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3 Why don't some men with banked sperm respond to letters about their stored samples?

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Abstract

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Long-term storage of banked sperm, especially when it is not needed, for reproductive purposes, is costly and poses practical problems for sperm banks. For sperm banks to function efficiently, men must understand the implications of unnecessary storage, and make timely decisions about the disposal of their own samples. Men who bank sperm prior to cancer treatment are routinely offered follow-up consultations to test their fertility, update consent and, where necessary, expedite referral for Assisted Conception. Yet sperm banks report that men often do not respond to letters, suggesting samples are stored needlessly. We conducted semi-structured interviews with six men with a history of not responding to letters, to document reasons for non-response. Interviews were transcribed and analysed using Interpretive Phenomenological Analysis. Men's reasons for not responding are a complex interplay between past, present and future perspectives. In terms of their past, information is important on diagnosis, because men must understand that fertility can change after treatment. Present and future concerns focus on fears of being told fertility has not recovered and being pressured to dispose of banked sperm. The challenge is to devise invitation letters that address men's concerns while offering them tangible benefits and peace of mind.

Introduction

36

37 This study was prompted by the observation that cancer survivors with banked sperm seem reluctant to respond
38 to letters about their stored samples once their treatment is completed (Wasserman *et al.*, 1987; Tomlinson and
39 Pacey, 2003; Van Casteren *et al.*, 2008). In a recent UK study, more than a third of men who had banked sperm
40 for an average of 10 years had never responded to letters or attended for semen analysis (Pacey *et al.*, 2012),
41 suggesting that sperm banks may be storing samples that are not wanted. To understand this situation, it is
42 important to appreciate men's experiences of banking on diagnosis, and their long-term views about banked
43 sperm and its value to them. It is also important to understand the role of the oncologist, who is a key to
44 providing information and influencing men's decisions.

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46 Sperm banking is currently offered to all post-pubertal males where there is a risk of long-term gonadal damage
47 after cancer treatment (National Collaborating Centre for Women's and Children's Health, 2004; ESHRE, 2004;
48 Lee *et al.*, 2006; Royal College of Physicians, 2007; Loren *et al.*, 2013; NICE, 2013) and is a routine part of cancer
49 care (Pacey, 2007). Despite the availability of sperm banking services and relative ease with which sperm can be
50 banked, statistics suggest that sperm banking services are underutilised. Pacey and Eiser (2011) reviewed
51 seven studies which showed that only 0.01-30.4% of men agree to bank sperm at diagnosis, although a recent
52 study by our group in two UK hospitals concluded this had increased to 56.4% (Pacey *et al.*, 2013). These
53 figures remain lower than might be expected, as, on diagnosis, young men are concerned about risks of infertility
54 (Schover *et al.*, 1999; Tschudin & Bitzer, 2009). However, pressures to begin cancer treatment quickly may
55 cause decisions about sperm banking to be hurried or poorly considered (Zapzalka *et al.*, 1999; Schover *et al.*,
56 2002). Some men may think they do not want children in future, have concerns about treatment delays (Schover
57 *et al.*, 1999) or about abnormalities and teratogenic risk for children born from frozen sperm (Lass *et al.*, 2001),
58 all of which factors may contribute to low uptake of banking services.

59

60 Critical to men's decisions is the view of the oncologist (Schover *et al.*, 2002; Saito *et al.*, 2005). Many men bank
61 sperm simply because it was what their doctor/ oncologist advised (Eiser *et al.*, 2011; Yee *et al.*, 2011).
62 Conversely, men may be advised that their sperm count may recover and that there is no need to bank (Gilbert
63 *et al.*, 2011). Clinic staff may not be clear about whose responsibility it is to discuss sperm banking with a patient,
64 with some oncologists feeling this is the responsibility of social workers or nursing staff (Quinn *et al.*, 2007).
65 Oncologists may lack the confidence or knowledge to discuss fertility issues with patients (Gilbert *et al.*, 2011) or
66 have their own prejudices about who is most eligible. For both oncologists and men who may wish to consider
67 sperm banking, the lack of relevant or easily accessible information may compromise decision-making (Achille *et al.*,
68 2006; Gilbert *et al.*, 2011; Quinn *et al.*, 2007).

