

# Facilitators and obstacles to sperm banking in young men receiving gonadotoxic chemotherapy for cancer: the perspective of survivors and health care professionals

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**BACKGROUND:** Testicular cancer and Hodgkin's disease are among the most common malignancies to affect young men of reproductive age. Although both are associated with high rates of infertility, sperm banking (SB) remains underutilized by both diagnostic groups. Reasons for this remain elusive. **METHODS:** This study used a qualitative design. In-depth interviews were conducted with 20 cancer survivors and 18 health care professionals (HCPs) to examine their perspectives on factors that facilitate or hinder SB. Interview data were analysed using a mixed approach and a three-step process of data reduction, data display and conclusion drawing and verification. **RESULTS:** Eight factors were identified as having an impact on SB, and findings suggest that effective promotion of SB involves adequate communication around the severity and personal risk for infertility, assessing the importance of patients place on having children, emphasizing the benefits of SB and addressing possible obstacles such as cost, misperceptions or cultural and other factors. In addition, the communicator should be perceived as appealing. **CONCLUSIONS:** These results are conceptually consistent with both the Health Belief Model and the Elaboration Likelihood Model of health promotion and are useful in informing HCPs on how to better promote SB.

**Key words:** male infertility/psychology/sperm cryopreservation/testis cancer

## Introduction

Testicular cancer and Hodgkin's disease are among the most common malignancies to affect young men of reproductive age, testicular cancer accounting for 26.1% of all cancers diagnosed in men aged 20–24 years and Hodgkin's disease accounting for an additional 15.2% in the same age group (Wu *et al.*, 2003). With 5-year survival rates established at 95 and 80%, respectively (Sonneveld *et al.*, 2001; Jemal *et al.*, 2004), both diseases are now considered highly curable, with low risk of long-term effects on quality of life (i.e. overall physical, psychological and social functioning) (Dahl *et al.*, 2005).

Although this positive outlook is encouraging, one issue that remains of concern for patients diagnosed with testicular cancer and Hodgkin's disease is their high risk for infertility. At diagnosis, 50–70% present with oligozoospermia (i.e. low sperm count) (Howell and Shalet, 2002). In the case of testicular cancer, it is suspected that pre-existing germ cell defects may lead to both cancer and defective spermatogenesis (Agarwal and Allamaneni, 2005). In the case of Hodgkin's disease, it is

suspected that cytokine secretion activated by the disease may lead to a reduction in fertility rate (Rueffer *et al.*, 2001). Treatments for both diseases compound this effect to increase the risk for infertility. Surgical treatment such as retroperitoneal lymph node dissection can lead to dry ejaculation or anejaculation (Puscheck *et al.*, 2004). Cytotoxic treatments, especially alkylating chemotherapy agents, further damage germ cells, with toxicity of treatment depending on type and number of antineoplastic agents used, duration of treatment, cumulative dose and age of the patient. Radiotherapy near the pelvis can lead to additional gonadal damage, with combination therapy having a synergistic effect on risk for infertility (Colpi *et al.*, 2004).

Spermatogenesis and sperm concentration are expected to return to normal levels in 50% of patients 2 years after treatment and in 85% of patients 5 years after treatment (Giwerzman and Petersen, 2000; Howell and Shalet, 2005). However, 15–30% of survivors remain permanently affected (Schrader *et al.*, 2001a), and although the final effect is likely to be dose dependent (Howell and Shalet, 2005), it is currently impossible

to predict who will be affected permanently (Colpi *et al.*, 2004).

It is for this reason that many professionals recommend that sperm banking (SB) be offered systematically to all men about to undergo gonadotoxic cancer treatment (Kliesch *et al.*, 1997; Schover, 1999; Puscheck *et al.*, 2004). Sperm cryopreservation is a simple and accessible intervention and remains the most effective way to preserve fertility potential (Puscheck *et al.*, 2004). It is also emerging as a factor that may help alleviate the future emotional burden of cancer among survivors (Saito *et al.*, 2005). Even when sperm is of low quality, SB should be encouraged because recent advances in assisted reproduction technology (ART), namely ICSI, require only a few spermatozoa for successful IVF outcome (Chan *et al.*, 2001; Agarwal and Allamaneni, 2005).

Surprisingly, however, despite the high threat to fertility and the availability of a simple intervention to preserve it, it is only a few patients who store semen before treatment (Schover *et al.*, 2002a). Patients are not always presented with information about SB as part of standard care (Bazeos *et al.*, 1999), and even among properly counselled patients, 42–54% of patients do not use SB (Kliesch *et al.*, 1997; Rousillon *et al.*, 1999).

Only one survey to date has examined reasons invoked by cancer patients for not banking sperm. These reasons included the option was not presented, patients were told by their doctor that they were not at risk of infertility or they were interested but lacked sufficient information about SB. Communication between health care professionals (HCPs) and patients therefore seems to play a key role in influencing SB behaviour. Additional reasons cited included patients had already completed their family, they did not want to have children, patients themselves did not believe they were at risk for infertility, patients did not want to delay treatment, cost of SB, patients were too young or patients had religious or ethical concerns about SB (Schover *et al.*, 2002a). In turn, factors most strongly associated with SB include being childless at the time of diagnosis, having a greater desire for future children, having more current anxiety about the impact of cancer treatment on fertility and being younger, Jewish and more educated (Schover *et al.*, 2002a).

