this is irrespective of whether an IFCA procedure is required (usually from 24 weeks) or not. IFCA is simply a part of the abortion procedure in later gestation and is not accorded a separate legal status by the Choice Act. The use of IFCA is therefore a poor reason for compulsory referral to an institutional review board (IRB). On the other hand, factors such as the indication for abortion should obviously be important in decisions to refer, but are assigned only secondary importance by the Circular.

This is not to suggest that IFCA has no importance. In local healthcare, it already requires an additional consent to that for abortion at earlier gestations. This is because it adds an additional step to the abortion procedure, of which a woman should be informed, and it is a step that is potentially psychologically difficult

[15] Albertyn, C. (2015). Claiming and Defending Abortion Rights in South Africa. *Revista Direito*, *11*(2), 429–454.

[16] Kozhimannil, K., Hassan, A., & Hardeman, R. (2010). Abortion Access as a Racial Justice Issue. *New England Journal of Medicine*, *21*(4), 372.

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for her[17] and may have an impact on the woman's choice for or against abortion.

We have argued that a specific focus on IFCA is legally irrational. In addition, the specific focus on IFCA is ethically questionable, because it has significant potential to stigmatise the procedure. The Circular singles out IFCA in a manner that makes it seem morally suspect. This may convey to the patient that her access to abortion with IFCA after 23 weeks and 6 days is not fully endorsed. It is very plausible that this will contribute to stigma, shame or guilt associated with the procedure, when eventually she is informed of her options. Medical professionals who provide IFCA are often wary of the fact that it carries a stigma for the health professional involved,[18] and a focus on IFCA therefore sends the same message to the health professionals involved.

IFCA is portrayed as a unique event in the Circular, requiring specific ethical consideration. The general legal and ethical milieu in South Africa requires promotion of access to safe abortion and protection of the woman's rights. The Circular obstructs and delays access to IFCA by introducing additional, unnecessary processes commonly utilised in countries where abortion after 20 weeks is illegal.

3.2 | Undermining of professional roles

For the fetal medicine specialist, carrying out IFCA for termination of pregnancy requires technical expertise in a procedure that can take an emotional toll, and has been characterised as 'unpleasant and difficult, yet necessary'.[19] A survey of maternal fetal medicine specialists who perform IFCA found that when they were not allowed to 'travel the journey alongside patients', as they put it, their sense of professionalism was undermined and they felt reduced to mere technicians. Their participation in a 'supportive multi-disciplinary environment', 'an ongoing doctor-patient relationship' and 'shared decision-making' were found to be important for their sense of emotional well-being.[20] Maternal-fetal specialists carrying out IFCA at the behest of a committee reported the anxiety of moral distress when they were not involved in the decision-making process and reported feeling 'pushed into a corner' especially when they disagreed with the committee's decision.[21]

The professional role of other members of the prenatal diagnosis team is similarly undermined. The genetics health professionals on the team (medical geneticists and genetic counsellors) are responsible for assessment of the psychosocial context of the pregnancy, as a basis for non-directive counselling and support to facilitate informed decision-making. The Circular requires that this be reprised by a social worker attached to the IRB (see the next section, "Is an IRB a good option?").

Removing the locus of decision-making from the healthcare team and the woman thus has significant potential to undermine the professional role of the team. As such, it requires justification that is consistent with constitutional themes such as respect, dignity and autonomy. It could potentially be justified if there is evidence of health professionals obstructing access to care. No such evidence was provided by the Circular; in fact, the unstated concern seemed to be that unduly broad access was provided, though no evidence was provided for this either.

3.3 | Is an IRB a good option?

Although an IRB appears to allow independent arbitration in an ethically contentious domain, there are several further problems. In addition to those outlined above, there are other practical issues. The need to convene a large committee of senior staff can very easily become inefficient and reduce access to care. Although the Circular specifies that the IRB be convened within 2 days of receiving a referral, it appears that much longer delays have occurred. It is very plausible that delays may result in preterm birth, of a live infant despite criteria for abortion being met and result in women being denied their legal right to an abortion. In addition, unnecessary delays may exacerbate the difficult psychological and emotional issue of being told that 'there are concerns' but with further discussion being deferred. It may be especially difficult for indigent and often disempowered women using state health care in South Africa, who often do not know their rights, how to exercise them, and who are more likely to be afraid of questioning the process.[22]