69

70 In the UK banked sperm can be stored for up to 55 years (Human Fertilisation and Embryology Authority, 2009)
71 provided there is evidence of 'significant or premature infertility' and consent must be renewed every 10 years.
72 Following the end of treatment, it is considered good medical practice to offer men with banked sperm the

73 opportunity for regular fertility monitoring (semen analysis) to help them make decisions about appropriate use of
74 contraception, or where necessary suggest referral for Assisted Conception (Pacey and Eiser, 2011). Men with
75 banked sperm may also need to return to the sperm bank to update their consent. Under UK law (Human
76 Fertilisation and Embryology Authority, 2009) men must specify their wishes with regard to the fate of banked
77 sperm (or embryos subsequently created) in the event of their death or mental incapacity. This allows the option
78 of posthumous conception by a named partner, but must be specified in writing on a statutory consent form and
79 held by the sperm bank for inspection by regulatory authorities. Given that men may bank sperm at a young age
80 and their personal relationships and views about posthumous conception may change with time, it is therefore
81 important to engage them about updating their long-term preferences.

82

83 Once their families are complete or fertility recovers sufficiently to make natural conception possible men should
84 attend the sperm bank to discuss issues of sample disposal. Very little is known about how men make these
85 decisions (Hallak et al., 1998), but most disposals occur following death, and very few elective disposals take
86 place (Pacey and Eiser, 2011). Thus, it is important for men to engage with the service after banking, both for
87 their own benefit and to ensure an efficient, cost-effective sperm-banking service.

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89 Therefore, when men fail to respond to letters and engage with the sperm bank, there are adverse implications
90 for themselves and the National Health Service (NHS). In the UK, fertility monitoring now serves an important
91 regulatory function and when men cannot be contacted, or refuse to renew consent or return for fertility testing,
92 banked sperm must be destroyed when consent expires, even if they remain sub-fertile. Given some men's
93 reluctance to respond to letters (Tomlinson & Pacey, 2003), sperm banks may be burdened by storage of
94 samples that may ultimately be discarded, with considerable implications for healthcare resources.

95

96 There may be practical reasons for why men do not respond to letters from the sperm bank or attend follow-up
97 appointments. These may include difficulties with transport, or pressures from family members (Crawshaw *et al.*,
98 2008). As part of a wider study concerned with men's views about sperm banking, we sought to recruit men
99 who were not responding to letters from the sperm bank. We aimed to describe their reasons for not responding
100 and identify any fears or barriers to attendance for fertility monitoring or follow-up consultations generally.

101

102

Method

Sperm banking procedures

104 In Sheffield, men who wish to bank sperm are referred by their oncologist to the Andrology Laboratory located in
105 the Jessop Wing of the Royal Hallamshire Hospital. At referral they are given an information sheet that
106 describes the local procedures in place and the availability of independent fertility counselling. At the sperm
107 bank, a Biomedical Scientist takes consent and with the patient completes the relevant HFEA consent forms. An
108 independent fertility counsellor is available if requested. Once the samples are banked, the patient is offered a
109 medical consultation to discuss sample quality. Further contact is made 2 years later (and every 2 years

110 thereafter) when each man is sent a letter to invite him to make contact with the sperm bank with options to: (i)
111 attend for fertility testing/monitoring (semen analysis); (ii) renew or update his consent; (iii) attend a face-to-face
112 consultation to discuss any aspect of *his* fertility; or (iv) give permission for disposal of banked samples if they
113 are no longer required. This is in line with section 17.7 of the HFEA Code of Practice (Human Fertilisation and
114 Embryology Authority, 2009).

115

116 *Recruitment*

117 Between April 2008 and December 2010, all men who had banked sperm prior to gonadotoxic treatment for
118 cancer more than five years previously were sent the routine contact letter (see above). Those who failed to
119 respond within 4 months were written again and were sent an information sheet inviting them to participate in a
120 research study. If they agreed, they were asked to return a signed consent form in a pre-paid envelope. The
121 Trent Research Ethics Committee (Ref: 07/H0405/61) approved all recruitment procedures.

122

123 *Sample*

124 We used a homogenous, purposive sample with the aim of gathering data from a closely defined group. Inclusion
125 criteria were: (i) currently aged 18-55; (ii) sperm banked prior to gonadotoxic treatment for cancer; (iii) sperm in
126 storage for more than five years; (iv) no known mental health problems, and (vi) English language competence
127 sufficient to be interviewed.

128

129 *Data collection and analysis*

130 We used in-depth semi-structured interviews to explore men's experiences before the diagnosis of cancer, their
131 understanding of treatment and impact on their fertility. The following prompts were used as needed: (i) recall of
132 banking sperm on diagnosis; (ii) follow-up after treatment, (including fertility monitoring and experience of
133 oncology follow-up); and (iii) attitudes to disposal of stored samples. Interviews were conducted by trained
134 interviewers and took place in men's homes. Interviews lasted on average 30 minutes and were audiotaped,
135 transcribed verbatim and analysed using Interpretative Phenomenological Analysis (Smith & Eatough, 2007).