A companion survey of HCPs indicated that only 10% reported offering SB routinely, and reasons for this included lack of time to discuss SB, difficulty finding adequate facilities and cost of SB (Schover *et al.*, 2002b), again highlighting the role of communication between HCPs and patients. Other causes for delay in referring patients for semen cryopreservation that have been identified include low level of awareness of the need for semen preservation by the medical team, lack of data on the effectiveness of this option and longer latency before accurate diagnosis and staging of tumours (Joint Council for Clinical Oncology, 1998), as well as lack of nearby fertility clinics, urgency of the process, anxiety and cost to the patient (Leonard *et al.*, 2004).

Because preserving fertility potential in young men treated for cancer is a high priority and because communication between HCPs and patients about SB appears to have an important impact on SB behaviour, we designed this study to further explore factors that facilitate or hinder SB among survivors

of testicular cancer and Hodgkin's disease, from the perspective of both patients and HCPs. Instead of replicating prior work that relied on surveys, which limit response options, we opted for an exploratory, hypothesis-generating qualitative design that is particularly well suited to an in-depth discussion with both patients and HCPs and to the identification of the range of factors that likely affect SB behaviour.

## Methods

### Design and procedure

We chose a qualitative methodology for this study because it allows the researcher to gather data directly from a participant to capture rich normatives close to the participant's perception of a given phenomenon that is well grounded in the description they give of this phenomenon (Miles and Huberman, 1984). As such, the data are considered highly valid (Richardson, 1990).

The present investigation was part of a larger retrospective qualitative study on risk communication about chemotherapy-induced infertility among young male cancer patients. Semi-structured interviews, 60–90 min, were conducted with 20 male cancer survivors and 18 HCPs. Selection of the participants was based on the principle of sample diversification, the most important selection criterion in qualitative research (Laperrière, 1997), and the diversification of sampling was based on the clinical goal to be achieved and the degree of generalizability desired (Miles and Huberman, 1984). In this research, our team's work is geared towards developing guidelines to help HCPs of various disciplines involved in caring for patients with testicular cancer and Hodgkin's disease promote SB more effectively.

Diversification can be further broken down into external diversification and internal homogeneity. In this study, external diversification was achieved by selecting patients who were 2–10 years post-diagnosis, to capture the experience of individuals currently at various stages of survivorship, whereas homogeneity was achieved by recruiting patients who had all received gonadotoxic chemotherapy treatment for either testicular cancer or Hodgkin's disease. In the case of HCPs, external diversification was achieved by selecting HCPs from several disciplines involved in caring for these two cancer populations, whereas homogeneity was achieved by selecting only HCPs who had direct experience in either counselling these patients around, or referring them for, SB.

Eligibility criteria for cancer survivors included (i) being adult at the time of diagnosis ( $\geq 18$ ); (ii) having received chemotherapy alone or as part of combination treatment and (iii) being 1–10 years post-treatment. Patients were identified by physicians from two university hospitals in large urban area and subsequently recruited by a research coordinator once they met eligibility criteria. Patients were recruited until data saturation was reached, in other words, until the addition of novel interviews only reiterated information that had already been collected in prior interviews without adding any novel information about facilitators and obstacles to SB.

Eligibility criteria for HCPs included (i) being male or female and (ii) having experience treating testicular cancer or Hodgkin's disease patients. Health care providers were accrued through a snowball technique, that is, study's investigators invited colleagues who work with testicular or lymphatic cancer patients to participate in the study and asked them if they knew other HCPs who work with the same populations of who could be interviewed. Nominated HCPs were invited to participate and again asked if they knew other professionals who could be contacted, and so on. This process was repeated until a sufficient number of HCPs were recruited to reach data saturation.

Interviews

Interviews were conducted by trained interviewers (psychologists or graduate students in psychology) and proceeded according to an interview guide developed for the purpose of the study. Cancer survivors were asked probing questions encompassing five domains: (i) general experience of cancer and cancer treatment, (ii) communication about SB and fertility, (iii) personal experience with infertility and SB, (iv) psychological impact of cancer and infertility and (v) the impact of infertility on mood, self-image and sexual functioning. HCPs were asked about knowledge, attitude, behaviours and practice about chemotherapy-induced infertility. Specifically, interviews included questions about (i) general experience with testicular cancer and Hodgkin's disease patients and knowledge regarding fertility issues, (ii) attitudes towards the need to sperm bank and current practice in discussing fertility issues and SB with patients, (iii) perceived long-term effects of illness and treatment-induced infertility and (iv) training needs for communication skills around infertility and SB. Both survivors and HCPs were asked specifically about what they perceived to be facilitators and obstacles to SB.

When appropriate, interviewers asked additional questions to explore novel issues that were brought up spontaneously by survivors or by HCPs. Only data on facilitators and obstacles to SB from the perspective of survivors and HCPs are presented here.

Coding and analysis

Interviews were audio taped and transcribed verbatim, and transcripts were imported into N'Vivo software (version 2). Data analysis proceeded according to the theoretical approach described by Miles and Huberman (1984), which consists of three flows of analysis: data reduction, data display and conclusion drawing and verification. In the qualitative research tradition, this approach is considered to be at the crossroad between grounded theory (Glaser and Strauss, 1967) and ethnography (Laperrière, 1997).