It is questionable whether an abortion-specific hospital IRB, even if very efficient, and consistent with the Choice Act would be an appropriate solution. These IRBs are usually found in one of two contexts that do not apply in South Africa. In Israel, abortion is allowed as an exception to illegality,[23] and the approval of a committee provides legal protection for the fetal medicine specialists and gynaecologists. In the case of Denmark, abortion is allowed at any gestational age for indications including severe fetal physical or mental defects, but the law provides that a committee must consider the woman's age, working conditions, personal, financial and health status, with the decision subject to an appeal process.[24]

Neither of the above situations pertain directly to South Africa, though there is no denying that the emphasis in the latter example on

[17]IFCA is a lawful part of the abortion process. Govender, L., & Moodley, J. (2013). Late Termination of Pregnancy by Intracardiac Potassium Chloride Injection: 5 Years' Experience at a Tertiary Referral Centre. *South African Medical Journal*, *103*(1), 47–51.

[18]Fay, V., Thomas, S., & Slade, P. (2016). Maternal-fetal Medicine Specialists' Experiences of Conducting Feticide as Part of Termination Of Pregnancy: A Qualitative Study. *Prenatal Diagnosis*, *36*(1), 92–99.

[19]Ibid.

[20]Ibid.

[21]Ibid.

[22]De Crespigny, L., & Savulescu, J. (2008). Pregnant Women with Fetal Abnormalities: The Forgotten People in the Abortion Debate. *Medical Journal of Australia*, *188*(2), 53; Kozhimannil, Hassan & Hardeman, op.cit. note 16, p. 372.

[23]Gross, M.L. (1999). After Feticide: Coping with Late-term Abortion in Israel, Western Europe, and the United States. *Cambridge Quarterly of Healthcare Ethics*, *8*(4), 449–462; Section 94 of the Danish Health Act.

[24]Theibel, S. S., Petersson, B. H., & Christensen, A. V. (2014). Increased Number of Applications for Late Termination of Pregnancy in Denmark. *Danish Medical Journal*, *61*(2), 1–4.

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context is important. However, in our setting the psychosocial context is directly addressed in genetic counselling by the healthcare team and is not a sufficient reason for an IRB process. This is especially so, because in terms of the Circular, the IRB assessment of the psychosocial context is performed by a social worker, who is very unlikely to have any training on the complexities of fetal malformations and their immediate and long-term implications. Interestingly, the Circular permits the social worker to discuss abortion with the patient, after forbidding fetal medicine and genetics professionals from doing so.

3.4 | Right to life arguments

As outlined in the case scenario, the Circular bases its argument for an IRB for abortion cases requiring IFCA on a (somewhat confused and contradictory) notion of a fetal right to life and dignity.

Section 11 of the Constitution of South Africa, the 'right to life' section, is not applicable to the fetus and cannot be inferred from the Choice Act as the Circular tries to do.[25] There is case law to back this up: in the case of *Christian Lawyers v Minister of Health*, there was a challenge to the constitutionality of the Choice Act as being in conflict with the right to life of the fetus.[26] This challenge to the Choice Act was struck down on the grounds, inter alia, that

- the Constitution explicitly grants everyone reproductive rights i.e. control over their bodies without limiting these rights in favour of the fetus or against abortion;
- a child is defined as a person under the age of 18 years and age starts on the day of birth;
- if section 11 – the right to life section – applied to the fetus, legal contradictions would result e.g. the fetus would enjoy the same protection in law as the mother and abortion would be constitutionally prohibited under all circumstances even if the mother's life was in danger or the pregnancy was a result of rape or incest;
- this consequence could not have been intended by the legislator, therefore it was determined that the fetus does not possess a right to life in law.

This point has been extensively canvassed in the case law and in legal literature.[27]

In summary, South African law provides for increasingly narrow conditions for abortion from 13 weeks onward in South Africa. These do not rest on a fetal right to life – however the language of fetal rights has been used recurrently by the local anti-abortion movement in challenges to the Choice Act.

3.5 | Process issues

As previously discussed, there are numerous factors mitigating against women's legal right of access to abortion, but these have not arisen from acts of commission at policy level. This changed when the above-mentioned Circular was issued by the office of the deputy director-general of the provincial Department of Health.

