How do men in the United Kingdom decide to dispose of banked sperm following cancer treatment?


1Academic Unit of Reproductive and Developmental Medicine, Department of Human Metabolism, University of Sheffield, Level 4, The Jessop Wing, Tree Root Walk, Sheffield, S10 2SF, UK.

2Department of Psychology, University of Sheffield, Sheffield, S10 2TP, UK.

3Fertility Unit, Nottingham University Hospital, East Block, B Floor, Derby Road, Nottingham, NG7 2UH, UK.

*Address for correspondence (A.Pacey@Sheffield.ac.uk)

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Abstract

Current policy in the UK recommends that men bank sperm prior to cancer treatment, but very few return to use it for reproductive purposes or agree to elective disposal even when their fertility recovers and their families are complete. We assessed the demographic, medical and psychological variables that influence the decision to dispose by contacting men (n = 499) who banked sperm more than five years previously and asked them to complete questionnaires about their views on sperm banking, fertility and disposal. From 193 responses (38.7% response rate) 19 men (9.8%) requested disposal within four months of completing the questionnaire. Compared with men who wanted their sperm to remain in storage, they were significantly more confident that their fertility had recovered (OR = 1.78, 95% CI = 1.05-3.03, p = 0.034), saw fertility monitoring (semen analysis) as less important (OR = 0.61, 95% CI = 0.39-0.94, p = 0.026), held more positive attitudes to disposal (OR = 5.71, 95% CI = 2.89-11.27, p<0.001), were more likely to have experienced adverse treatment side effects (OR = 4.37, CI = 1.61-11.85, p = 0.004) and had less desire for children in the future (OR = 0.41, 95% CI = 0.26-0.64, p<.001). Information about men’s reasons to dispose of banked sperm may be helpful in devising new strategies to encourage men to engage with sperm banking clinics and make timely decisions about the fate of their samples.
Introduction

Sperm banking is routinely recommended for post-pubertal males prior to anti-neoplastic treatment (National Collaborating Centre for Women's and Children's Health, 2004; European Society for Human Reproduction and Embryology, 2004; Lee et al., 2006; Royal College of Physicians, 2007; National Institute for Health and Clinical Excellence, 2013; Loren et al., 2013). In the UK, sperm may be stored for up to 55 years (Human Fertilisation and Embryology Authority, 2009) and audits and reviews are needed to comply with legislative requirements. The low rates of use (Lass et al., 2001) or disposal (Hallak et al., 1998) mean that sperm banks are increasing in size and therefore compliance with these legal requirements is becoming time-consuming and expensive. Therefore, an understanding of how men make decisions about disposal is needed to contribute to more appropriate and cost effective use of sperm banks.

Previous work suggests that disposal rates range from 8.7% (Meseguer et al., 2006) to 23.8% (Blackhall et al., 2002). Across nine studies, most disposals followed the man's death and few 'elective disposals' were reported (see Pacey and Eiser, 2011). Hallak et al., (1998) reported that most men who chose to dispose did so because their fertility improved. In an interview study (Eiser et al, 2011), men described complex and unresolved views about banked sperm. Many saw banked sperm as psychological protection against fertility decline if they relapsed, although others saw psychological benefits to disposal in that it allowed them to put the cancer experience behind them and 'move on'.

In a cohort of men who banked sperm at least five years previously (Pacey et al., 2012), we reported that the men's experience of adverse side effects, their initial experience of banking sperm and attitudes to disposal contributed to whether or not they attended for fertility monitoring. Using the same cohort of men, we now report the (i) frequency of elective disposal of banked sperm, and (ii) demographic, medical and psychological variables contributing towards this decision.
Method

Recruitment and Measures

We contacted a cohort of 499 men between April 2008 and December 2010 who had banked sperm more than five years previously, prior to gonadotoxic treatment for cancer as described in Pacey et al., (2012) and approved the by Trent Research Ethics Committee (Ref: 07/H0405/61). Briefly, the eligibility criteria included age (18-55 years), no known mental health problems, and sufficient English language ability to provide written informed consent and complete questionnaires. The men were recruited from sperm banks in Sheffield Teaching Hospitals NHS Foundation Trust (Jessop Wing, Tree Root Walk, Sheffield) and Nottingham University Hospitals NHS Trust (Queen's Medical Centre, Derby Road, Nottingham). In both hospitals, the subjects were written to and regularly informed about the need to attend follow-up and check any changes to their fertility and were given the opportunity to update their consent. In both centres, long-term storage was free of charge with the cost being covered by the National Health Service.

