

Disposal of fetal tissue following elective abortion: what women think

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ABSTRACT

Background and methodology UK regulations on managing fetal tissue after pregnancy loss, including abortion, are underscored by the concept of 'sensitive disposal'. This involves offering women burial or cremation and, when disposal is by the health care provider, separating fetal tissue from other clinical waste before incineration. We interviewed 23 women who had undergone one or more abortions about their understanding, attitudes and experiences of fetal tissue disposal and 'sensitive disposal'. Transcripts were analysed for representative themes.

Results Prior to the abortion, most participants did not give consideration to disposal methods because their focus was on ending the pregnancy. Appropriate disposal by health professionals was assumed but some women undergoing early medical abortion reported anxiety about how to manage disposal at home. The term 'sensitive disposal' was unfamiliar to most respondents. Participants generally favoured separation of fetal tissue from other clinical waste and approved of incineration as a means of destruction. Ceremonial disposal was approved of following the loss of a wanted pregnancy but not following elective abortion. Most wanted the opportunity to access information about disposal but did not favour being asked or required to make decisions about disposal.

Discussion and conclusions Knowledge about the management of fetal tissue after abortion or the concept of 'sensitive disposal' was limited among the women we interviewed. Current guidelines appear discordant with the views of women terminating an unwanted pregnancy. Further research is needed to better inform policy on this issue.

INTRODUCTION

In Britain, the disposal of fetal tissue is governed by the Department of Health (DH) with guidance from the Human Tissue Authority.^{1–3} [NB. The term 'fetal tissue' will be used throughout the document to describe the products of

Key message points

- ▶ Women had limited knowledge of the management of fetal tissue after elective abortion, or the concept of 'sensitive disposal'.
- ▶ The method of disposal by incineration was generally thought to be acceptable after elective abortion, whereas ceremonial methods such as burial or cremation were considered inappropriate in those circumstances.
- ▶ Some women undergoing early medical abortion were challenged by managing disposal at home and would have benefited from more advice or preparation.

conception from any abortion performed up to 24 weeks' gestation.] Options for disposal now include incineration, burial and cremation.^{1–3} A key policy change occurred in November 1991, when the DH issued a directive on the disposal of fetal tissue that had been provoked by adverse publicity about the practice of maceration and sluicing of fetal tissue following abortion.¹ The policy change prohibited maceration and sluicing, requiring instead that fetal tissue be stored in a secure opaque container in a safe place, before being disposed of via the clinical waste stream.¹ A month later the DH, in an executive letter circulated to senior National Health Service managers, recommended the adoption of 'sensitive disposal', a concept which, it claimed, marked respect for the fetus "based upon its lost potential for development into a fully-formed human being".² The aforementioned respect, as a minimum, would be shown by separating fetal tissue from other clinical waste during storage, loading and delivery to the incinerator.² Women should alternatively be offered

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'ceremonial disposal', that is burial or cremation arranged by a health care provider, or privately.³⁻⁷ Subsequent guidance, from professional organisations such as the Royal College of Nursing and the Institute of Cemetery and Crematorium Management has gone further, suggesting that the disposal of fetal tissue from early miscarriage and abortion as clinical waste, although sanctioned by regulation, is "completely unacceptable", and that women in those circumstances instead be provided, both in verbal and written terms, with the option of burial or cremation, as they would in the circumstance of a stillborn child.^{5 6}

Anecdotal evidence suggests differing degrees of implementation of the 'sensitive disposal' guidance, with specialist abortion service providers generally separating fetal tissue from other clinical waste followed by incineration, while other service providers might routinely bury or cremate fetal tissue, regardless of its provenance. Some providers make a distinction between fetal tissue from an unwanted or wanted pregnancy, incinerating the former and burying or cremating the latter.

The guidelines on 'sensitive disposal' apply to all fetal tissue, irrespective of whether it is a result of pregnancy loss (e.g. miscarriage, stillbirth, perinatal death) or elective abortion. This approach to 'sensitive disposal' fails to take into account the potentially differing needs of women ending an unplanned or unwanted pregnancy as compared with those experiencing the loss of a wanted pregnancy. In addition, there is little account of early medical abortion (EMA) where expulsion of the pregnancy often occurs in the privacy of the woman's home;^{8 9} a method that now accounts for 61% of abortions under 9 weeks' gestation in England and Wales.¹⁰

There is a lack of research in the UK and globally on women's understanding about the disposal of fetal tissue following pregnancy loss or elective abortion. Elective abortion is used here to describe abortion of an unwanted pregnancy for reasons other than fetal anomaly. Several qualitative studies have produced insight into women's experience of elective abortion including their motivation in choosing to have an abortion and the abortion method, however none has addressed the concerns women may have about the management of fetal tissue.¹¹ Studies have explored women's opinions regarding donation of fetal tissue for research purposes but have shed little light on routine practices whereby fetal tissue is destroyed following donation.^{12 13} A focus group investigation into women's opinions about donating an aborted fetus for use in stem cell research found that women wanted reassurance that the fetus no longer existed in any material form;¹² however, this study did not specifically address methods of disposal. We were unable to identify any research that focused on the disposal of fetal tissue either by health care providers or women themselves. We therefore decided to explore

women's understanding, attitudes and experiences of disposal of fetal tissue, by interviewing women who had undergone at least one elective abortion.

