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Conducting research in a sensitive area

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A researcher's reflective account of the joys and pitfalls of doing research on termination of pregnancy for fetal abnormality

Tags: teaching and learning, work and practice

Short introduction

Perinatal loss has received widespread coverage with the Baby Loss Awareness Week that took place in October 2018. But what is it like to do research in such a sensitive area? This article offers a researcher's reflections on the joys and pitfalls of conducting research on pregnancy termination for fetal abnormality.

Introduction

The UK Baby Loss Awareness Week took place in October (9-15th October) for the 17th time running. As parents came together to commemorate the lives of their babies, a cross-party group of MPs initiated a debate in the House of Commons about baby loss and the care provided to parents. These initiatives complement the work currently undertaken by the National Bereavement Care Pathway, whose mission is to devise a care pathway for parents who have lost a baby during pregnancy or shortly after birth. On the media side, perinatal loss has also received widespread coverage, as documentaries on BBC and Channel 4 on stillbirth illustrate. In a context in which perinatal loss is increasingly talked about, it is topical to turn our attention to the subject of what conducting research in this field may involve. My aim, in this article, is to provide a reflective account of my experience as a researcher in a particular type of perinatal loss: termination of pregnancy for fetal abnormality (TFA). I will discuss the specificities of TFA and what makes TFA a particularly sensitive topic. I will then provide a commentary on the joys and pitfalls of conducting research in this area.

Specificities of TFA

TFA represents 2% (n = 3,158) of all terminations in England and Wales (Department of Health, 2018). It is more common than stillbirth (n = 2,873 [Office for National Statistics, 2017]) and its prevalence has risen by almost 50% in the past 10 years (Department of Health, 2008-2018). This is mainly due to developments in prenatal diagnosis technologies, which have led to earlier detection of more abnormalities, and increased maternal age, which is associated with increased rates of fetal abnormalities.

TFA shares many characteristics with other perinatal losses such as miscarriages, stillbirths or neonatal deaths. In all cases, parents lose a child before birth or at the very early stage of life, and the loss occurs at a time when people would, in theory, rejoice. Furthermore, although the baby may be 'very real' to parents, he/she remains an abstract entity for those around them. Yet, TFA also fundamentally differs from other perinatal losses because it is

the result of parental choice. The decision to terminate the pregnancy is itself complex and some parents report experiencing guilt and self-blame as a result (Nazaré, Fonseca, & Canavarro, 2014). TFA is also different from termination for non-medical reasons as the pregnancy is, in most cases, wanted.

TFA can have negative, long-term psychological consequences for women, with many displaying high levels of perinatal grief post-TFA (Lafarge, Mitchell & Fox, 2013), whilst others experience depression, complicated grief and posttraumatic stress (Wool, 2011). TFA may also negatively impact upon the psychological wellbeing of women's partners and alter family dynamics (Robson, 2002). TFA can also negatively affect women's experiences of subsequent pregnancies (Rillstone & Hutchinson, 2001), their relationship to the baby and the baby's development (Alexandre et al, 2015).

In addition, TFA has social implications. It can be stigma-bearing because it is linked to the wider, polarised, abortion debate. Many women who have undergone TFA choose not to disclose that they have terminated their pregnancy for fear of being judged (Hunt et al, 2009). They are keen to distance themselves from the pro-life *versus* pro-choice abortion debate and tend not to regard their experience as an abortion (Fisher & Lafarge, 2015), which illustrates the stigma surrounding abortion.

The fact that the pregnancy is terminated on the grounds of fetal abnormality also results in TFA being linked to the eugenics debate. This debate is underpinned by the coexistence of prenatal diagnosis, which could be regarded as aiming to prevent disability, and the drive for social integration of people with disability (Ville, 2011). Fundamentally, it raises the issue of whether prenatal diagnosis and pregnancy termination on the ground of fetal abnormality is discriminatory towards people with disability. So, what is it like to conduct research in a sensitive area such as TFA? What have been the joys and pitfalls?

