Who should be offered sperm banking for fertility preservation? A survey of UK oncologists and haematologists

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Background: Fertility after cancer therapy is a significant quality-of-life concern for many patients, their partners and families. Authoritative guidance states that men whose fertility may be affected by impending therapies should be offered sperm banking. Yet some patients are not offered this opportunity and are thereby disadvantaged. We sought to understand oncologists’ and haematologists’ decision making concerning sperm-banking referrals.

Design: We surveyed all oncologists and haematologists on the Royal College of Radiotherapists’ Faculty of Oncology and British Society for Haematology circulation lists.

Results: From 2357 across all specialities, 499 responses were received: 253 haematologists and 246 oncologists (21% response rate). Twenty-one percent of respondents were unaware of local policies on sperm banking and 42% considered that sperm banking should be offered to more patients. Respondents’ decisions reveal either assumptions about patients’ needs based on characteristics such as age, sexual orientation and severity of illness or the influence of their own moral conclusions upon their patients. The survey identified paucity of training for clinicians, information for patients and systematic recording of discussions about fertility.

Conclusions: A robust care infrastructure supporting male fertility storage is needed urgently to include targeted information for cancer clinicians and patients, identified individuals responsible for coordination and documentation of discussions with patients.

Key words: cancer, clinical guidelines, fertility, oncofertility, sperm banking

Introduction

As survival rates increase and cancer survivors become more numerous, quality-of-life (QoL) issues are moving increasingly to the fore. Fertility is one of the predominant QoL concerns for many cancer survivors of reproductive age [1, 2] and its loss, or fear of its loss, is a well known cause of psychological morbidity among survivors [3]. The importance of protecting future options for parenthood at the time of a cancer diagnosis is widely recognised, so it is surprising that sperm banking has remained underutilised over a number of years [4–6].

Human sperm cryopreservation has been practised since the 1960s and became a routine assisted conception technique during the 1980s and 1990s. Today, it is widely recognised as a safe and effective means of preserving fertility potential in male cancer patients, regardless of semen quality [7], and its psychological benefits are also well known [8, 9]. Many authors and several authoritative national and international guidelines recommend that sperm banking should be offered to male patients before they receive chemotherapy or radiotherapy that may render them infertile [10–14]. However, many cancer survivors attending specialist fertility treatment centres have not banked sperm. Most studies to date have taken place in the United States, e.g. Schover et al. [4] found that 50% of male patients aged 14–40 years at diagnosis reported being offered the opportunity to bank sperm. In a separate USA study, only 28% of adolescent cancer patients who were offered the opportunity accepted it [15]. Those of higher socio-economic status and older adolescents were more likely to bank. In other USA studies, only 24% of childless men <35 years banked sperm before cancer treatment [16], while Nagel et al. [17] found that only 18% of adolescents and young adults aged <30 years had banked sperm. In contrast, the situation appears more promising for UK paediatric services, where 83% of post-pubertal boys with a high or medium risk of infertility due to cancer therapy were referred for sperm banking [18]. Even so, Crawshaw et al. [19] found that some young UK patients who initially declined the invitation to bank sperm wished in retrospect for more encouragement from clinicians.

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Invitation and uptake rates among UK adults are currently unknown. A study of men in Italy showed that patients appreciated the invitation to consider fertility preservation at all ages, even when uptake was low [20]. In a USA study by Boyd et al. [21], 3.7% of prostate cancer patients named infertility as their primary concern, above erectile dysfunction and incontinence in terms of importance as a side-effect. Thirty-two percent of their cohort of 522 patients wished to bank sperm before therapy.

Authoritative guidance on sperm banking for oncology patients has recommended that men and adolescent boys preparing for medical treatment likely to render them infertile should be offered semen cryostorage [10–14]. These recommendations aim to improve service provision and patient QoL, but it is important to understand why such explicit guidance has not been widely implemented. The literature identifies a range of factors that may influence cancer clinicians’ decisions about whether to offer sperm banking, e.g. lack of knowledge of suitable fertility preservation options and discomfort around discussing fertility; the urgency of starting cancer treatment; organisational issues such as a nearby banking facility; patient factors, such as prognosis and age; and clinical factors such as time pressure during consultations, complex funding arrangements and lack of prioritisation of fertility issues [12, 22–26].