The document was rapidly withdrawn as provincial policy following a complaint from one unit but despite not being legally binding, it was imposed on the fetal medicine group at the other tertiary hospital. The exact origin of the document remains unclear, as a result of the non-transparent process involved, but it appears to have originated from one or more senior figures in the women's health services at that hospital. It is also unclear how the contents of the Circular were initially accepted at provincial level without following the procedural requirements for provincial policy, and how following their withdrawal at provincial level, they remained in force at institutional level at one hospital.

The World Health Organisation (WHO) in a recent document recommends that guidelines should be developed in an inclusive, transparent and consultative process and must conform to the law of the country.[28] Most importantly, the best interests of the patient should be the key consideration in medical guidelines.

It appears that both the process by which the Circular was developed, and the outcomes proposed, fall far short of those recommended by the WHO. Given the facts of the case it appears unlikely this was a simple good-faith error. It seems more likely that powerful individuals in the medical establishment, with beliefs about IFCA and abortion that are at odds with the South African Constitution, were able to manipulate the hospital and provincial policy in a manner that undermines women's reproductive rights and the professional role of the maternal-fetal medicine team.

It is reasonable to ask what underlies this, and we can give no firm answer. South Africans have become accustomed to widespread corruption and maladministration, usually for pecuniary gain and to wield power, often with factional overtones. While there is no obvious pecuniary gain involved in this case, other ingredients of high-handedness and unprocedural conduct are visible. The incident speaks of an entrenched anti-democratic

[25] *Christian Lawyers Association of South Africa v Minister of Health* 1998 (4) SA 1113 (T). The Circular states that 'the right to life… can be applied to the fetus' (punctuation removed).

[26] There have been legal challenges to abortion rights in South Africa and there will no doubt be others. See *Christian League of South Africa v Rall* 1981(2) SA 821(O); *Christian Lawyers Association of SA v Minister of Health* 2005(1) SA 509(T) and *Doctors for Life International v Speaker of the National Assembly* 2006 (6) SA 416 (CC). The African Christian Democratic Party's Private Members Bill (2017) sought, inter alia, to outlaw late abortion for fetal anomalies. In *S v Mshumpa* 2008 (1) SACR 126 (E), where the biological father hired a 'hitman' to shoot the pregnant woman and kill the 38-week old fetus, the crime was found to be attempted murder of the woman, as the fetus lacks legal personhood and therefore is not covered by the definition of murder, the unlawful killing of a person.

[27] Jogee, F. (2018). Is there room for religious ethics in South African abortion law? *South African Journal of Bioethics and Law*, *11*(1), 46; *Christian Lawyers Association* 1998, op. cit. note 25.

[28] WHO Pan American Health Organization. (2018). Strengthening National Evidence-Informed Guideline Programs. Washington DC. Retrieved November 30, 2022, from https://www.paho.org/en/knowledge-translation-and-evidence-program/strengthening-national-guideline-programs

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culture, which perhaps created space for individuals with qualms about access to legitimate abortion after 24 weeks to further their agenda. This is a clear and present danger to women's reproductive rights.

4 | CONCLUSION

The case scenario describes an attempt to impose a policy Circular requiring an IRB for IFCA at provincial level in South Africa. We show that the notion of an IFCA-specific IRB is legally irrational in South Africa. We further contend that any abortion-specific IRB is questionable in our legal and healthcare environment: it undermines the professionalism of the healthcare team, has a high chance to delay and obstruct access to care, and to stigmatise recipients or providers of IFCA (or abortion more broadly).

The founding statements of the Circular argue that there is a fetal right to life. This is false under South African law but is consistent with that used in legal challenges to the Choice Act by local anti-abortion organisations.

The facts of the case highlight a need for transparency when handling policy contentious areas such as abortion and reproductive rights more generally. As such, there is a good case for a formal investigation into the circumstances that led to the publication of Circular H146/2019.

We consider that ethical issues that arise in clinical care related to abortions should, in South Africa, be handled in the same way as those arising in most other areas of healthcare. This provides for efficient care and sends an important signal that abortion care is not an exception to general medical care. More specifically, decisions regarding the offer of abortion and associated counselling should be handled by the prenatal diagnosis team, and ethically difficult cases should be referred to a general Hospital Clinical Ethics Committee with terms of reference that are not confined to abortion. Where tertiary hospitals lack such committees (as most SA tertiary hospitals do) these should be established with some urgency.