Conducting research on TFA

There have been many joys

Collecting data has been a major highlight. My research has involved collecting data from women who had undergone TFA, and I have had the privilege to encounter beautiful stories, some very sad but some also uplifting. Anecdotal feedback from women has indicated that women were grateful for the opportunity to share their stories and that, for some, the process of talking to me had helped them process their loss. If women have benefited from talking to me, I have benefited from their stories too. I have learnt a lot about human resilience and the many ways to adjust to TFA. I have learnt that personal growth can coexist with distress, that some women still feel raw years after the termination, whilst others feel inadequate if they are not overwhelmed with grief.

During my journey, I also met individuals who dedicate their professional life to helping women and their partners. These include health professionals working in fetal medicine. As part of a project on the practice of prenatal diagnosis, I was lucky enough to gain access to fetal medicine consultations. As I waited in busy corridors, I was struck by the frantic pace at which these health professionals were working, and later, I was humbled by the significance of the decisions they had to make and the skilfulness of the medical acts they performed. I was struck by their humanity and desire to get the best outcomes for that particular woman or couple. I also met individuals working in support organisations who spent time talking to women and their partners, helping them to make decisions and come to terms with these, as well as lobby policy makers.

Ultimately, the research I undertook has been and continues to be meaningful to me. If my research can contribute, in any way, to helping women navigate the challenging field of prenatal diagnosis and the difficult experience of TFA then, I have achieved my goal.

What have been the pitfalls?

The first one is ethics. Whilst I adhere to and agree with strict ethical guidelines in research, the process of obtaining ethical approval for sensitive topics can be protracted. The research project, mentioned above, which involved observations of fetal medicine consultations required NHS ethical approval. I was not asking permission to interview women, I was requested permission to be in the consultation room. Yet, it took me over six months to obtain ethical approval, after my application had been initially rejected by the panel on the grounds that the research might be too upsetting to participating women. I had to dispute the assumption that women who find themselves in potentially stressful situations (although most cases do not result in negative outcomes) are, somehow, unable to give consent. I also, privately, argued that refusing to grant me ethical approval for research that may benefit women would be unethical although, of course, I did not share my thoughts with the panel.

Another pitfall lies in the fact that because TFA is a challenging topic, it attracts strong opinions. I recall the time when I had an abstract accepted for an oral presentation to a conference outside the UK only to be told, two weeks before the conference, that the committee had decided to withdraw my paper because they feared local protests. I have also encountered comments about my research, some of these openly questioning 'how could women do something like this'. This issue may also apply to research funding. As a niche, potentially stigma-bearing topic, some funders may be reluctant to fund TFA research.

Finally, being an emotionally challenging topic, TFA may impact upon researchers' wellbeing. Over the years, I have been exposed to many sad stories, stories of loss: of a pregnancy, of a baby, of the dreams that accompany it, of innocence, of previously held-dear values (e.g. pro-life values or beliefs in a 'just world'), of relationships. Collectively, these stories have had an emotional impact. Another challenge lies in what I would call researcher's compassion fatigue. A plethora of articles have focused on compassion fatigue

amongst health workers, social workers, community staff and carers, but none amongst researchers. Yet, I realised this had happened to me when I found myself desensitised to the stories I was reading. This sends a clear signal that taking a break is imperative, because if you are no longer engaging with your data, you are no longer doing good research.'

Conclusion

Conducting research on TFA is extremely rewarding, but also very challenging. Still, to me, the positive aspects clearly outweigh the negative, and whenever I feel myself thinking of other research topics I could get involved with, none seem quite as riveting as TFA.

Although the topic of TFA may be uncomfortable for some, it is worthy of research precisely because it is a sensitive area, and because it is still a misunderstood and stigma-bearing phenomenon. However, it is essential to approach it in a non-judgemental way, whether it is with research participants, professionals, academics or the public, and accept that TFA can trigger strong emotions.

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