The available evidence therefore highlights a lack of consistency in clinical practice and a missed opportunity for many men [2]. However, much of the available literature is not representative of the UK, where the National Health Service (NHS) and the legal framework of fertility regulations are unique factors. Moreover, much UK literature focuses on adolescent and young male cancer sufferers in particular [18, 19, 27], so that questions about older men remain. This study aims to provide new quantitative information about how UK oncologists and haematologists decide which of their adult male patients are offered referral to sperm banking.

methods

A questionnaire was designed for use in a national survey of oncologists and haematologists. The aim of the questionnaire was to collect quantitative evidence about clinicians’ beliefs, attitudes and usual practices regarding offering sperm banking. The questions were based on data arising from semi-structured interviews conducted with 13 oncologists and 16 haematologists based in the Midlands, exploring factors that clinicians found influential in their decision making with regard to offering sperm banking (E. Gilbert, G. M. Hartshorne, H. Mehanna, B. Harrison, A. Adams, in preparation). It was further informed by our experiences of issues raised by cancer professionals attending courses on fertility preservation at the University of Warwick. Before use, the draft questionnaire was piloted with 24 such delegates. The questionnaire invited both freehand and Likert-scale responses. A copy is available upon request. The questionnaire was posted to all members of the Royal College of Radiotherapists’ Faculty of Oncology and the British Society for Haematology (n = 1007 and 1350, respectively). There were two mailings for each organisation, between November 2006 and May 2007. Responses were received until August 2007.

Responses were received from 499 clinicians—253 haematologists and 246 oncologists, representing a 21% response rate, based on the total number of questionnaires distributed. However, the organisations could not selectively mail members according to subspecialisation, so the mailing lists included, for example, many specialists in breast and gynaecological cancer, for whom the questionnaire was largely irrelevant. Thus, the response rate for relevant clinicians cannot be calculated but is >21%. This response rate is similar to that in previous surveys (24%, Schover et al. [4]). Questionnaire data were entered into SPSS for analysis, using descriptive statistics and comparative analyses.

The research was approved by South West Multi-centre NHS Research Ethics Committee (ref: 05/MRE06/76).

case

The findings provide evidence of great diversity in opinion and practice among cancer clinicians when making decisions about offering patients sperm banking. Responses from oncologists and haematologists showed similar patterns of diversity, so they are reported together.

knowledge and information about sperm banking

A reasonable level of basic knowledge about sperm banking was evident among respondents, with 68% aware that safety and effectiveness was established and >99% knowing the distance to their nearest sperm banking facility. However, some questions highlighted important gaps in clinicians’ knowledge: 42% of respondents would offer sperm banking to patients who had already been through chemo- or radiotherapy, which contradicts National Institute of Clinical Excellence (NICE) guidance [11], and 32% would offer it to patients unable to give their own consent.

Nearly all respondents agreed that discussing fertility issues with patients is part of their role at diagnosis and only 2.2% would rely upon the patient to raise the topic. Most preferred face-to-face communication to written information as the best way of introducing sperm banking to patients, and only 3% reported feeling uncomfortable about discussing it. However, only half the respondents agreed that information about fertility preservation was readily available to their patients and 38% said that they would be interested in receiving specific training about discussing fertility and sperm banking with cancer patients.

Forty-nine percent of respondents knew of a local policy relating to provision of sperm banking. However, free comments received showed that such policies were highly variable. Some respondents were aware that their policies were in need of review.

documentation of discussions about fertility preservation

The survey revealed that systematic processes for recording the discussion of fertility issues with patients are often absent, with only 38% of haematologists and 26% of oncologists reporting any such processes operating in their department.

time pressure and access to services

A quarter of respondents (25%) reported that the urgency of commencing cancer treatment affects their decision making. Moreover, 15% of respondents reported their nearest fertility centre being >50 miles away, with the greatest
distance being 165 miles. Long distances were considered a deterrent for patients who were too ill to travel, especially when treatment needed to be started urgently. On the other hand, well established links to on-site or nearby fertility centres sometimes positively influenced the decision to offer sperm storage.