136

137 Data were coded independently by two researchers and disagreements resolved by discussion. Each interview
138 was read a number of times and initial notes and observations developed into preliminary themes. These
139 preliminary themes were then combined and resulting themes for each individual were compared and combined
140 to create shared themes. These themes were then organised to 'tell a story' relevant to research aims.
141 Connections were made between the super-ordinate themes from each individual for a final set of themes that
142 were then translated into a narrative account. The results section provides a description and commentary of the
143 themes evidenced with verbatim extracts from interview material.

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Results

Of the 213 men contacted by letter, 39 had not responded within 4 months (18.3%) and were therefore invited to participate in the study. Six men responded to these letters (15.5%) and were enrolled. Five men were interviewed alone, and the sixth with his partner present. Five of the six men had been treated for testicular cancer and two of the six had experienced a recurrence and undergone considerable additional treatment. The average age of men at the time of banking was 31.3 ± 7.2 years (mean \pm SD) and their samples had been stored for 9.7 ± 2.7 years. At the time of interview, men lived 10.9 ± 10.8 miles from the sperm bank, were 41.0 ± 7.8 years old, had been sent 7.2 ± 1.9 letters about their samples and replied 1.3 ± 1.0 times. None of the men had attended for semen analysis or a clinic consultation about their banked samples, prior to being enrolled in the study.

Analysis revealed that some of men's explanations for not responding stemmed from their *past* experiences on diagnosis. They described a general lack of understanding about what happened during this initial period and how they simply followed the doctor's advice about sperm banking. They were confused about whether or not their fertility would be affected, and if so, for how long. Non-response was also related to *present* circumstances, including whether or not they needed to know about their fertility, and *future* concerns that they would be pressured to dispose of banked samples. We describe each of these in turn.

Past Experiences

The single most common explanation men gave for not responding to letters from the sperm bank related to their experiences on diagnosis. They argued that at diagnosis there was no time to assimilate all the information about cancer and what needed to be done. Typically, men described the time around the diagnosis as traumatic. They were concerned about whether or not cancer was curable, and experienced difficulties explaining their situation to others at home and work. Although they were given information, they felt the urgency was to treat the cancer rather than worry about future fertility. Men did not ask questions and simply followed the advice and instructions given by the medical team. They signed consent forms without questioning in depth what they meant.

"we kept going back and forth to Hospital and then next thing I know they said right we're going to take you over to store some sperm before we start with the chemotherapy. So I just thought it were like normal practice you know before. And then I remember at time I had to sign this consent form, well one in a million consent forms, 'cos once I'd signed my name a few times" (2).

However, for some the lack of time acted as a catalyst for a speedy decision:

"... just had no time to think about it so it seemed a bit of a no brainer because if I hadn't and my fertility hadn't recovered then would have been no chance of having a family" (3).

183 Men rarely understood that fertility could recover over time. Failure to appreciate this was one of the reasons for
184 not responding to letters.

185

186 "I didn't know it could go and come back. Impression I got is that if the chemo made me infertile, it
187 would make me infertile and that would be that you know?" (5)

188

189 *Present circumstances*

190 Men identified some practical reasons for not responding to the letters. One man had major and unexpected late-
191 effects and was currently housebound. Two others lived some distance away and described considerable
192 difficulties reaching the hospital. Crucially, men did not want to think about the disease. They were in remission,
193 and wanted to put the whole experience behind them. Returning to the sperm bank might challenge their fragile
194 sense of wellbeing.

195

196 "Open up a barrel of worms you know what I mean that I just really didn't want to think about. ...
197 Time heals everything and I thought about it less and less and got more and more used to it you
198 know what I mean until it sort of became normal and I just didn't want to start thinking about it again.
199 So I didn't actually have a fertility test I just went down there to change my consent form." (1)

200

201 Men described how simply coming to the hospital raised many issues they were emotionally unable to deal with.
202 Inevitably, retracing the journey to the hospital would raise memories of when they did the journey regularly as
203 part of treatment. They did not want to re-live that period of their lives. At the same time, many just did not want
204 to know whether their fertility had recovered.

205

206 "I was just in denial about it. All I did know was I had sperm banked successfully. So it didn't matter
207 whether I was fertile or infertile and I didn't want to know that I was infertile basically. And what I did
208 know, what I'd been told was that I'd successfully banked sperm so that well ... I suppose my mind-
209 set was that it just didn't matter. I'd got sperm banked so when push came to shove if I wanted kids
210 then deal with it then. (3)"

211

212 Although men could persuade themselves that they did not need to know about their fertility, they could be
213 devastated to be told it had not recovered. Fear they might be told they were not fertile, and how this would
214 challenge their current wellbeing, was a prime reason for not responding to letters and arranging an appointment
215 with the sperm bank.

