

Healthcare service provision for parents who terminate a pregnancy following fetal anomaly diagnosis in countries where abortion is criminalised

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Background & Rationale

Global development goals relating to the sexual and reproductive health of women stress the importance of promoting equal access to education and services, and empowering women to make informed decisions and take control of their fertility (UN, 2015); sentiments which are echoed in current UK maternity strategies (DOH, 2012). The attainment of these goals is hindered by a number of factors including limited and unequal access to safe abortion on a world-wide scale. Currently, 42% of the world's women live in the 125 countries in which abortion is criminalised (Guttmacher, 2017). Northern Ireland is one such country where abortion is permitted only in cases where the woman's long-term physical or mental health is impacted (Dyer, 2016). Therefore, in countries like Northern Ireland, when parents are presented with a fatal or life limiting diagnosis of fetal anomaly at routine scans their choices are limited to continuing with the pregnancy in the knowledge that their child will die before or soon after birth, or be born with severe disabilities; seeking an unsafe abortion in their country of origin; or travelling abroad to have a termination.

Fetal anomaly diagnosis and perinatal death is associated with post-traumatic stress and long-term psychological and emotional distress for mothers, and a growing body of research reports the healthcare experiences and needs of women who terminate pregnancies following prenatal diagnosis (Asplin., 2014; Sullivan & de Faoit, 2017; Korenromp et al., 2005; Coleman, 2015; Nazaré et al., 2014; Kersting & Wagner, 2012). Little is known, however, about the healthcare experiences and needs of women who experience abortion following prenatal diagnosis in countries such as Northern Ireland where abortion is criminalised, and there is a particular dearth of research on the experiences and needs of fathers in this regard. Possible complicating factors for these parents include the additional trauma of being away from home and loved ones during this difficult time; not being able to rely on the emphatic support of known healthcare professionals; fragmented care and limited aftercare in their country of origin; social isolation and associated stigma and taboo; stress associated with having to organise the abortion themselves; and possible financial hardship associated with the costs of abortion and travel.

If we are to ensure that these parents receive equitable access to safe and appropriate healthcare, as outlined in global development goals and UK policy, there is an urgent need for research which examines their healthcare experiences and needs in-depth. The proposed study will aim to address this gap in research knowledge and is novel in two respects. First, it will examine the specific healthcare experiences and needs of parents who terminate a pregnancy following fetal anomaly diagnosis in a context where abortion is criminalised. Second, it will uncover the seldom documented healthcare needs of fathers in this respect. Improvements in the provision of healthcare services to parents who experience a fetal anomaly in countries where abortion is criminalised would have the potential to impact on long-term psychological outcomes for this vulnerable population. The findings will have implications for health service reform in Northern Ireland and international applications in the 61% of countries around the world that do not permit abortions in cases of fetal anomaly (UN Population Division, 2002) and in others where women seek unsafe abortion because of stigma and unequal access to services.

Aims and Objectives

The study aims to identify the healthcare needs and experiences of parents who terminate a pregnancy following fetal anomaly diagnosis in a country where abortion following fetal anomaly is not permitted.

The study will meet the following objectives:

- Conduct a systematic review of the international literature, identifying promising service provision models and gaps in evidence;
- Explore the healthcare experiences of parents, paying particular attention to the less understood needs of fathers;
- Identify parents' healthcare needs;
- Record the experiences and needs of healthcare professionals working with this group of parents;
- Record the views of parents and professionals on promising service provision models identified in the literature; and
- Make recommendations for intervention development, clinical practice and policy reform.

Methods

The proposed research is an exploration of parents' healthcare experiences and needs incorporating a systematic review of the literature and primary qualitative research with women, their partners and healthcare professionals.

SYSTEMATIC REVIEW

Relevant reviews and primary research reporting the healthcare needs and experiences of parents who have an abortion following prenatal diagnosis in countries where abortion for fetal anomaly is not permitted will be located by searching electronic bibliographic databases for published work; grey literature for unpublished work; trial registers for recently completed trials; and the reference list of published studies. Studies will be assessed for quality and we will use the PRISMA Statement (Moher et al., 2009) as a guideline for reporting the review findings.