In the first step of analysis, the data reduction phase, data are reduced to theme codes (i.e. units of analysis), identified by experienced coders. Coders use a coding key that contains a core of themes already identified in the literature that are expected to be reflected in participants' discourse, to which novel themes that emerge from the verbatims are added as new codes. This mixed approach allows researchers to combine inductive work with prestructured ideas informed by the existing literature. Each theme identified is therefore assigned a code that represents its content. In the present study, each transcript was coded by two independent coders, and all coders (four) met regularly to discuss and refine the coding framework. New codes were added when intercoder consensus was reached. In addition, coders kept detailed memos, summaries and field notes to document and compare their work during this process.

In the second step of analysis, data display, the narrative text now broken down into codes is displayed in either tables or matrices that allow for the categorization of large sum of data into manageable amounts of information (Miles and Huberman, 1984). In the present study, two types of matrices were used: (i) checklist matrices, which indicate whether a particular element is present or not in a participant's verbatim transcript, and (ii) conceptually clustered matrices, which cluster research questions that belong together to see possible links between them. We used checklist matrices to identify how many survivors had banked sperm, as well as their fertility and fatherhood status at the time of the interview. We used conceptually clustered matrices to display facilitators and obstacles to SB and the association between them when indicated.

In the third step, conclusion drawing and verification, many strategies are used to confirm interpretation, avoid biases and ensure that conclusions are well founded. The goal is to ensure that interpretation

of the data is valid, reproducible and accurate (Huberman and Miles, 1991). The strategies most applicable to the present study included search for plausibility, regrouping variables, looking for patterns and identifying relations between variables (Huberman and Miles, 1991). We also sought to identify whether a larger conceptualization or existing theory of health promotion could help organize the findings and provide a conceptual and theoretical framework that would lend greater plausibility to the results. This strategy of achieving theoretical or conceptual coherence is also described by Huberman and Miles (1991).

Participants

The final sample was comprised of 20 cancer survivors who were between the ages of 22 and 47 (mean = 32, SD = 5) and were between 1 and 8 years post-cancer treatment at the time of the interview. Their ages at the time of diagnosis ranged from 18 to 42 years (mean = 27, SD = 7). Ten had been treated for testicular cancer, nine for Hodgkin's disease and one for both testicular cancer and Hodgkin's disease. Twelve patients had received surgery and chemotherapy; four patients had undergone surgery, chemotherapy and radiation; three patients had undergone solely chemotherapy and one patient had undergone chemotherapy, radiotherapy and bone marrow transplantation. Four patients had had a cancer recurrence but were at least 1 year post-treatment for this recurrence at the time of the interview. At diagnosis, six participants were single, five were married, five were common law or in a long-term relationship, two were in a new relationship and two were divorced/separated or widowed. Six cancer survivors were high school graduates, eight had completed post-secondary education and six had a university degree. At the time of the interview, all survivors were employed full-time except for one who worked part-time and one who was temporarily out of work.

Thirteen patients (65%) had banked sperm before the initiation of treatment. Eight indicated they were infertile (i.e. had either been tested or had tried unsuccessfully to conceive), four were fertile (i.e. had either fathered a child after cancer or their sperm count was back to normal) and eight indicated they were still unsure of their status. At the time of the interview, two were trying to conceive, three had fathered at least one child before cancer, three had fathered a child after cancer naturally and one had fathered a child through IVF using banked sperm (Table I).

HCPs were between the ages of 33 and 71 (mean = 45, SD = 11). All 18 HCPs were working either with testicular cancer (n = 8) or Hodgkin's disease patients (n = 5) or both (n = 5) and had between 1.5 and 38 years of experience (mean = 13 years, SD = 11) working with either or both populations. Six were urologists, four were haematologists, three were medical oncologists and five were nurses. Eleven were men. Fourteen were married or common-law spouses, three were

Table I. Sperm banking, fertility status and fatherhood status among survivors

Banked sperm
Yes = 13
No = 7
Fertility status
Fertile = 4
Infertile = 8
Unsure = 8
Fatherhood status
Trying to conceive = 2
Parent before cancer = 3
Parent after cancer (natural) = 3
Parent after cancer (in vitro) = 1
Childless = 11

separated or divorced and one was single. All of them were employed full-time in hospitals ( $n = 17$ ) or in a private office ( $n = 1$ ).

## Results

### *Survivors' perspective*

Across the 20 survivor interviews, six factors emerged as having influenced SB decisions. These factors are summarized in Table II.

### *HCPs' role in discussing infertility and SB*

All survivors commented on the central role of HCPs, especially oncologists, in presenting information about infertility and SB and the impact of the way in which this information was presented. Of the 13 survivors interviewed who had banked their sperm, all indicated that their HCP had told them

clearly about the risk of infertility and had presented SB as part of standard care:

[. . .] I can still see [my doctor] very well, he was filling his little pad with the coordinates of the [sperm banking] clinic and he said 'Here, you go there, you have to go before such date, before I operate on you'.

They just told me to go to the sperm bank and then take care of that first [before] chemotherapy.

My physician told me you'll assume that you'll be infertile . . . it's so close that we're not going to even say there's a chance [you won't be] . . . he told me to do it . . . and for him . . . for him it wasn't a question either. For him it's like you have to go.