216

217 "...depending on what's happening in your life, maybe you're not strong enough to deal with it if they
218 say you're not (fertile) because it would have been a big thing to me. I would have been gutted." (5)

219

220 "You know what I mean I wasn't particularly looking forward to it and I thought to myself, cos it was a
221 double edged sword, I thought I don't want to be infertile and if they tell me that I am fertile it might
222 be a bit of an anticlimax. You know just actually – not thinking oh I'll be really disappointed if I'm you
223 know if I am fertile – but it was a really bizarre sort of mind-set really. This is me being sort of
224 analytical over what was going through my mind. But yes it was a 'do I want to be?', 'do I not want to
225 be?', 'how am I going to feel if I am?', 'how am I going to feel if I'm not?' you know." (3)

226

227 Going back to the sperm bank also had the potential to stir up past social and emotional issues particularly
228 regarding the consent given when samples were placed in storage.

229

230 "At the time I was diagnosed I was in a long term relationship and I put her name on it and got up to
231 probably a year afterwards when I split up with her. So like maybe a couple of years after I'd been
232 diagnosed, had my treatment and everything. Then it dawned on me that she would have quite a lot
233 of power if anything was to happen to me, if she said yes I want to have his children then my mum
234 and sister wouldn't be able to say "no psycho." Or you know what I mean, cos I'd split with her. I just
235 thought I'd better go down there and sign the consent – like change the consent form just to say let it
236 perish. Once I had done that I was asked, told that I could if I wanted you know, did I want to go and
237 have a check and I was you know what I mean, open door policy, if I want one let them know and
238 they'll be more than happy to see what's happening. And didn't want to. Just didn't want to know."

239 (2)

240

241 Given these views, it is not surprising that letters from the sperm bank were ineffective. The letters were either
242 ignored or deemed irrelevant (as they had already convinced themselves about their fertility and did not
243 understand it could change). Further, the letters were not sufficiently persuasive to make the men go for testing
244 or overcome their fear of the potentially negative results.

245

246 "We kind of ignore reminder letters because its been in storage for quite a while and I still think its
247 worth storing although I've not decided to go on the route of having a baby I'm still very strongly
248 thinking that until I die basically that it should be stored. Men can have children providing the sperm
249 you know is fine until quite late in life and like I say you never ever know what happens. You don't
250 know what could happen in the future and I still think that it should be stored and I think that's
251 probably why I've not answered those letters. (4)

252

253 *Future options*

254 Men also hesitated to respond to letters because they felt they would be put under pressure to dispose of their
255 banked samples. All those interviewed wanted to keep their sample in storage so there remained a chance of
256 having a child at some point in the future. This was even when they knew having a child was not a practical

257 option (e.g., they accepted that they and their partner were becoming too old to look after a child; realistically
258 they understood that any child they now had might grow up from a young age without a father, or having a child
259 was not possible for financial reasons.

260

261 "...these letters what I get through saying do you want to terminate it or do you want to keep it stored
262 it's like a catch 22. If I say no we can't really, can't afford it at the moment you know it's not just the
263 money for the IVF but you know money for bringing up the children ... I didn't want to write on the
264 letter no its ok don't want it no more. And then the day after win the lottery you know?" (2)

265

266 They described their banked sperm as a protection against worsening health in the future.

267

268 "I suppose it's the same as I said earlier about getting hit by a bus or something. I could get hit by a
269 bus tomorrow and God forbid but like it could be ... I could lose my other testicle do you know what I
270 mean? Stranger things have happened." (5)

271

272 At the same time, knowing they had banked sperm made it possible to extend the possibility of having a child
273 into older age. It contributed to feelings of youth and virility and enabled them to keep options open. They saw
274 other men as being able to have children into old age and wanted to retain that option themselves and indulge in
275 real fantasies of sexual prowess.

276

277 "Yes young and ... virility yes. Whether that's... you know you see people who are in their 70s or
278 whatever becoming fathers and the rest of it and you see more and more of that as things go on so
279 whether I'd say well that's got to be the age cycle and the way it goes or not I don't know". (4)

280

281 They were also able to justify their decisions in terms of insignificant costs to National Health Service.

282

283 "You know I've got a job and when our colleagues and obese people and drug addicts you know are
284 on disability whatever you know and we are supporting them I'm thinking equally who says they've
285 got more right than me to store this sample? I've paid my taxes, so has N, over all these years you
286 know. We are not a drain. This is the one and only thing a don't feel one iota of guilt". (4)

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Discussion

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Long-term storage of banked sperm, especially when it is not needed, is costly and poses a number of logistical problems for sperm banks. For sperm banks to function efficiently, it is vital that men understand the implications of unnecessary storage and are helped towards making timely decisions about disposal of their samples. We estimate that for a man to keep his samples banked for the maximum time allowed by UK law (55 years) will cost between £10,000 and £25,000 at 2013 costs, depending on the frequency at which capital items are replaced and modernised. Our results provide significant insights into reasons for men's reluctance, and to the need for more successful communication between men and clinic staff.