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CIRCULAR H146/2019

(Choice Act not included, for brevity. Typographical and grammatical errors remain as in original)

A.1 | EXECUTIVE SUMMARY

Certain fetal abnormalities identified before birth are known to be associated with either inevitable death or poor quality of life. The existence of conditions that lead to suffering are grounds for termination of pregnancy in South Africa and elsewhere. The ethical framework allowing termination of pregnancy to take place also supports the promulgated South African law which permits intervention designed to end pregnancy with escalating regulatory stringency associated with increasing gestational age.

The Choice on Termination of Pregnancy Act is the accepted law governing access to termination of pregnancy up to 12 weeks of gestation for any reason and up to 20 weeks.

Feticide is the injection of potassium chloride into the fetal heart with the intention of ending intrauterine life prior to delivery. Other methods include the injection of lignocaine into the placental end of the umbilical cord or cord occlusion in the case of monochorionic twins. These measures may be deemed necessary in circumstances where delivery may lead to avoidable suffering in the newborn after birth. Termination of pregnancy is currently authorised by the Choice on Termination of Pregnancy Act and contemplates ending the pregnancy if the fetus is at risk of having a severe malformation or where continuation of the pregnancy would pose a risk of injury to the fetus. The wording of clause c) ii) of this Act (TOP after 20 weeks "if continuation of the pregnancy would result in a severe malformation of the fetus") is vogue and the meaning of "severe" is untested in the judicial system and open to wide interpretation. Thus, the law does not prescribe or proscribe feticide. The provisions of the Act beyond the 20th week of pregnancy imply that termination of pregnancy will alleviate the suffering of the newborn by way of allowing delivery under circumstances where survival beyond the neonatal period remain unlikely. The provisions of the Act insofar as they have reference solely to the interests of the fetus are therefore only applicable up to the point of viability, despite the absence of any cut-off gestational age for termination of pregnancy.

Ending the pregnancy and ending fetal life are distinctly different interventions. Ending pregnancy beyond the point of viability (as contemplated in the Act) will have different consequences to feticide carried out beyond the limit of viability. Hence, feticide beyond viability requires separate, explicit consideration prior to any such intervention. 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. The process must be fair, consistent and transparent. Which is best achieved by relying on ethical principles and professional integrity.

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This document provides a guideline to assist the health professionals on whether to suggest feticide to parents and their families when a fetal anomaly is diagnosed, within ethical guidelines, the constraints of the law and the hospital's resources.

A.2 | PREAMBLE

Routine antenatal care together with advances in imaging techniques have resulted in the earlier detection of congenital abnormalities and a better understanding of the natural history and prognosis of such abnormalities; this creates the opportunity for health care professionals to offer termination of pregnancy. In accordance with the law, this can be done up to the age of viability under specific circumstances, but late terminations of pregnancy with or without feticide continue to raise ethical debate in association with advancing gestation. Late terminations are being practiced throughout South Africa although specific aspects of the practice vary between hospitals.[29] Additionally, the law is silent on the matter, leaving interpretation open to the preferences and a value judgement of individuals.

Factors that need to be taken into account include:

- The legislation on Termination of Pregnancy in South Africa
- The value judgement of human suffering
- The ethical and moral obligations

A.2.1 | Legislation governing termination of pregnancy in South Africa

A.2.1.1 | The South African Constitution

The Constitution guarantees basic human rights, including female reproductive rights. These rights protected by the Constitution, include the right to life, privacy, bodily and psychological integrity, dignity, equality, access to information and health care.[30]

These rights together with children's rights, and are recognised as important elements implicit in the establishment of reproductive rights and indirectly, the freedom of choice concerning early and safe termination-of-pregnancy services.[31]

Among these rights, the ‘right to life’ (1996: Clause 11) can be applied to the fetus and is inferred by the South African Choice on Termination of Pregnancy Act,[32] which limits the reproductive choices available to women beyond the first trimester. The rights of the fetus have no influence on the choices made by the women during the first 12 weeks of pregnancy and are partially expressed in the second trimester of pregnancy (between 12 weeks and 20 weeks) and considerably so in the third trimester (after 20 weeks). These limitations to female reproductive rights are based upon assumptions made about the moral status of the fetus at more advanced gestational ages and where ending the life of the fetus may conflict with the constitutional right to life even though the fetus is not a legal person.