In some cases, the HCP had appeared unsure or unconvincing in presenting SB. As one patient stated:

**Table II.** Summary of the factors that influence sperm banking (SB) from the perspective of survivors and health care professionals (HCPs)

Survivors' perspective	HCPs' perspective
<p>HCPs' role in discussing infertility and SB</p> <p>SB facilitated when it was presented as part of standard care</p> <p>SB was hindered when it was not presented, when HCP did not insist enough, when HCP lacked information or suggested patient was at low risk for infertility</p> <p>Regrets were expressed when infertility or SB was not discussed adequately</p> <p>Fatherhood</p> <p>Importance of fatherhood</p> <p>Desire to have children is a direct and powerful motivator for SB</p> <p>Desire to parent in the future is not equally salient across patients</p> <p>Associated themes: age and role of HCP: patients who were at a stage where fatherhood had not been considered seriously appreciated being told by their HCP that fatherhood may become more important to them later on</p> <p>Fatherhood status</p> <p>Patients with children, particularly those who have completed their family, less likely to SB</p> <p>Childless patients perceive SB as a way to keep their options open</p> <p>Influence of a parent or partner</p> <p>Involvement of a parent or partner facilitates SB</p> <p>Attitudes towards survival at the time of diagnosis</p> <p>SB less likely if considered secondary to treatment and perceived as delaying onset of treatment by patients preoccupied by survival</p> <p>Optimism about survival encourages SB</p> <p>Cost of SB</p> <p>For most, not a consideration</p> <p>In a few cases, prohibitive, especially in the context of the overall financial cost of cancer</p> <p>Associated theme: influence of a parent: in some cases, a parent pays for SB</p> <p>Perceptions about the complexity and efficacy of SB</p> <p>Patients can be discouraged by the perceived complexity of SB</p> <p>Concerns about transmitting the disease to progeny may be an obstacle to SB</p>	<p>HCPs' role in discussing infertility and SB</p> <p>HCPs believed that if SB is presented to patients in a timely manner, all will use it</p> <p>Some HCPs may lack sufficient information to adequately promote SB</p> <p>Fatherhood</p> <p>Importance of fatherhood</p> <p>Desire to have children is a primary influence</p> <p>Desire is not equally salient across patients</p> <p>HCPs who believe fatherhood is important to most patients will push SB more</p> <p>Associated theme: age: young patients may be less likely to have thought about the importance of fatherhood</p> <p>Fatherhood status</p> <p>If patients do not consider their family complete, more likely to SB</p> <p>Patients who do not SB consider their family complete; some have had a vasectomy</p> <p>Influence of a parent or partner</p> <p>A parent's or partner's involvement can positively influence SB</p> <p>Patients may be influenced by their parents' desire for grandchildren</p> <p>Attitudes towards survival at the time of diagnosis</p> <p>Shock of diagnosis, preoccupation with survival and concerns about delaying treatment are obstacles to SB</p> <p>Positive outlook on survival facilitates SB</p> <p>Discussing SB can encourage a more positive outlook on survival</p> <p>HCPs may not push SB as much if patient appears to be in a critical state</p> <p>Associated theme: age: younger patients perceived to be more at risk of feeling overwhelmed by the diagnosis and more concerned about survival</p> <p>Cost of SB</p> <p>Opinions were split regarding the impact of cost</p> <p>Believed to be a consideration but not an obstacle in most cases</p> <p>May be prohibitive for some</p> <p>More likely to be prohibitive in the context of the overall financial cost of cancer</p> <p>HCPs poorly informed about the actual cost of SB</p> <p>Perceptions about the complexity and efficacy of SB</p> <p>SB less accessible to patients in rural areas</p> <p>Fear of transmitting disease or fear of abnormality in progeny may act as obstacle</p> <p>Cultural factors</p> <p>Quebecers less likely to SB than patients of immigrant descent</p> <p>Homosexuality</p> <p>Gay patients less likely to SB</p>

If the doctor had told me to do it, I would have done it, that is clear. But because he did not insist [...] it did not seem that important to do it.

Two patients did not recall being told about the availability of SB, and two indicated they had either not been told about the risk of infertility or told they were at low risk:

(Interviewer: And did they offer at any point sperm banking, or was it an issue that they raised at all?) No . . . no I was never offered that.

We spent a minimum amount of time discussing [infertility and sperm banking], it was like 'there is a chance [you might be infertile] but you are young so the chances are very very low'.

These situations appeared to lead to regret, with patients indicating they wished HCPs had been more directive in presenting SB and more insistent on making sure patients exercised this option:

(Interviewer: You seem to have some regrets about it?) Yeah because it's like . . . I didn't like realize like I said that . . . how important it is to get that thing done and maybe if he was more insistent on that.

If he had told me there was a 50/50 chance that I would be infertile, I would have done it. But instead, he said there was very little chance that I would be infertile, but it's a possibility, so you could [sperm bank].

### *Fatherhood*

Two subthemes were grouped under the broader theme of fatherhood: the importance survivors placed on having biological children and fatherhood status at the time of diagnosis. They are presented as conceptually related but different subthemes rather than as associated themes because there was no predictable association between them (i.e. a patient may recognize that fatherhood is important to him but still decide not to bank sperm because his family is complete; if a patient does not consider fatherhood important, being childless does not motivate SB).

Among patients who had been told about SB by their HCP, if their desire for children was high, SB was described as an obvious choice:

I didn't have a wife at the time [...] but it was clear I wanted children in the future, it was out of the question to think about not having children [...]. It was unthinkable to take that risk.

I knew I wanted to have children, it was always in my plans.