The men completed specially developed questionnaires to determine: (a) Experience of banking sperm (e.g., “I had the right amount of support from others in making this choice,” and “I am pleased I decided to bank”); (b) Information about Fertility (number of samples they recalled banking, quality of banked samples (“did not have any sperm to bank”, “good enough for fertility treatment” or “don’t know”), usefulness of knowing the quality of banked sperm (rated on a five point scale from “definitely very useful” to “definitely not very useful”), and current use of contraception (rely on partner, trying for a child, not in a relationship, fertility too low)); (c) Views about follow up (e.g., “I don’t want to know if my fertility has recovered or not”, “I am certain my fertility has already or will recover”); d) Attitudes to disposal (e.g., “If tests show my fertility has recovered, I would agree to disposal”); and (e) Children and Parenting (e.g., “How much has your experience of cancer affected your wish to have children in future?,” “I worry that children born from banked sperm will have health problems”). Current late effects and perceived vulnerability were assessed using a standardized measure (Absolom et al., 2006). Responses were made on 5-point Likert rating scales with appropriate end-points or multiple choice options.

Relevant medical and demographic information was extracted from medical records held by the sperm bank.

Analysis

All continuous variables were standardised prior to analysis. We used independent samples t-tests and chi-square analyses to examine differences on all variables between those who decided to dispose of their samples and those who wanted them to remain in storage.

Results
Frequency of elective disposal

A total of 193 men returned completed questionnaires (38.7% response rate) as summarized in Figure 1. Of those men who responded, samples had been banked for 9.18±3.70 years (range = 4.94-26.21) and their current age was 35.08±7.08 years (range = 21.58 – 54.34) (mean±SD). One third (35.7%) had never attended for semen analysis [as reported in Pacey et al. 2012] and in addition, over the study period, 34 men (17.6%) disposed of their sample. However, the men joined the study over an extended period of time and the duration of follow-up differed between patients (range 4 – 43 months). We therefore modelled the men’s decisions about banking to meet minimum follow-up possible (4 months after completing questionnaires) and nineteen men (9.8%) requested disposal within this 4-month window.

Demographic, medical and psychological variables predicting the decision to dispose of banked sperm

Preliminary analyses of the information in medical records held in the sperm bank, indicated that there were no significant differences between men who agreed to disposal and those who did not, in terms of diagnosis, treatment, co-morbid conditions, participation in a clinical trial, relapse, reported late effects, or the number of ejaculates banked, the number of years that banked sperm was held in storage, pre-freeze motile concentration of the first banked sample, or number of attendances for fertility monitoring since banking. Importantly, there was no difference in post-treatment motile concentration between the disposers (mean = 15.87 ± 14.75 x 10^6 per ml) and those who continued storage (mean = 17.72 ± 26.52 x 10^6 per ml). However, disposers were more likely to have experienced adverse treatment side-effects (OR=4.37, CI=1.61-11.85, p=0.004).

Men who agreed to disposal were significantly older (mean ± SD: 38.81 ± 6.13 versus 34.64 ± 7.07) than those who retained the sperm in storage (OR for 1 year increase=1.09, 95% CI=1.02-1.17, p=0.017), more likely to have left full-time education under 18 years of age (OR=3.23, 95% CI=1.03-10.11, p=0.045) and to live with a partner (OR=4.47, 95% CI=1.00-20.01, p=0.050) and had significantly more children (1.42 ± 1.30 versus 0.75 ± 1.17) than men who did not agree to disposal (OR for an additional child=1.45, 95% CI=1.05-2.01, p=0.019). There were no differences in employment (working or not; OR=0.99, CI=0.31-3.15, p=0.980) or distance from home to the sperm bank (OR for 1 mile increase=0.99, CI=0.96-1.01, p=0.165).

The men who requested disposal were significantly more confident that their fertility had recovered (OR=1.78, 95% CI=1.05-3.03, p=0.034), saw fertility monitoring (semen analysis) as less important (OR=0.61, 95% CI=0.39-0.94, p=0.026), held more positive attitudes to disposal (OR=5.71, 95%
CI=2.89-11.27, p<0.001) and had less desire for children in the future (OR=0.41, 95% CI=0.26-0.64, p<0.001) than men who wanted their sperm to remain in storage.