South African Statutory Law does not have any legislation 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.

The Constitution of South Africa provides for human rights and constitutional values, among these, human dignity and human worth. This value can be inferred onto the fetus, since they are part of humanity. Using these values allows for an interpretation that can be argued either way for the rights of the fetus.

However, the South African Constitutional Law of South Africa does provide for human rights and constitutional values, among these, human dignity and human worth. These values can by inference be held to be applicable to the human fetus, since such a fetus is also part of humanity. These values allows an interpretation that can be argued to support the existence of fetal rights.

The South African Constitution 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 legal rights on the fetus. This implies that decisions and interventions that affect the fetus have to be taken by another rational person on his/her behalf.

A.2.1.2 | The South African Choice on Termination of Pregnancy Act (Act 92 of 1996)

The Act allows terminations up to and beyond the 20th week of pregnancy. 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 includes a clause allowing that social and economic circumstances need to be taken into account.

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 moral considerations. This highlights the lack of guidance when a feticide may be indicated. This balance of considerations arising has reference to the need to protect the fetus versus the need to protect the rights of the mother, who may exercise her autonomy to the extent that the medical team allows. 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 on 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

[29]Patel B. (2009). A review of the ethical and legal principles used in the decision making process for feticides at seven sites in South Africa. Available at: http://wiredspace.wits.ac.za/handle/10539/7437

[30]The Constitution of the Republic of South Africa. 1996. [online] Available from: https://www.gov.za/documents/constitution/constitution-republic-south-africa-1996-1

[31]Pickles C. (2012). Termination of pregnancy rights and foetal interests in continued existence in South Africa: The Choice on Termination of Pregnancy Act 92 of 1996. Potchefstroomse Elektroniese Regsblad. Vol 15. No 5. Online version ISSN 1727-3781.

[32]The Choice on Termination of Pregnancy Act 92 of 1996. [online]. Available from: www.info.gov.za/gazette/acts/1996/a92-96.htm

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refuse to perform terminations of pregnancy, but they do not have the right to prevent access to such services. This right to refuse care is inferred but not stipulated as a right to conscientious objection in the Act.

Termination of pregnancy and hence feticide for a fetal abnormality may only be considered if there is a substantial risk that the child, if born, would suffer severe physical or mental abnormalities that would result in serious handicap. There is no legal definition of substantial risk. Additionally, the terms 'severe malformation' and 'risk to the fetus' can be interpreted differently by different people, leading to termination of pregnancy for different reasons. The term 'severe' may be interpreted as life-threatening to the fetus or resulting in significant disability.[33] In the some way, 'risk' may be a probability of fetal malformation combined with the possibility that this could be severe in terms of being life threatening.

The term 'risk' includes the possibility that a decision could lead to inappropriate termination of pregnancy because some diagnoses are based on probability. The vagueness of these terms leaves the decision to terminate pregnancy entirely at the discretion of the experience and understanding of the healthcare practitioner.

Decisions made on the basis of probability, could result in an abnormal fetus being born alive because termination of pregnancy has not taken place. This may be cited as wrongful birth where utilisation of the provisions of the act have not been implemented in order to secure preterm delivery and certain death of a child with varying degrees of disability. Claims of wrongful birth and wrongful life have been made in South Africa and may continue to be made under circumstances where increasing application of the res ipsa loquitur principle shift the burden of expected intervention increasingly in the direction of medical practitioners.

Legally, there is also confusion regarding the definition of viability of a fetus. Which is implicit in the definition of 'late' termination of pregnancy. 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.[34] Internationally. The Royal College of Obstetricians and Gynecologists (RCOG), suggest that the management should be in accordance with the British Association of Perinatal Medicine's framework for Practice.[35] 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 off 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.[36]

[33]FIGO committee. (2006). Ethical issues in Obstetrics and Gynecology. United Kingdom: FIGO House. [online]. Available from: http://www.figo.org/docs/Ethics.pdf.