Just [...] being 120% confident that one day if I lived I would want children and that I didn't have a choice, like I am not a gambler [...] so I am not going to gamble with this [...].

For these survivors, the decision to bank sperm appears to have been straightforward.

The desire to father a child, however, was not equally salient for all patients. Even among patients who had been advised by their HCP to bank sperm, those who did not plan on having children in the future declined the option:

They asked if I had any kids, which I don't. They asked if I planned on having kids, which at the time I didn't . . . I still don't. They asked if I would like to look at the possibility of depositing a sample to be kept for the future. [...] I opted not to.

I wasn't interested, I literally was not interested. I could not foresee having children in the next 10 years. [...] My principal reason for getting up in the morning is myself, I don't need children to live my life.

There was a pattern association between the importance of fatherhood, age and the role of HCPs. There were patients who indicated that having been young at the time of diagnosis, they were not sure whether they wanted children in the future and it is their HCP in many cases who had warned them that fatherhood might become more important to them over time. One survivor indicated that overcoming cancer had strengthened the importance of fatherhood for him:

He kind of made me realize that it's not a choice [...] and I think it's the right thing that he did [...] he did not tell me . . . oh, do you think that you want to have kids later . . . because he knows that I don't know and he knows that my decision at that time . . . is . . . is . . . is very likely to change . . .

[...] now that I'm . . . I'm infertile [...] almost as a reaction to my disease . . . I want to leave something [behind] . . . so it's ironic.

The other subtheme under the broader theme of fatherhood was fatherhood status, which influenced SB in two ways. Those who not only already had children at the time of diagnosis but also considered their family to be complete chose not to bank sperm, and their decision appeared straightforward:

My family was complete and I didn't want other kids. No matter what, even if my wife passed on [...] I've got enough of two kids.

I had already had a vasectomy and I had two children, I did not want to have any more kids.

For other survivors who either had not yet had children or had not completed their family, SB was described as a means to keep their options open for the future, especially in the event that their health condition would worsen:

Again just in case after treatment my sperm count didn't come back, we'd like to have the opportunity to have our own children . . . biological children.

If I am fertile after great, you know, but if I am not, I have a back up plan.

Even among patients who already had children and considered their family complete, some recognized that had it not been the case, they would have banked sperm:

If I hadn't had children and had wanted them, absolutely I would have done it.

### *Influence of a parent or partner*

When either a parent or partner was involved in the treatment process or present when SB was discussed, this external support often encouraged patients to bank sperm:

It was mostly my mum that was worried about me not having children in the future.

You know what, if my mother wasn't around I may have not done it.

It was probably more important for my girlfriend at that time. (Interviewer: Was she present when sperm banking was discussed?) Yes she was.

*Attitude towards survival at the time of diagnosis*

One factor that in some cases acted as an obstacle was patients' immediate preoccupation with survival. There were survivors who reported that surviving and getting treated as soon as possible was the only thing that mattered at the time and that everything else, including SB, did not have the same priority:

[He told me] just that I might be infertile at the end, I might not have the same libido, but this was you know, information that didn't really concern me because all my focus was to get over the cancer.

It did not interest me, in fact I couldn't have cared less. I was on a save my skin mode, get cured.

I never seriously think about . . . I was young, no family here and I'm kind of like . . . I did have the possibility, but my mind was not there . . .

In contrast, optimism about survival facilitated SB:

I was sure I was going to survive [ . . . ] but I wasn't sure whether I was going to be fertile or not.

*Cost of SB*

As an indication, the cost of sperm banking in the area where the study was conducted is ~\$450 for withdrawal and banking and \$250 per year of storage afterwards. The cost of sperm banking is not covered by medicare in Canada.

Although most survivors interviewed indicated that the cost of SB had not influenced their decision, for others, cost had been a major reason why they had not banked sperm:

Especially given the cost, it was completely outside of my means.

Cost was also mentioned in the context of the broader financial impact of cancer. As one patient mentioned:

[ . . . ] you're on chemo you can't work as if you . . . a regular person, and then you get sent a bill of \$22,000.00 on top of being sick, on top of having cancer. I find the government not very good in that.

In instances such as these, where cancer has already had a sizeable financial impact on a patient, cost consideration might become more important.

An associated theme was the support of a parent. In some cases, a parent had not only been instrumental in encouraging SB, they had also paid for all expenses related to it:

I never paid for it anyways. My mother takes care of that.

*Perceptions about the complexity and efficacy of SB*

In a few cases, patients believed sperm banking was a complex procedure, which discouraged them from using this intervention:

He explained it to me like it was complicated [ . . . ] I had a little jar, I had to do it in there, then my wife had to cover it right away, then take it downtown, I don't know where [ . . . ]. He said the chances are not always positive that the sperm will be OK.

Others reported that they had had doubts about the efficacy of the procedure and concerns about the possibility of transmitting their disease to their progeny:

[Cancer] shakes up your plans because you start thinking, is it possible that I can transmit it to my children, or is it possible that I am at risk for other disease that I can transmit to my children.

*HCPs' perspective*

A few differences emerged in the discourse of HCPs compared with survivors. For example, the HCPs' role in presenting infertility and SB did not generate as much discussion, and HCPs considered age to be a risk factor for patients feeling overwhelmed by their diagnosis, an association that had not been mentioned in this context by survivors. HCPs also mentioned the influence of cultural background and sexual orientation on decisions to bank sperm, which had not been mentioned by patients. It appears plausible that HCPs would identify more factors than patients, because each HCP had had experience with a number of patients, whereas survivors only had their own experience to comment on. The eight factors mentioned by HCPs are summarized in Table II.