PRIMARY RESEARCH

Thirty women and their male partners will be recruited to the study. Parents will be recruited via advertisements placed in relevant online forums and with voluntary organisations. Snowball sampling will also be considered. Ten healthcare professionals including consultant obstetricians and bereavement midwives working in Health and Social Care Trusts and private clinics will be recruited via letter of invitation.

Data collection will involve in-depth semi-structured individual and (in the case of parents) paired interviews. Interviews will be audio-recorded, anonymously transcribed and subjected to inductive thematic analysis.

Ethical approval for research with parents and private clinic staff will be sought from Queen's University Belfast and approval to approach NHS health professionals will be sought from the relevant Health and Social Care Trusts and the Office of Research Ethics Committees Northern Ireland.

Research timetable

Year 1 will involve preparation of research documentation; ethical approval applications and publication of a systematic review of the literature. *Year 2* will include identification and recruitment of the sample; data collection and analysis and publication of findings. *Year 3* will involve further data analysis, publication of findings and thesis write-up.

Project Management

The project will be closely supervised by Dr Áine Aventin (Queen's University Belfast) and Prof Mark Tomlinson (Stellenbosch University South Africa) who have a strong track record of delivering high quality, policy relevant research to time. The supervisory team will meet weekly with the student for the first two months of the project and thereafter fortnightly.

Clinical Links and Collaborations

The project will take place in the context of a broader programme of work led by Dr Áine Aventin exploring the healthcare needs and experiences of families who have experienced fetal anomaly and stillbirth. At the outset of the project the PhD student will join a Project Advisory Group which includes midwives, obstetricians, representatives from relevant statutory and voluntary organisations and parents who have experienced fetal anomaly.

References

- Asplin, N., Wessel, H., Marions, L., & Öhman, S. G. (2014). Pregnancy termination due to fetal anomaly: Women's reactions, satisfaction and experiences of care. *Midwifery*, 30(6), 620-627.
- Berer, M. (2017). Abortion law and policy around the world: in search of decriminalization. *Health and human rights*, 19(1), 13.
- Coleman, P. K. (2015). Diagnosis of fetal anomaly and the increased maternal psychological toll associated with pregnancy termination. *Issues L. & Med.*, 30, 3.
- DoH (Department of Health for Northern Ireland). (2012). Maternity Strategy for Northern Ireland 2012 - 2018. Available at: <https://www.health-ni.gov.uk/publications/strategy-maternity-care-northern-ireland-2012-2018>
- Dyer C. Abortion in Northern Ireland: is change on the cards? *BMJ* 2016;352:i629. doi:10.1136/bmj.i629.
- Guttmacher Institute (2017). Abortion Worldwide: Uneven progress and unequal access. Available at: <http://clacaidigital.info/bitstream/handle/123456789/1114/abortion%20worldwide%202017.pdf?sequence=5&isAllowed=y>
- Kersting, Anette, and Birgit Wagner.(2012). "Complicated grief after perinatal loss." *Dialogues in clinical neuroscience* 14.2, 187.
- Korenromp, M. J., Christiaens, G. C. M. L., Van den Bout, J., Mulder, E. J. H., Hunfeld, J. A. M., Bilardo, C. M., ... & Visser, G. H. A. (2005). Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study. *Prenatal diagnosis*, 25(3), 253-260.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2010). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *International journal of surgery*, 8(5), 336-341.
- Nazaré B, Fonseca A, Canavarro MC. Trauma following termination of pregnancy for fetal abnormality: is this the path from guilt to grief? *Journal of Loss and Trauma* (2014);19(3):244–61. doi:10.1080/15325024.2012.743335.
- Sullivan, N., & de Faoite, E. (2017). Psychological Impact of Abortion due to Fetal Anomaly: A Review of Published Research. *Issues L. & Med.*, 32, 19.
- UN (United Nations). (2015). Transforming our World: The 2030 Agenda for Sustainable Development. Available at: <https://sustainabledevelopment.un.org/post2015/transformingourworld/publication>
- UN (United Nations). (2002). United Nations Population Division. "UN Population Division issues updated study on abortion policies" Available at: <http://www.un.org/esa/population/publications/abortion/pop830.pdf>