Memorandum 8

Submission from Ruth Graham et al, Newcastle University

Inquiry into scientific developments relating to the Abortion Act 1967

This memorandum has been prepared as a submission to the Select Committee on Science and Technology Health’s inquiry into scientific developments relating to the Abortion Act 1967 by Ruth Graham, Stephen Robson, Judith Rankin - Newcastle University (School of Geography, Politics and Sociology; School of Surgical and Reproductive Sciences; Institute for Health and Society) and Helen Statham – University of Cambridge (Centre for Family Research). Prior experience in research on late termination of pregnancy following prenatal diagnosis of a fetal anomaly and feticide exists within the author group: (1) Robson, Rankin and Graham have worked together previously on the topic of feticide; and (2) Statham has worked with other researchers on late termination of pregnancy. Both groups have investigated parents’ and health professional perspectives but worked within a limited number of specialist centres. The findings presented here are drawn from an ongoing project which has allowed the authors to work collaboratively on these topics. The results described below represent preliminary and interim findings from an ongoing survey of all UK fetal medicine sub-specialists’ views on late termination of pregnancy after the identification of a fetal abnormality, and the subsequent practice of feticide in some cases. This submission relates to question 1(b): whether a scientific or medical definition of serious abnormality is required or desirable in respect of abortion allowed beyond 24 weeks.

Summary of recommendations/findings

Professional discretion in making decisions about the provision of late termination of pregnancy for fetal anomaly can be perceived as problematic by some lay commentators and by some within the medical profession. However, the responses of the majority of the specific clinical community that provides these services suggest that it may be more problematic to reduce the level of their professional discretion in deciding which cases fall within the legal criteria for late termination of pregnancy.

Introduction

1.2.1 The ongoing study draws on the experiences and insights from earlier studies conducted independently by both research groups. Brief details of the studies are provided here, for information. Important contextual issues relate to the timing of these previous studies. The data collection for that of Statham and colleagues preceded the legal challenge to how UK abortion law is enacted when Jepson argued that termination for cleft palate at 28 weeks gestation did not meet the criterion of ‘a substantial risk of serious handicap’ for legal abortion at that gestation. This study also preceded amendments to RCOG guidance on how to undertake late terminations and feticide. In contrast, the data collection for the study involving Robson, Rankin and Graham was undertaken in 2004-2005, after the challenge had been made in 2003, and after professional guidance on feticide had been clarified in 2001.
1.2.2 Prior research. H Statham, in collaboration with Wendy Solomou and Josephine Green

Our paper ‘Late termination of pregnancy: law, policy and decision-making in 4 English fetal medicine units’ was recently published in the BJOG and a copy is attached (Appendix A (not printed)). This paper explored UK abortion law which allows terminations for fetal abnormality without gestational limit, the professional guidance around the formation of policy concerning late abortion and individual decision-making about the provision of this service within the existing legal framework. The study was qualitative and data derived from semi-structured interviews with 15 doctors and midwives working in 4 English fetal medicine units and the Director of a related voluntary sector group. In summary, we reported our findings as: 1. Fetal medicine specialists acknowledged the difficulties of ensuring that they worked within the law and within their own ethical frameworks when making decisions about offering terminations after viability. 2. Practice regarding which abnormalities meet the legal criteria appeared to be governed largely by consensus between colleagues within their own and other units and in discussion with other specialists. 3. Study participants reported individual differences about abnormalities where they personally would not wish to be involved in a termination. 4. Participants also noted a shift in general attitudes over time as to conditions that were believed to meet the legal criteria. 5. A proscribed list of conditions where termination would or would not be allowed under Clause E at gestations when terminations for non-medical reasons were not permitted was felt to be both unworkable, given the variability in diagnoses, and unhelpful, leading to reduced patient care (see Table 3 in Appendix A (not printed)). We suggested following that research that a further exploration was required to monitor attitudes to, and interpretation of, UK abortion legislation which permits termination after a late diagnosis of fetal abnormality without gestational limit. If attitudes are changing it is important to understand why, and what the consequences will be for parents and for health professionals.

1.2.3 Prior research. S Robson, J Rankin and R Graham, in collaboration with K Mason

This research team undertook a small scale qualitative exploratory study to understand better the potential impact that feticide prior to termination of pregnancy for fetal anomaly could have on those most closely involved: the parents; the consultants who perform the procedure; and the midwives who assist and support both parents and consultants in this process. The study involved collecting data from three sites, and involved 23 health professional participants, and 12 parent participants. A copy of the Executive Summary for the study report is attached (Appendix B (not printed)). The findings suggest that when performed sensitively, the experience of feticide does not dominate parents’ narratives of distress at their loss. The findings also suggested that health care professionals are generally successful in developing varied
strategies that allow them to be both responsive and empathetic to those around them, yet professional enough to carry out their task well under difficult circumstances. However, a key finding from the study for the purposes of this memorandum was the variation in how professionals interpreted the professional guidance on the gestational age at which feticide should be performed in late termination of pregnancy. In relation to this aspect, the findings suggested that: 1. a degree of professional discretion was an important factor in helping the consultants to provide good quality late termination of pregnancy services to their patients; and 2. the role of professional discretion in provision of late termination of pregnancy is not well understood and requires further examination. Graham, Robson and Rankin have recently had a paper accepted for publication which discusses the issue of professional discretion in the provision of feticide prior to late termination of pregnancy. A copy of the abstract for this paper is attached (see Appendix C (not printed)).