[34]SASOG. [online] Available at: https://www.sasog.co.za

[35]Royal College of Obstetricians and Gynaecologists. (2001). Further issues relating to late abortions, fetal viability and registration of births and deaths. Available from: http://www.rcog.org.uk/index.asp?Page1D=549

[36]British Medical Association (BMA). (2005). Abortion time limits. Part two - Factors influencing views on abortion time limits: Fetal viability, [online].

In the developing world, viability is placed at 27 weeks and 800 grams in estimated fetal weight. These are criteria applicable to babies needing full neonatal intensive care and smaller babies than this may survive despite having limited access to intensive care. Babies born at less than 26 weeks are unlikely to survive without access to full neonatal intensive care. (Personal communication with Obstetricians). However, there are vast disparities in social circumstances within South Africa 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. 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.

A.2.2 | The value judgement of human suffering

Suffering is a universal human experience with both physical and psychological components. As such, its existence requires no further delineation other than to state pain requires perception in the absence of which there is no sentient life. In general, we have interest in avoiding suffering but also have the certain knowledge that some suffering will be unavoidable. In that respect we all understand that death is part of life and although we may seek ways to alleviate suffering associated with that event we will nevertheless need to accept at the very least some psychological pain and likely elements of physical distress as well.

Life lived in the absence of human sensory and physical amenities may be viewed as less than complete and those affected seen as suffering to a greater or lesser extent. Disabled people may be judged by fully functional human beings as having lives less worth living than themselves because they cannot conceive of a life in which one attribute or another is diminished or missing altogether. In some circumstances predicted disability is taken as grounds cited in support of termination of pregnancy based upon the apparent desire to obviate the suffering of others. There are some parents who will decline a termination of pregnancy while knowing that their child will be born with physical and intellectual impairment and will also likely live far less than an average lifespan. Yet others may choose to argue that such a life is not without meaning and still worth living. It is evident therefore that the perceptions of those called upon to witness the suffering of others is material to their moral judgements which are made not only on the basis of reason but an amalgam of value judgements that are both perceptual and emotional in content. It is therefore important to interrogate not only our reason when reaching conclusions about having to witness the suffering of others but also the content of our emotional responses to such circumstances.

In deciding whether others who are disabled have a life worth living or not, some of the moral considerations that call us to account will be concerned with our desire to minimise suffering while maximising happiness. Whether a fetus facing foreseeable childhood disability should not live because it faces some degree of suffering relative to our own existence is unclear: a sentient (even partially

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sentient) life may bring rewards and happiness that outweigh some suffering caused through disability although there is no calculus for such value judgements. Any consideration of a moral position with regard to these circumstances may be further confounded by the need to take account of all the role-players, including the parents and others, who will be involved in providing care to a disabled person.

A.2.3 | Ethical considerations on termination of pregnancy following feticide beyond the point of viability

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 limited-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
6) the laws that guide these decisions.

The ethical arguments concerning termination of pregnancy generally revolve around the moral and legal status of the fetus. For some, the basis of this arises from religious conviction while others have secular concerns. Various dividing lines have been suggested which identify the point at which the fetus is assumed to have a moral status and when it should be regarded as having the same rights as a person. Certain secular arguments are that 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.[37] 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.[38] However, these characteristics by themselves do not confer personhood; viability is the gestational age at which the fetus can maintain an independent vegetative existence outside the uterus, which is at 24 weeks (1). This should only relate to the biological factors that allow the fetus to survive but ongoing technological advancements allow survival from an earlier age, thereby making viability a less plausible as a criterion of personhood.

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. 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.[39] This benefit should extend towards promoting the health of the pregnant woman as well as the fetus.

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, nonaggressive management, the option of doing nothing, or termination of the pregnancy with feticide. The discussion should also include the probability of the diagnosis and the possible outcomes in order for her to make an informed decision.[40] 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. However, bringing competing principles of beneficence and autonomy into reflective equilibrium will require both the physician and the parents to consider their beneficence-based obligations to the fetus and to act in his or her best interests.[41]

While the most important part of the management of these patients rests on obtaining an informed consent from the parents after explaining all the treatment options, there also 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 may be 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 the 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 provided after delivery
- Offer pregnancy to continue, and full care provided after delivery.