Men's decisions about how to respond to letters from the sperm bank were a complex interaction between their recall of their experiences on diagnosis, their current need to know about their fertility and fears that, in responding and making an appointment they might be pressured to destroy banked samples. Part of their reluctance stems from the failure to assimilate information on diagnosis. Men were unsure about the trajectory of fertility loss and potential recovery and were unclear about the implications of disease and treatment for future fertility. The oncologist may facilitate decisions to bank sperm (Eiser *et al.*, 2011; Yee *et al.*, 2011) but this can mean that many men are unclear about the long-term implications.

In addition, factors related to current life-style contributed to men's reluctance to respond and attend for follow-up. Although no-one felt it would be difficult to have time off work, they were fearful both of being told their fertility had not recovered and that they would be put under pressure to dispose. There were concerns that returning to hospital would stir up the past, bring back memories of the illness, threaten self-esteem and compromise current functioning. Understandably, men saw no point in attending for semen analysis simply to be told that their fertility remained poor. These men claimed to be ambivalent about whether or not their fertility had recovered but they knew they did not want to be told that it had not.

Reluctance to respond was also related to concerns about storage and disposal of banked sperm. Circumstances change and men were concerned if previous partners could now challenge ownership or gain access to banked sperm. These men did not want to be reminded about their past illness, or about past relationships. None of the men wanted their banked sperm to be discarded. Stored samples represent security against future cancer relapse and against any further declines in fertility.

Limitations of this study include the small sample size. However, we set out to understand why men did not respond to letters from the sperm bank and it was therefore inevitable that recruitment would be difficult. We adopted a qualitative method and analysis previously used successfully to provide insight as to how people make complex decisions about testing for Huntington's disease (Smith *et al.*, 2002) or genetic testing for hereditary breast or ovarian cancer (Dancyger *et al.*, 2010).

326 Clinical implications may be considered by comparison with previous findings involving men who attended more
327 frequently for fertility monitoring (Eiser *et al.*, 2011). All experienced difficulties on diagnosis, were unable to
328 assimilate all the information available and depended on the oncologist to help them decide whether or not to
329 bank. All were confused about whether or not fertility might recover after chemotherapy and reticent about the
330 need for fertility monitoring. However, those who did attend (Eiser *et al.*, 2011) described some positive aspects
331 of doing so: they wanted 'to give something back' to hospital staff and be reassured about their own health and
332 fertility. In the present study, men did not mention any positive aspects of attending follow-up consultations.
333 Instead they focused on the possible negatives; they were concerned about their fertility but also anxious that
334 they would be pressured to dispose of their samples. However, noone was willing to agree to disposal.
335 Continued storage was seen to be a form of security against future relapse, even where the probability of relapse
336 was statistically very low. Few men acknowledged they were unlikely to use banked sperm, but the non-
337 responders described here had quite unrealistic reasons for refusing, including vague expectations of fathering
338 children into old age.

339

340 For all men, there is a need to rethink how information is given on diagnosis and in the longer-term (Quinn *et al.*,
341 2011). Given the distress and shock of diagnosis, it is inevitable that many will fail to assimilate all the available
342 information and consequently there may be uncertainty at a later date. Although all men banking sperm at our
343 centre are offered the opportunity to have fertility counselling, both at the time of banking and subsequently, very
344 few take up this offer unless they are considering using their samples in assisted conception or are
345 contemplating disposal. The reluctance to engage with this support may suggest that front-line staff are
346 inadequately skilled to provide men with the support required to engage with the sperm bank in the long term.
347 We need to appreciate that men often have unpleasant memories of their cancer journey and these may be re-
348 ignited when the sperm bank makes contact. Simple fact-sheets summarising information about infertility after
349 cancer treatment could be useful communicate key information when it is needed. Information available online
350 about sperm banking typically requires more sophisticated reading skills than held by the average member of the
351 public (Merrick *et al.*, 2012). Fact-sheets therefore need to use very clear language. The challenge is to devise
352 information that recognises the legitimacy of the broad range of concerns that men may harbour but offers them
353 tangible benefits and peace of mind.

354

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358

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