Fertility treatments, including sperm banking, are not universally funded by the NHS, despite NICE guidance and interventions by health ministers and patient organisations seeking to end the so-called ‘postcode lottery’. Individual Primary Care Trusts (PCTs) restrict fertility services according to a variety of social criteria, e.g. age and whether children already exist within a partnership. Sperm banking for cancer patients is often viewed sympathetically by PCTs, and funding may be forthcoming if the patient satisfies the locally applied criteria or can make a case for an exception; however, there is no standard process. In some areas, sperm banking for cancer patients is not NHS funded; while in others, it is considered on a case-by-case basis or is included in block contracts for fertility treatment, andrology services, cancer services or other classifications. A further complexity is that even if PCTs fund the initial banking procedure, their policies then support sperm storage for different lengths of time (e.g., 5 years). If patients still require the sperm to be stored beyond the funded period, which is often the case for cancer patients, the continuing costs of storage (currently around £100–200 per annum) may then become payable by patients. In this environment, some fertility centres only accept referrals if funding is secured; however, most offer private sperm banking if NHS funding is unavailable. No national data are available presenting the policies of different PCTs and the devolved governments on sperm banking for cancer patients (Infertility Network UK, Human Fertilisation and Embryology Authority, CancerBACUP, personal communications). This lack of clarity and uniformity in funding is a challenge for both patients and cancer clinicians. Even so, our survey found that 84% of respondents would not take the patient’s ability to pay into account when considering referring for sperm banking, while 70% would still offer sperm banking even if the patient fell outside the local NHS funding criteria for sperm storage.

Free comments from two oncology respondents highlighted difficulties when patients referred for sperm banking are found to have no sperm present. This may arise from the impact of their condition or an underlying deficit occurring in ~12% of referrals [28]. They considered that the diagnosis of azoospermia caused additional upset to affected patients. For these particular clinicians, the resulting difficult consultations were spontaneously identified as a significant cause of concern, which could potentially influence their referrals for sperm banking.

Patient factors

In our survey, 6.4% of respondents stated that they had a fundamental moral objection to offering sperm banking in some circumstances. Table 1 presents the responses regarding patient factors that affect clinicians’ decisions. The results show the diversity of opinion among clinicians on the influence of factors such as patient age, prognosis and sexuality. Free comments highlighted the different approaches of clinicians, some expressing the view that it is their responsibility to decide whether to offer sperm banking to individual patients, others commenting that it is a patient’s right to receive the offer, and to make an informed decision whether to take it up.

Patients’ characteristics therefore affect clinicians’ decisions whether or not to offer sperm banking. Almost all respondents (96%) would discuss sperm banking with teenagers; however, for older patients, responses were more variable. Thirty-five percent of survey respondents were unlikely to discuss sperm banking with patients >50 years of age, while 47% would do so. Similarly, some respondents (11%) felt that the patient’s sexuality was a material factor in whether to offer sperm banking.

The likely prognosis for patients was an important factor for clinicians when deciding whether or not to offer sperm banking. Forty-seven percent of survey respondents would not discuss sperm banking with a patient who was unlikely to survive, rising to 79% if the patient was terminally ill. In response to this same question, 35% and 13% of respondents

<table>
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<tr>
<th>Table 1. Patient factors potentially influencing oncologists’ and haematologists’ likelihood of discussing sperm banking</th>
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<tr>
<td>I would tend NOT to discuss sperm banking with patients who:</td>
</tr>
<tr>
<td>(a) Are not in a current relationship</td>
</tr>
<tr>
<td>(b) Are single</td>
</tr>
<tr>
<td>(c) Are homosexual</td>
</tr>
<tr>
<td>(d) Have children already</td>
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<tr>
<td>(e) Are in their teens</td>
</tr>
<tr>
<td>(f) Are 40 years of age and over</td>
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<td>(g) Are 50 years of age and over</td>
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<td>(h) Have already been through chemo- or radiotherapy</td>
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<tr>
<td>(i) Are unlikely to survive their treatment</td>
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<tr>
<td>(j) Are terminally ill</td>
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<tr>
<td>(k) Will probably regain their fertility after treatment</td>
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<tr>
<td>(l) Fall outside local NHS funding criteria for sperm storage</td>
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<tr>
<td>(m) Could not afford to pay for it</td>
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<td>(n) Do not ask about it</td>
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<tr>
<td>(o) Cannot give their own consent</td>
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<tr>
<td>(p) May find the questions offensive, e.g. for religious reasons</td>
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For ease of presentation, results in response categories ‘strongly agree’ and ‘agree’ have been merged, as have ‘strongly disagree’ and ‘disagree’.
would offer sperm banking to patients having a poor prognosis or terminal illness, respectively. The remaining 18% and 8%, respectively, did not express an opinion.