*HCPs' role in providing information about infertility and SB*

The belief of HCPs in this regard was that if information about SB is offered to patients and if it is presented early enough so as not to interfere with the onset of treatment, most patients would bank sperm:

If the opportunity is offered to them they will go for it. Just giving the information and the resources available that we know we can easily send the patient to.

If they get a consult at the right time and without interfering with their treatment [they will bank].

As such, the decision was described in rather straightforward, rational terms.

However, one interviewee volunteered that HCPs may, in some cases, lack sufficient knowledge about SB to promote it adequately:

[ . . . ] one aspect about sperm banking that is why perhaps some doctors don't do it it's because they don't know where it's done, they don't know how to do it, so they don't open the door.

*Fatherhood*

Both the importance of fatherhood and fatherhood status were mentioned by HCPs as having an influence on decision to sperm bank. In addition, HCPs' belief that fatherhood is important to most patients appeared to motivate them to push for SB and make sure patients keep their options open:

I think that the idea of fatherhood is precious to most men.

[ . . . ] even when they are not sure, what we tell them is that it is much easier to have some and to preserve it during a few years.

HCPs recognized, however, that the desire to parent was not equally salient for all patients:

Some people say look you know the thoughts of fatherhood is the furthest thing from my mind right now and I don't even want to think about it or talk about it.

Age was a theme associated with the importance of fatherhood from the perspective of HCPs, as they perceived younger patients to be less likely to sperm bank in part because less likely

to be at a stage in life where they would have given fatherhood serious consideration:

[. . .] they have never thought about a family at 19.

It's not what's first and foremost on their mind. First and foremost thing being, okay I want to get out of here, I want to go play basketball.

In terms of fatherhood status, HCPs believed that whether or not a patient considers his family to be complete has a direct impact on SB:

I'd say that the vast majority choose to [sperm bank] if they have not completed their family.

Yeah, they have a couple of kids and they say I'm happy with that.

They also mentioned that in some cases, patients who come for testicular cancer or Hodgkin's disease treatment have already had a vasectomy:

[. . .] if that is the case then they'll tell me well you know, I have three kids or I've had a vasectomy, which is more and more common, and they say well I'll manage [without] having any [more] kids.

#### *Influence of a parent or partner*

Much as survivors, HCPs suggested that when someone supportive of SB was involved in the treatment process, this acted as a facilitator. The presence of either a spouse or a parent was identified as potential facilitators of SB:

If they are seeing me as a couple, the wife is present and usually she's supportive and therefore it gets done.

[. . .] Often there's a parent or the other that's with them and that helps them to make the decision because they push very strongly for it usually as well.

Patients' desire to fulfil their parents' wish for grandchildren was also mentioned as a facilitator of SB:

Because sometimes they want to fulfil their parents' dream of grandchildren, so they may want to bank some sperm [. . .].

#### *Attitudes towards survival at the time of diagnosis*

As did survivors, HCPs mentioned attitudes towards survival in two different contexts: immediate preoccupation with treatment, concerns about survival and feeling often overwhelmed by these issues made SB a secondary consideration, while perceived hope about survival and about the future was identified as a factor likely to promote SB:

I think that a lot of it is that they have so many darn things on their mind that this seems pretty low in their priority. Some of them are still not convinced that they'll survive. They almost think it's trivial in reality.

One HCP mentioned that encouraging SB was a way to emphasize the positive outlook on survival:

[. . .] many people are encouraged when I bring this up because . . . oh the doctor thinks I am going to live you know?

There were HCPs who indicated that when a patient appeared to be in a critical state, they did not push for SB:

People who are very sick often refuse, because they are very sick, I don't push either, I just want to go for the treatment.

Especially when the collection of sperm sample may delay the initiation of the treatment, HCPs perceived patients as more likely to be reluctant to freeze their sperm. As one HCP recalled:

He wanted to begin his treatments at all cost, it would have taken an extra week, so he said no, it's out of the question, I am not sure enough I want kids, I refuse.

Age emerged as an associated theme in the context of preoccupation with survival, with HCPs perceiving young patients to be at greater risk of feeling overwhelmed by the diagnosis and the idea of having cancer and, in turn, less likely to bank sperm:

Yes sometimes for the youngest, they don't have that in their mind [. . .] and the shock of diagnosis makes it difficult to go toward that.

It depends on how the patient will react, it's because when you deal with these young patients, my experience is that 3/4 of them are blown away and don't know what to do.

#### *Cost of SB*

Opinions about the impact of cost were split. In some cases, HCPs mentioned that it did not seem to have a negative impact on the likelihood of SB:

Cost I think does go through people's head a bit, but usually they'll go for it anyway under the circumstances I think and most of our patients I think financially it is not as much of a concern of the patients that we see. Occasionally there's some where perhaps it is an issue, but they go through it anyway.

Other HCPs, however, believed the cost of SB to be prohibitive for some:

[. . .] some patients [. . .] couldn't even pay the \$250 or whatever cost was needed.

HCPs believe cost may be especially prohibitive when considered in the broader context of the financial impact of cancer and its treatment:

(. . .) you do have to pay a fee for it and that's actually a problem because the population of patients we see usually it's life destructing, they lose jobs, they don't have income, have trouble paying rent . . . I mean it's very disruptive and even though it's a nominal fee, in fact it's a real problem for some of them.