METHODS

Women were recruited at four abortion clinics operated by the British Pregnancy Advisory Service (BPAS), one of the largest independent providers of abortion care in Great Britain. Each year, BPAS conducts approximately 58 000 abortions, including over 20 000 EMAs where women complete the abortion at home.

Participation was offered by word of mouth, on posters displayed in clinics, and by trained clinic staff familiar with the study who mentioned the research after consent to abortion had been given. Women eligible for inclusion were: (1) 18 years of age or older; (2) undergoing or having undergone an elective abortion; (3) able to provide written consent; (4) willing to comply with the study protocol; and (5) English speaking. Women were excluded if they were (1) unable to provide written consent; (2) cognitively impaired to a degree or in a way which would mean that they were not able to tell their story; or (3) unable to undergo a verbal interview without special assistance.

Women expressing interest in the research were provided with information. Permission was obtained for a member of the research team to explain the study and, if the woman agreed, arrange an interview. Prior to the interview, the study goals and methods were reviewed, all questions addressed, and informed consent obtained. Women were advised that they could withdraw from the study at any time and an honorarium was provided to cover expenses. Individual, semi-structured interviews were conducted as 'guided conversations'¹⁴ and respondents were encouraged to give their own accounts and meanings in relation to the main research questions; their experience associated with disposal of fetal tissue; whether concerns around disposal influence choice of method of abortion; what women understand happens to fetal tissue following an elective abortion; and what women understand about 'sensitive disposal'. Where women were not aware of disposal practices, an explanation was provided. Interviews lasted up to 90 minutes and were recorded. Anonymous transcripts of the recordings were read and re-read by the researchers for representative themes, and analysis organised around the research objectives. Demographic information was collected during the interview. Recruitment continued until saturation of themes was reached.

Participants were assigned an enrolment number (1-23) and coded for method of last and any previous abortion: M (medical) and S (surgical).

RESULTS

Between November 2009 and June 2010, 75 women gave permission to be contacted. Of these, 36 women agreed to participate and had interviews scheduled;

nine did not attend their scheduled interview, three cancelled and did not reschedule an interview, and one participant's interview was cancelled by the interviewer and subsequent attempts to reschedule failed. Twenty-three interviews were completed. No participant withdrew consent after the interview began. The demographic characteristics of participants are detailed in Table 1.

Participant 6-MM was interviewed a few days prior to undergoing her second medical abortion. All of the other women were interviewed after the only or most recent abortion. Participants volunteered a variety of reproductive histories including 25 pregnancies resulting in live birth, eight in pregnancy loss, 30 terminated electively (six twice) of which nine were EMA (one participant twice), and 21 were by a surgical method. The length of time that had elapsed between the reported abortion(s) and participation in the study varied widely, with the longest period being 27 years.

Understanding and attitudes towards disposal by providers and at home

At BPAS, fetal tissue is routinely collected and stored separately from other clinical waste, followed by incineration. Contemporary BPAS literature for clients undergoing elective abortion states that the fetal tissue will be disposed of in a sensitive way, and invites women with specific wishes regarding fetal disposal to discuss those with clinic staff so that they can be facilitated.

Table 1 Demographic characteristics of the study participants (n=23)

Characteristic	Value	
Age [mean (range)]*	30 (18–45) years	
Ethnicity [n (%)]		
White	18	(78)
Asian	3	(13)
Black, Black British or Black African	2	(9)
Marital status [n (%)]		
Single	9	(39)
Married/partnered	11	(48)
Divorced/separated	3	(13)
Employment status [n (%)]		
Employed†	16	(70)
Unemployed/homemaker	4	(17)
Student	3	(13)
One or more prior pregnancy	18	(73)
One or more prior abortion	7	(30)
Method of only or most recent abortion [n (%)]		
Medical	8	(35)
Surgical	15	(65)
Mean gestational age (range) of only or most recent abortion	9	(6–23) weeks

*Age not recorded for two participants.

†Three participants reported currently working in abortion care.