1.2.4 Aim of current research project

The aim of this ongoing, national study is to take the insights from these prior qualitative studies and seek to understand in more depth the viewpoint of the larger clinical community that provides these essential but sensitive aspects of health care. The study focuses on Fetal Medicine Sub-Specialists working in tertiary referral units, as the members of the clinical community that (a) have the most involvement in the provision of late termination of pregnancy; and (b) are most likely to be influential in the development and implementation of professional policy and guidance in this area.

Methodology and Sample

1.3.1 Email and postal questionnaires are being sent to the 84 fetal medicine sub-specialists who occupy consultant level posts in 22 tertiary level fetal medicine units in England, Scotland and Wales. A copy of the questionnaire is attached (Appendix D (not printed)). The findings presented here relate to preliminary analysis of questions relevant to the Enquiry. Further details of the methodology can be obtained from the research team if required.

1.3.2 Of the 84 eligible consultants, 44 have so far been approached and reminded. Completed questionnaires have been received from 30 (68%) and this sample comprises 36% of the total eligible sample. Of the responses received so far, twenty-six (87%) participants are routinely involved in providing late termination of pregnancy for fetal anomaly, and the remaining 4 (13%) are sometimes involved. Socio demographic characteristics for the study population so far are shown in table 1 below.

<table>
<thead>
<tr>
<th>Socio demographic characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>19</td>
<td>63</td>
</tr>
<tr>
<td>Women</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;46</td>
<td>19</td>
<td>63</td>
</tr>
</tbody>
</table>
Findings

1.4.1 Is a scientific or medical definition of serious abnormality required or desirable in respect of abortion allowed beyond 24 weeks?

As we have described above, the research team members have conducted prior research that investigated the provision of late termination of pregnancy for fetal anomaly, and the role of professional discretion in aspects of providing late termination of pregnancy. The findings from these respective projects suggested that ‘definitive’ rules to determine legitimate professional practice were problematic in the provision of late termination of pregnancy. For example, the notion of a ‘defined list’ of permissible terminations was seen as problematic, as was the view that the ‘gestational threshold’ for feticide should be followed in all circumstances. We have asked direct questions in our current study about these issues, and the responses received to date on the issue of a ‘defined list’ in particular are of interest here. The data collected so far are shown in Table 2 below:

<table>
<thead>
<tr>
<th>Some have suggested that a common list of abnormalities could be compiled to guide clinical practice in offering late TOP. Do you think that such a list of ‘eligible’ conditions would be:</th>
<th>N</th>
<th>% of 29 responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>An enabling idea in principle, and a workable idea in practice</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>An enabling idea in principle, but an unworkable idea in practice</td>
<td>13</td>
<td>43</td>
</tr>
<tr>
<td>A constraining idea in principle, but a workable idea in practice</td>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td>A constraining idea in principle, and an unworkable idea in practice</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td>Don’t know</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 1. Socio demographic characteristics of the study participants (incomplete sample)
Table 2. Participant responses to the proposition of a list of ‘eligible’ conditions for late termination of pregnancy (incomplete sample)

Overall, of the 29 respondents who answered this question, 26 (87%) gave negative feedback on this idea, reporting that they felt the ‘common list’ would be too restrictive or unworkable (or both).

1.4.2 Further data on the perceived status of ‘eligible’ conditions

In addition to the question on a list of ‘eligible’ conditions, the survey also includes a question that asks the participants to indicate, for a list of 8 specific conditions, in which cases they would provide termination of pregnancy. For each condition, participants were asked to indicate whether they would offer the procedure up to 21 weeks, up to 26 weeks or never. The research team cannot disseminate this information until the study sample is complete and the data analysed in full; however, it is important to note that in only one of the 8 conditions listed was there a unanimous viewpoint on the provision of termination of pregnancy for fetal anomaly. For the remaining 7 conditions, the consultant responses suggest that there are differences in how the diagnosis and gestational age impact on the provision of late termination of pregnancy for fetal anomaly. In the analysis phase of the study, we will explore the possible explanations for this variation in consultant perspectives.

1.4.3 Further results available when the study is complete

Further results on the above will be available when the data collection has been completed, and the full analysis for the study has been undertaken. The research team will also have data on related issues, such as participant responses to professional understandings and interpretations of the gestational threshold in the provision of feticide prior to late termination of pregnancy for fetal anomaly. The research team will be happy to provide an account of these further results when the data set is complete; because of the limited coverage of the clinical community involved (36%) to date, the team feel that it would be problematic to report on other aspects of the data in this memorandum. The interim results reported above should be interpreted with caution as they represent a partial picture of the overall data set.

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Relevant Reports and Publications