While these obligations act as a guide to offering the parent(s) treatment options that are available within the law, taking into account the ethical considerations and the likely expected outcome

[37]Strong C. (1992). An ethical framework for managing fetal anomalies in the third trimester. *Clinical Obstetrics and Gynaecology*, *35*(4), 792–802.

[38]Paintin, D. (2002). Ethical issues in Maternal-Fetal Medicine. *Journal of the Royal Society of Medicine*, [online], *95*(7), 371–372, Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1279947

[39]Chervenak et al. (2003). Ethical issues in the management of pregnancies complicated by fetal anomalies. *Obstetrics and Gynecology Survey*, *58*(7), 473–83.

[40]Chernevak, **F.** A., McCullough, L.B. (1990). An ethically justified, clinically comprehensive management strategy for third-trimester pregnancies complicated by fetal anomalies. *Obstetrics and Gynecology*, *75*(3), 311–316.

[41]Chernevak, F. A., McCullough, L.B. (1985). Perinatal ethics: A practical method of analysis of obligations to mother and fetus. *Obstetrics and Gynecology*, *66*(3), 442–446.

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of the fetus, all possibilities need to be discussed with them and their final decision should be respected.

A.3 | GUIDELINE

Practitioners needing to provide care in this environment are required to comply with the law unless they have compelling moral reasons not to do so. Such exemptions are accepted and practiced in relationship to the abortion law and no-one is required to become morally complicit in the actions of others.

The question to be addressed then is whether there are sufficient moral grounds for endorsing deliberate acts of feticide and under what circumstances those criteria can be applied. Based upon the prior discussion it is clear that two different situations may be evident during pregnancy: the first occurs when fetal abnormalities are identified leading to inevitable death sometime after birth. The second circumstance is that of finding fetal abnormalities that may lead to the birth of a child facing a lifetime (however long) of impaired existence which may be sufficiently restrictive to lead some to consider life not worth living.

The following procedure will be deemed necessary for any feticide or late termination of pregnancy for a fetal abnormality contemplated beyond 23 weeks and 6 days gestation and will be engaged before any counselling about feticide takes place with the parents of the baby:

1. Ultrasound investigations confirm a congenital abnormality

- The parents must be told that there are some concerns with the findings on the scan.
- The finding must be explained to the parents, but no options are to be presented until this has been discussed and a consensus view is made.

2. An institutional review committee will be established, whose representation will consist of:

- Medical Manager for Obstetrics and Gynaecology (ex officio)
- Head of Clinical Unit (ex officio)
- Head of Maternity Nursing division (or appointed representative)
- Representative(s) of the Fetal Medicine Unit other than the HCU
- Geneticist
- Neonatal sub-specialist(s)
- A social worker from the Maternity Centre
- An ethicist (if available), if no other representative of the panel has formal training in bioethics.
- The institutional review committee will be asked to meet urgently (Within 48 hours) to discuss the case.

No person(s) outside of the invitees should be present unless authorised by the Chair. All proceedings must be documented, treated as confidential and stored for a minimum of 10 years.

3. The evidence presented to the committee will include the following:

- A case history to be presented by the Fetal Medicine consultant
- A discussion of the prospective disability arising from an ongoing pregnancy.
- A description of any institutional barriers preventing intervention before 24 weeks gestation
- A psychosocial assessment of the client and her immediate support structure which may be presented to the committee. This support will remain ongoing after agreement has been reached that the intervention should be offered.

4. Considerations to be made by the committee

There must be (near) certainty of diagnosis and (near) certainty of outcome and the expected outcome (with currently and realistically available standard of care and taking all the specifics of the case into account, including the impact on outcome by a combination of different anomalies) is one (or more) of the following:

- Early death in spite of currently and realistically available standard of care (these can be seen as "no chance" conditions, where active intervention is regarded as futile since it often only prolongs suffering with little or no benefit in terms of long term survival (suggested definition of "virtually lethal":> 90% death in infancy)
- Severe and irreversible deficit in developmental capacity, with one or more disabilities (intellectual, visual, hearing, physical), resulting in inability to achieve a reasonable level of self-awareness or reasonable level of functioning within society or inability to develop meaningful interpersonal relationships (conditions for which active intervention is regarded as futile since it often only prolongs suffering with little or no benefit in terms of developing the capacity to experience human life in a meaningful way).
- Unbearable pain and suffering on the part of the child, in order to survive, with at best a very poor quality of life being anticipated.
- Unreasonable burden of care on the part of the parents or society when an unreasonable amount of medical care will be needed to ensure a reasonable quality of life, which is deemed unfeasible within the current context of available services and resources (this can be specific to the individual family unit and could include conditions with fully dependent ultimate performance). The assessment of whether the burden of care is deemed unreasonable is determined by a multidisciplinary team including a subspecialist knowledgeable in the specific anomaly/anomalies and, when needed, a clinical social worker.
- Conditions for which neonatologists and paediatric subspecialists generally only offer palliation and comfort care (but no curative intervention) or for which they would have a low threshold for withholding or withdrawing active intervention, will generally be regarded as being suitable for late TOP. The prognosis of a condition is often worse when detected prenatally instead of

postnatally however and the best evidence from the prenatal literature will guide the ultimate decision.

5. All decisions will be made on the basis of:

- Legal considerations arising from promulgated law
- Moral considerations
- Specific considerations related to the case in question

6. Decision making and implementation will be based upon:

- More than a two thirds majority vote (at least 5 members) in favour of the intervention
- Following authorisation, the deliberations leading to a particular outcome will be documented and signed by all members present at the meeting.
- The procedure, if authorised, will be offered to the parents and informed consent obtained.
- Where access to a prior requested intervention is denied, alternative measures will be explored following counselling.
- Such alternative measures will include giving the parent(s) on option to be referred to another tertiary public health institution for re-consideration if so requested. This referral decision will only be made by the institutional review committee.

7. The hospital, through the Province, will indemnify its staff from any action arising from authorised intervention:

- Provided the action happens in accordance with the committee decision.
- Conscientious objection to involvement will be noted and accepted.
- This guideline will be subject to annual review and amendment in accordance with changes in the Law. Consideration will be made on a case by case basis depending on the circumstances of the legal challenge.

8. Audit, Control and review mechanisms:

- The management team will conduct an audit annually to ensure that the committee is functioning appropriately.
- The audit will monitor if the guidelines are being followed, that the committee is representative and that the decisions are conveyed to the patients in a proper manner to allow for an informed decision.

9. Informed consent:

- Before initiating the procedure, the parent(s) must be counselled on the condition and the treatment options.
- The parent(s) must be allowed time to discuss this between themselves. other family members, religious leaders, etc.
- Once a decision is made by the parents, on explanation of the procedure must again be made to the parent(s) and written informed consent must be obtained from the patient, preferably in the patient's handwriting stating what had been explained in her understanding.
- Both the geneticist and Fetal Medicine Specialist must be present when toking such consent.
- Information given to the parent(s) must be factual, properly noted in the folder and in a language that the parent(s) understands in order to allow for an autonomous decision on their part.
- If the parent(s) refuse the presented option, then the decision must be accepted.
- All decisions must be respected irrespective of the healthcare providers beliefs or clinical judgements

10. Ongoing care

- Following the acute intervention, counselling services must be provided/offerred to the parent(s) for support and future pregnancy planning.
- Counselling services must also be provided/offerred to the parent(s) who decline the procedure, for support and future pregnancy planning.
- This includes a 6-week follow up appointment with the clinical geneticist for karyotype or post mortem results as well as debriefing.
- The psychologist and social worker will avail themselves for support to the parent(s) at anytime after the delivery as well as at the 6-week appointment.

H146/2019: CLINICAL GUIDELINES

Feticide could be considered for the following conditioned: (NOTE: These are merely guidelines of the types of conditions where feticide can be done, but the multidisciplinary discussions and joint decision making with informed consent are paramount to performing the procedure). Each case is to be considered individually.

Group 1:

Conditions that will always qualify for offering late TOP, irrespective of gestation and presentation.

Group 2:

Conditions that will qualify for offering feticide only in individual cases that meet certain severity criteria (severity in the individual can be determined with acceptable accuracy).

Group 3:

Conditions that will generally not be considered for feticide.

Group 4:

Conditions that do not meet strict criteria for group 1 and 2 but where individual characteristics of the anomaly or may constitute significant aggravating factors warranting further assessment for an individualized decision.

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