A majority of the women we interviewed did not know what happened to the fetal tissue after abortion. A few participants did wonder about it prior to the procedure, although only two made active enquiries with clinic staff. Two other participants reported that squeamishness had prevented them from raising the issue. Most reported not giving disposal any consideration at the time of the abortion, because their priority was to expedite an end to the pregnancy:

"I mean I think most people, me in particular, had so many other things going on that I just wanted to get rid of it at the time, and, sort of, without thinking too much about, 'Oh what happens now?' to it." [20-S]

"I didn't actually know and ... It sounds really mean, but I just got it over and done with." [3-S]

"As far as my brain went it was you got rid of it, end of." [9-S]

Consequently, where women had a choice of abortion method, disposal was not influential. A variety of other factors such as anaesthetic options and, with regard to medical abortion, the challenge of managing the process at home, were priorities:

"I specifically waited two more weeks to have the general anaesthetic, for the main reason that I had a little baby and I wanted it ... You know, it's just the easier option, whereas if I had to go home, and the EMA is quite a painful experience, I really didn't want to do that around my son." [3-S]

Two participants rejected EMA because it might be "messy".

Most participants understood disposal of fetal tissue by abortion providers as part of the procedure:

"I just felt that you could deal with it how you deal with it to be honest." [9-S]

They assumed that the process would be managed within clinics based on their understanding of regulations, hygiene, and public health considerations. They "trusted" the professionals to manage disposal appropriately:

"... I mean I am just assuming that it would be disposed of in a sanitary, you know, safe manner..." [13-S]

For women managing disposal of the fetal tissue at home or on other private premises after EMA, such reliance on the professionals to dispose of the tissue appropriately was not available. This was not problematic for some:

"... I don't think I thought anything. I just wrapped it up, put it in a nappy bag and put it in the bin." [5-MM]

But for others, a lack of knowledge of how to deal with the tissue caused anxiety:

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"... I said to my mum 'Do I put it down the toilet?' because I thought will it flush, because it's quite big? Where will it go? We just wrapped it up and put it down the toilet. We didn't know what to do with it. You don't know [how] to dispose of it if it comes out like that." [7-SM]

"It's weird because usually we go to hospital and everything is disposed there and we don't see it. But now that it's in my own hands I'm just wondering what's going on there." [15-MS]

After the abortion took place, some women reported curiosity about disposal. In some cases that curiosity persisted some significant time later and the lack of knowledge led to dissatisfaction:

"I didn't really ... I always ... I've always wondered what happened to the fetus afterwards." [1-S]

"I feel cheated because nobody sat with me and talked to me about, well, anything at all, let alone how the fetus would be disposed of." [2-S]

"But it was really one of the points I dwelt on for quite a while ... you know, I thought it was going to sit somewhere in some kind of cold room or something you know? Like this really ... some kind of really impersonal place." [21-S]

Six participants took part in the research in order to find out about providers' disposal methods, two of whom wanted to check the veracity of (inaccurate) information on the Internet.

For some women, not knowing what happened to the fetal tissue after abortion invoked an incipient duty of care¹² that to the woman could seem incongruous with the decision to end the pregnancy:

"As soon as it's come out of the body to be somehow destroyed there and then rather than be put into containers and taken away. Because then it's something that belongs to someone else, taken." [18-S]

One participant described flushing the fetal tissue down the toilet:

"Now I want to know where it is, which is really strange because obviously I'm never going to know ..." and "... you feel protective, even though I knew I weren't keeping it." [16-M]

Following a description of providers' disposal practices, a majority of participants approved of incineration, for some because it ensures complete destruction of the fetal tissue:

"So it doesn't bother me from that point of view that it is just in a container and then it is just incinerated and that is what I imagine would happen." [17-S]

"I would like it to be destroyed completely, so burning it sounds reasonable." [12-MS]

Understanding of and attitudes to 'sensitive disposal'

The two participants who had heard of the term 'sensitive disposal' had experienced pregnancy loss. The terminology suggested little of its principle or process to most participants. Following a description of 'sensitive disposal' several women expressed approval for the principle of separation of fetal tissue from other clinical waste, some because they viewed this as an acknowledgement of the fetus' potential for personhood:

"I thought everything just went in together so it has made me feel a little ... not better but probably put my mind at rest a little bit knowing that it is separate, even though it's with other women's it is separate and it's not just thrown into one slop bucket shall I say, with everything else" [1-S]

"I don't think it's necessary but I think, as you said, it is more sensitive and I could see that some people would like the fact that it is kept separate. I suppose I do in a way as well but I can't explain why. But, yeah, I quite like the idea that it is kept separate. Maybe just because that thing could have become a living, I don't know." [17-S]