Discussion

This study was initiated in response to an urgent practical question regarding extended and unnecessary storage. Our data support previous findings that disposal rates are low: of 193 men, 19 (9.8%) requested elective disposal of banked samples within four months of completing questionnaires, lower than previously reported (18.6% across 9 studies summarised in Pacey and Eiser, 2011). However, previous studies were usually longer-term audits where disposal rates are reported over a substantially longer period of time (e.g. 22 years: Kelleher et al., 2001). Our disposal rate may well be higher in the longer-term, and indeed over the course of the study we found that 34 men (17.6%) requested disposal. However, the shorter follow-up is more meaningful in order relate decisions about disposal to questionnaire responses.

Given the low rates of disposal, we attempted to identify variables that distinguished between those who did, and did not, dispose of samples in the study period. These included being older, leaving full-time education before reaching 18 years of age, having more children and living with a partner, suggesting some relationship between the decision to dispose and family structure. Men who leave full-time education under the age of 18 generally start families sooner than those who enter a period of further education and training (Eggebeen, 2002). Other variables significantly associated with disposal included whether the treatment side-effects were recorded in medical notes, and self-rated confidence in fertility recovery, lower importance of fertility monitoring (semen analysis), desire for children in the future, and attitudes to disposal. Hallak et al., (1998) also found that the decision about disposal was not related to age, number of specimens stored and time between diagnosis and treatment but did depend on the type of treatment. Both Hallak et al. (1998) and Meseguer et al. (2006) concluded that aside from death, most reasons for elective disposal included recovered fertility and no desire for further children. However, in the context of our study it is interesting to speculate if our questionnaire itself may have acted as an intervention by prompting men to consider disposal when they otherwise would not have done so. This effect has been noted before in the context of blood donation (Godin et al., 2008) where the receipt and completion of a questionnaire among registered donors increased their participation rates in comparison to a control group. This is an area for further investigation.

Limitations of the study include the poor response rate (38.7%) but this may reflect the general difficulties encountered when trying to recruit men to research fertility (Stewart et al., 2009) or other fertility related
follow-up (Chawla et al., 2004). We have only limited information about non-responders, although we
have recently published a summary of interviews with six men who had held their sperm in storage for
almost 10 years and who had never returned to the sperm bank (Eiser et al., 2014). This suggests that
men’s reasons for not responding are a complex interplay between past, present and future perspectives
including fears of being told fertility has not recovered and being pressured to dispose of banked sperm.
Responses to questionnaires relied on recall of events many years previously and may reflect some
recall bias. Our results are limited to views of men following cancer treatment and may differ for those
who bank sperm for other reasons. Our decision to focus on men who bank sperm following cancer
treatment were justified because referrals to sperm banks following cancer diagnosis are more prevalent
than for other causes (Pacey, 2009). We investigated a finite range of variables that might contribute to
men’s decisions and other variables may be worthy of investigation in the future. For example, decisions
may well be influenced by cost where charges are collected for storage and concerns about the possible
teratogenic nature of the treatment which could affect the health of any children born. For some, this
may be a justifiable concern, but for others sensitive counselling may be needed to ensure that rational
decisions are made.

Information and counselling may assist men in making timely decisions (Pacey and Eiser, 2011). On-line
information currently available about sperm banking typically requires more sophisticated reading skills
than generally held the public (Merrick et al., 2012). Health professionals should provide easy to
understand information throughout cancer treatment, and not just on diagnosis. Men consistently
describe how they rely on medical staff and family to help them make decisions to bank when diagnosed
with cancer (Pacey et al., 2013). Health Professionals need to take into account men’s sources of
support and the wider issues that contribute to views about disposal. We suggest that men’s attitudes to
disposal are underpinned by a complex series of variables concerning their experience and particularly
the side effects of treatment, views about fertility, domestic arrangements, and desire for future children.

In order to answer questions about the viability of sperm banks (Lass et al., 2001), it is vital to increase
our understanding of why men bank sperm, their reasons for using banked samples for reproduction and
the rationale for retaining samples in storage even when they do not anticipate using them in the future.

Given that banked sperm can be stored for up to 55 years in the UK (Human Fertilisation and
Embryology Authority, 2009), it is important that those responsible for day-to-day management of sperm
banks are aware of the complexity of these issues. Storage of sperm allows men to achieve optimal
quality of life after cancer treatment but there are implications for health care resources. Men need to
understand from diagnosis that sperm quality will change in the years following treatment. They should
therefore, be encouraged to engage with the sperm banking service during treatment and beyond, in
order to make timely decisions about disposal of stored samples if they are no longer needed for assisted
conception.

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Declaration of interest

The authors report no declarations of interest. The authors alone are responsible for the content and writing of the
paper.


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Figure 1: Summary of recruitment and the disposal of banked sperm by participants