**discussion**

Our findings show that in the UK, as in other countries, authoritative guidance on sperm banking for cancer patients is not being followed, resulting in many patients not being offered the chance to store their sperm for future use. Instead, the practice of offering fertility storage to cancer patients is guided by clinicians’ own beliefs, attitudes, values and assumptions about patients’ fertility needs. Our results can be interpreted in two ways: either clinicians are making decisions based on assumptions about their patients’ wishes in relation to future fertility, extrapolated from information such as the patients’ age, condition, family circumstances and funding. Such assumptions are often inaccurate [24] or, alternatively, clinicians could be applying their own moral codes, offering fertility storage to only those patients who fit with their own ideas of suitability for parenthood. Modern reproductive medicine often challenges traditional attitudes about the family, and many people, including clinicians, hold strong views on what is right and fitting in this field. It is an interesting question whether the moral considerations of clinicians are a valid influence when offering or withholding sperm banking. In other controversial areas of medicine, such as termination of pregnancy, conscientious objection is common, with clinicians referring on to colleagues as appropriate. However, we consider it likely that improved awareness of the issues, clear information and access to training may increase both the opportunity and the uptake of sperm banking for cancer patients.

Regardless of which interpretation of our data is correct, or accepting a contribution from both, the result is that UK practice is unacceptably variable and deprives many patients of the opportunity to make an informed decision about fertility storage.

This study demonstrates that a patient’s chances of being offered sperm banking depend upon factors such as his age, sexuality and prospects of survival. His chances may also depend upon whether his local PCT funds fertility treatment in his particular circumstances, the urgency of his need to start cancer treatment and the distance to, and protocols at, the nearest fertility service. Similar factors influencing US clinicians’ decisions have been identified already [4], but detailed UK evidence has previously been absent.

Our survey attracted a relatively low response rate of 21%, comparable to that of other similar studies. The response rate was affected by our inability to target the mailings to clinicians who treat male patients, so the representativeness of our sample is uncertain. Despite this, several important findings have been derived from the data.

Our study has identified that cancer clinicians are interested in fertility preservation for their patients and would appreciate training opportunities, so it appears that the lack of implementation has not been due to a lack of interest but rather to the lack of a systematic approach to the provision of information and training about fertility storage. This is not surprising in view of the complex fertility service delivery pathway that has evolved in response to limited funding and the variable priorities and restrictions placed upon assisted conception by different PCTs. However, our study design did not enable us to elucidate whether those clinicians who were reluctant to offer sperm banking were the same ones who would appreciate training.

Some key gaps in respondents’ knowledge have been highlighted. Many respondents were willing to offer sperm banking to patients who had already received radio- or chemotherapy, which is not supported by guidance. Similarly, a large proportion were willing to offer sperm banking to patients who could not give their own consent, which would render the storage illegal (although changes in 2008 to the Human Fertilisation and Embryology laws now permit proxy consent). These two examples highlight the need for better communication between the fertility and oncology sectors. Researchers and clinicians in the fields of cancer and fertility need to work together more effectively to improve fertility outcomes for cancer patients [17]. In the United States, substantial National Institutes of Health funding now supports an ‘oncofertility’ consortium, thus overcoming the traditional lack of interface between these two groups. A similar approach may be beneficial in the UK.

Unfortunately, there are no predictive tests showing which patients exposed to potentially sterilising therapies will become infertile and who will recover fertility [29]; therefore, the opportunity to bank sperm should be offered to all in order to catch those who may benefit. This would be a relatively cheap intervention that should be NHS funded and may add greatly to patient well-being and QoL.