Two participants disagreed, one of whom commenting:

"I wouldn't necessarily expect you to go through a massive rigmarole of organisation, and, like you say, separate boxes, separate bags and things just seems like it's causing you more work." [6-MM]

Ceremonial disposal of fetal tissue following pregnancy loss was approved but was considered inappropriate for fetal tissue 'produced' by elective abortion:

"I think it's different if you miscarry naturally or you have a stillborn baby or whatever, I think that's totally acceptable to want a burial or whatever. But not if you're coming into a clinic to get rid of the baby" [8-S]

"I would assume that most people, if they are just having an abortion because they just simply don't want that child, I don't think it is a very major concern or should be. But if there is some kind of attachment between the mother and the fetus or the unborn child, it might make a difference to them." [13-S]

"But if I made the decision that I wanted this fetus to be buried or burnt or keep the ashes, so it would be like some kind of funeral, then in my mind it would be something like, I had a baby but it's dead, and shall I go and visit the cemetery, or ...? I would prefer not to have this thought, that there is a baby buried." [14-MS]

Provision of information

In general, participants believed that information about fetal tissue disposal methods should be available

to women who wish to access it, but that it should not be forced upon them:

"I think there should be that information available for people, because it's like a big secret behind it, because we know what we're going through, but not the end." [14-MS]

"I think women should be asked if they want to know that when they come for their appointment, you know, don't necessarily just blurt it out and tell them but they should at least be asked if they want to know ..." [1-S]

"... if somebody brings it up in conversation, it can be a lot – a bit more distressful than – or distressing than, sort of, reading it and then being able to pass it over sort of thing, put it away." [20-S]

"I think I would have found that even more traumatic if they turned round and said, 'Would you like to know how we're disposing of it?'" [18-S]

There was more ambivalence around the concept of women being asked to make choices about disposal. Some women found the notion of taking the fetal tissue away from the clinic for private disposal bizarre and unsettling:

"I'm not sure I want to be offered the service of 'Well, we can gift wrap it for you' almost. Because that's what it sounds like." [8-S]

"Do you save it in a jar or something? You have to keep it in the clinic, can't just take it home with you." [23-M]

Some participants felt that any invitation or obligation to engage with the decision about disposal of the fetal tissue would be unwelcome:

"If they'd said to me on that day, 'Now you would have to do something with what's-a-name', I don't know. I would feel then I would be pressured into ... I think, yes, I think I would feel pressured into [making a decision]." [9-S]

"From an emotional side, I wouldn't like to hear the options, because it would make things really difficult" [12-MS]

DISCUSSION

In 2012, 190 972 pregnancies were terminated in England and Wales¹⁰ mainly for unintended pregnancy.¹⁵ This exploratory study suggests that women's focus when undergoing elective abortion is on disposing of the state of being pregnant rather than disposal of the fetal tissue, and that method of disposal in general has little influence on decisions about method of abortion.

A majority of participants considered that for a method of disposal to be appropriate, it should

acknowledge that fetal tissue is different from other waste because of its past potential for development into a human being. Where disposal is the provider's responsibility, separation from other clinical waste was thought to be sufficient acknowledgement. The method of disposal by incineration, permitted by regulation^{1–4} but discouraged by guidance,^{5, 6} was generally thought to be acceptable, whereas ceremonial methods were considered inappropriate by most of the women.

Some women experienced curiosity after the abortion as to what had happened to the fetal tissue. The 'not knowing' could invoke a perceived duty of care that reflects findings from other studies.¹² Hence availability of information on disposal was thought to be important, but it should be the woman's choice whether, and to what degree, they access that. We found that women did not favour any obligation to participate in decisions about disposal.

Some women undergoing EMA were challenged by managing disposal at home and would have benefitted from more advice or preparation. Whereas law and guidelines regulate abortion providers' methods of disposal, nothing has been developed for women responsible for disposal of fetal tissue themselves.

There are a number of limitations to this study. The findings are based on a small sample of women who self-selected for participation, although the sample did include experience of both medical and surgical abortion, and across the full gestational range up to 24 weeks. A few of the women were recalling an abortion experience that had occurred several years before and their experience and perceptions may be different to those with contemporary experience. Three women worked for BPAS and this may affect, in particular, their level of knowledge about disposal, although their experience of abortion occurred prior to their employment.

This study suggests that current guidelines on the disposal of fetal tissue are not concordant with the views of women undergoing elective abortion for an unwanted pregnancy. Further research is needed to inform policy and, in particular, to fill the two gaps in information identified: namely abortion providers' disposal methods, and guidance for women on how to dispose of fetal tissue themselves. The study demonstrates the importance of this sensitive issue and that women are prepared to talk about it.

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