It was interesting to note that none of the HCPs interviewed had precise information about the cost of SB, which they estimated to range anywhere from \$250 to \$400. There were HCPs who did not know whether there were annual fees involved for storage.

#### *Perceptions about the complexity and efficacy of SB*

From the perspective of HCPs, it is not so much that the procedure itself appears complicated to patients but that other factors such as the location of SB facilities may pose an obstacle. Patients who live in rural area especially, and those who must travel a long distance to bank their sperm, appeared to HCPs as less likely to undergo the procedure:

[. . .] sperm banking will not be done in every little hospital in North America.

Embarrassment about the procedure was identified by HCPs as a factor that may also complicate SB:

I don't see why [they don't bank sperm] unless it's because they're embarrassed to go masturbate and provide a sample.

It is interesting to note that some of the survivors in our sample had also brought up embarrassment about the procedure, but that none believed it was sufficient to actually influence SB behaviour.

In terms of familiarity with reproductive technology and concerns about efficacy, one HCP acknowledged that lack of familiarity and concerns about risk to progeny may represent obstacles to SB in some cases:

There could be other factors that we don't know influence sperm banking, the availability of technology, genetic risk [. . .].

### *Cultural beliefs and sexual orientation*

Two additional factors were mentioned by HCPs that had not been mentioned by survivors: cultural background and sexual orientation. HCPs believed that patients of immigrant descent are more likely to sperm bank than native Quebecers (the present study was conducted in the province of Quebec, Canada, where the birth rate is one of the lowest in the world):

[. . .] any immigrant community normally will be more preoccupied with fertility than Quebecers, who are the lowest on the list.

As per sexual orientation, gay patients were perceived to be less interested in SB or less likely to be told about SB:

I mean, not everyone is heterosexual. We certainly have patients in our population that are male couples and I don't know what anybody says to them.

## **Discussion**

This study examined the perspective of survivors and HCPs on factors that promote or hinder SB among young men about to undergo gonadotoxic treatment for cancer. The aim was to understand why SB remains underutilized by patients at risk for infertility. The combined perspectives of survivors and HCPs led to the identification of eight factors that influence SB decisions and to the associations that exist among some of them. In addition, our choice of analytical strategy, which involved examining whether existing theories of health promotion could help achieve theoretical or conceptual coherence among our findings, led to the identification of two plausible models, the Health Belief Model (Janz and Becker, 1984) and the Elaboration Likelihood Model (Petty and Cacioppo, 1986).

In the Health Belief Model (Janz and Becker, 1984), the extent to which an individual is expected to engage in a health-promoting behaviour (e.g. SB) depends on four factors: (i) whether people believe the health threat (e.g. infertility) to be avoided by engaging in the said behaviour is severe; (ii) whether they are personally at risk for this health threat; (iii) whether there are benefits to engaging in a behaviour likely to help them avoid this threat and (iv) what obstacles may impede their ability to engage in the health-promoting behaviour.

Survivors clearly emphasized the need for HCPs to be clear and directive in addressing the high risk for infertility associated with chemotherapy regimen currently used to treat testicular cancer and Hodgkin's disease (severity), the need to make this information personally relevant (susceptibility) and the need to promote SB as a fertility-sparing intervention (benefit). Many of the survivors who took part in this study and had banked sperm indicated they had been told clearly about the high risk of infertility and the importance of SB to preserve fertility. Among the survivors who did not bank, some either had not been told about infertility or had been wrongfully told that their personal risk for infertility was low and expressed regrets about it.

Although this philosophy of communicating clearly around risk of infertility and advocating for the widespread offering of SB to all concerned patients is shared by a number of authors (Schover, 1999; Wallace and Thomson, 2003; Tournaye *et al.*, 2004), it has yet to translate into standard practice. Surveys show that only 10% of American physicians working with oncology patients adhere to this recommendation (Schover *et al.*, 2002a) and that only half of male cancer survivors who received cancer treatment that may impair fertility recalled being offered SB (Schover *et al.*, 2002b). In the UK, 68% of oncology units do not provide adequate information in regard to treatment-induced infertility and sperm cryopreservation (Bazeos *et al.*, 1999).

According to the Health Belief Model, the extent to which patients perceive fatherhood as important and whether they have had children will obviously influence their perception of the severity of the health threat posed by infertility and of the extent to which this threat is personally relevant to them. In the present study, both survivors and HCPs perceived patients with a strong desire for fatherhood as more likely to sperm bank, especially if they were still childless at the time of diagnosis or did not consider their family complete. This is consistent with a prior survey of young male cancer survivors, where men who reported a greater desire for future children were more likely to have banked sperm and where 15% of those who chose to omit the procedure stated the absence of interest towards parenthood as an important factor related to their decision (Schover *et al.*, 2002a). In the same survey, childless patients were also shown to be more likely to bank sperm (Schover *et al.*, 2002a). In a companion survey, 75% of HCPs indicated being more inclined to offer sperm cryopreservation when patients expressed a desire for future children (Schover *et al.*, 2002b).