Good quality information for patients needs to be made more widely available since only half of our respondents had information about fertility preservation that was readily available to their patients. Detailed information about storing sperm is not available to many patients unless they attend the fertility centre, which they may never do if not referred. Others close to the patient, including family members and other social contacts, also require information [12].

While age is a factor that will affect the patient’s wishes for or against sperm banking [20], any set ‘cut-off’ age or personal criteria applied by clinicians could be challenged under human rights or equality legislation. Baring in mind increasing social trends for second families, delaying parenthood and civil partnerships, an individualised approach is more appropriate. Moreover, posthumous use of banked sperm is legally accepted in the UK, with deceased fathers being named upon birth certificates, so severity of disease may also be challenged as a reason for withholding the offer of referral for sperm banking. Surviving partners of deceased men, who banked sperm with consent for their partner’s use, may consider its use a better outcome than losing both their partner and their chances of beginning or extending their family. Therefore, cancer clinicians should take care to avoid denying such possibilities to patients’ surviving partners and children on the basis of either applying untested assumptions about what is in an individual’s best interests or imposing their own moral decisions upon their patients.

Some prior publications highlighted uncertainties about who is responsible for providing men with information and
counselling, to help them make their decision [25]. Most of our respondents felt it was their role to raise the issue of sperm banking with appropriate patients, but sometimes it was not clear who in the multidisciplinary team would follow up on fertility issues. Allocating responsibility for coordination of patient advice and overseeing referrals for sperm banking to an identified individual within each cancer team could make a significant difference to men’s ability to make informed decisions about fertility storage and to bank successfully [24, 30]. Such a coordinator could also assist in requests to PCTs on behalf of patients wishing to access sperm banking. Allocation of responsibility could ensure that the necessary preparations for sperm storage are undertaken promptly and without delaying the start of cancer treatment. Such a role may also alleviate difficulties experienced by some clinicians in communication about fertility issues [23]. Sperm storage is technically straightforward, and government guidelines recommend its use for cancer patients. However, UK policy requires detailed consent forms and mandatory advance screening for human immunodeficiency virus and hepatitis B and C. Moreover, if sperm banking is to occur, it must take place before cancer therapy begins. Consequently, there may only be a brief window of opportunity.

A coordinator could also assist in systematically recording whether a discussion about fertility and sperm banking has taken place and documenting patients’ decisions. In light of the potentially serious consequences for patients and also the possibility of legal action being taken against clinicians if sperm banking has not been discussed or offered, the inclusion of a fertility checklist in the notes of cancer patients could be a simple but effective measure protecting the interests of both parties.

Finally, this national survey of oncologists and haematologists revealed marked differences in the local availability of fertility services for men wishing to bank sperm. We identified problems related to long distances to available services, which sometimes meant that patients who were seriously ill were not able to bank sperm. Other fertility services operated local policies that restricted men’s eligibility for sperm banking, due, apparently, to funding issues, although funding of sperm banking for cancer patients is often available from PCTs if requested. These situations need to be resolved with some urgency, to avoid continuation of the current inequities in service provision. The Human Fertilisation and Embryology Authority’s website has links to 51 centres nationally that specifically provide sperm storage for oncology patients, 46 of which provide NHS treatments and 49 of which provide private treatments (http://guide.hfea.gov.uk/guide/AdvancedSearch.aspx, accessed 24 November 2009).

In summary, many of the barriers to sperm banking for cancer patients identified in this paper appear amenable to relatively simple solutions. A coordinated approach to developing more systematic care infrastructures within NHS Trusts is likely to increase the number of men with cancer who make informed decisions about fertility storage. Such an infrastructure would comprise: training for cancer clinicians and clinical nurse specialists about fertility storage and how to advise patients about it; targeted information for cancer clinicians, nurses and patients; identified individuals within cancer teams being responsible for coordinating patients accessing fertility counselling and sperm banking; new patient documentation designed to capture fertility information in a rapidly accessible format and systematic recording of discussions about fertility and patients’ decisions about storage. These straightforward adjustments to practice would significantly improve patients’ QoL after cancer treatment, as well as that of their partners and families, and assist concordance with clinical guidance. The adoption of a multidisciplinary approach to this topic will be necessary in the future.

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disclosure
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references