Our data, however, suggest that the desire to parent is not equally salient for all patients at the time of diagnosis and treatment, which is consistent with data from Aass and Fossa (1988) and Ganz *et al.* (2003). In cases where patients clearly had no desire for children, they were less likely to bank sperm despite being advised to do so. In cases where patients were uncertain, survivors' reports suggest that it is desirable for HCPs to remind patients that their desire for fatherhood may increase with time and to encourage them to bank sperm to keep their options open. This is in keeping with prior research, showing that most cancer survivors desire children later on and that many consider that the experience of cancer would make them better parents (Schover *et al.*, 1999).

The third factor in the Health Belief Model, benefits, highlights the need for patients to believe that the health-promoting behaviour they are about to engage in will have benefits if they engage in it. For most survivors, this issue was not even addressed, suggesting that most probably believe SB is an efficient fertility-sparing intervention. However, this factor in the model seems especially relevant to the case of patients who may have misperceptions about the efficacy of SB or infertility treatment such as IVF and concerns about genetic risk for progeny. In this case, the model predicts that if patients do not perceive SB as offering a sufficient guarantee that they will preserve their ability to have normal children in the future, they will be less likely to choose this option.

When HCPs become aware that a patient entertains misguided beliefs about the efficacy of SB or risk to progeny, being proactive in educating the patient may help restore the patient's perception of the benefits associated with SB and promote the behaviour. Research indeed shows that the quality of the sperm of cancer patients is no more affected by the cryopreservation process than the sperm of healthy donors (Hallak *et al.*, 1999), and ARTs can lead to positive outcome when banked semen from cancer patients is used (Agarwal *et al.*, 2005). Even though a teratogenic effect of oncologic treatment has been shown in animal studies, there is no firmly established risk of increased birth defects among humans to date (Schrader *et al.*, 2001b).

To offer adequate information and education, HCPs need to have up-to-date knowledge in the field. This may not always be the case; indeed a survey of HCPs showed that 74% of oncologists were not aware of recent advances in ART, in particular those associated with ICSI (Zapzalka *et al.*, 1999). As a consequence, patients' concerns may not always be adequately addressed.

The fourth and last factor in the Health Belief Model that is a predictor of behaviour is people's perception of the obstacles associated with engaging in a given health-promoting behaviour. Obstacles identified in the present study included immediate preoccupation with survival may in some cases act as an obstacle to SB. Both survivors and HCPs mentioned instances when patients are solely preoccupied with beginning treatment and survival and that in these instances, SB becomes a consideration of low priority. This suggests that the guidance about SB we referred to earlier should be offered in a timely manner to avoid delaying the onset of treatment.

Urgency to begin chemotherapy has been identified in the past by oncologists as one of the major factors that hinders referral for semen storage (Zapzalka *et al.*, 1999). In a survey of young male cancer survivors, 9% had not banked sperm because they did not want to delay treatment (Schover *et al.*, 2002a). In parallel with this, 50% of physicians reported that patients are commonly worried that SB will postpone the beginning of treatment (Schover *et al.*, 2002b). Because an abstinence period of 24 h is sufficient for semen collection in cancer patients (Agarwal *et al.*, 1995) and because technically one sperm sample can allow several ICSI cycles to be performed, patients and oncologists can be reassured that the banking procedure will only delay minimally the initiation of the treatment.

HCPs who took part in the study perceived younger patients to be less likely to sperm bank, in part because they were perceived as being more susceptible to be overwhelmed by their diagnosis and less likely to have thought about fatherhood seriously, especially if they are diagnosed in their late teens. Although our data do not support a difference in age between survivors who sperm banked and those who did not, HCPs' perception is still important in pointing out that the susceptibility to feel overwhelmed by the diagnosis and desire for fatherhood should be assessed carefully when SB is presented.

Other obstacles identified included cost and beliefs about the complexity and efficacy of SB. In the case of cost, it was considered an obstacle in few cases but was sometimes a deciding factor. This is consistent with prior findings suggesting that financial constraints were a major obstacle for 7% of survivors who did not bank sperm (Schover *et al.*, 2002a) and suggests that physicians may overestimate the number of patients for whom SB is not affordable. In a survey by Schover *et al.* (2002b), half of the oncologists believed that SB was not affordable to most patients. This obstacle may be especially salient for young patients and for those with low support from others and may be especially important obstacle especially in the case of younger patients with no income or a limited one.

In cases where patients have misperceptions about the complexity of SB, Leonard *et al.* (2004) and Edge *et al.* (2005) suggest that providing patients with more detailed information, using appropriate terminology and giving written instructions about the correct method of semen collection may alleviate some of this discomfort. It may also help address some of patients' misperceptions about the complexity of SB, which emerged in our study as an obstacle to SB. Information leaflets were identified by survivors in our study as a potential aid to this discussion. To date, this option remains underused (Bazeos *et al.*, 1999) but has been recognized as a valuable tool in promoting SB (Schover *et al.*, 2002a). Sexual orientation was also perceived as a deterrent, with HCPs being less likely to present the option of SB to homosexual patients.

The second model that offers conceptual coherence to the findings of this study is the Elaboration Likelihood Model of Persuasion (Petty and Cacioppo, 1986). This model predicts that people's attitudes can be influenced either by the use of logic, facts and reason (central route to persuasion) or by an appeal to emotion and impressions about the communicator (peripheral route). Health-promotion programmes using the central route will be based primarily on educating individuals on the basis of statistics and medical facts. In contrast, health-promoting campaigns using the peripheral route will focus on features of the communicator that will appeal to those targeted by the campaign.

In situations such as when an individual receives a cancer diagnosis, the appeal to emotions may be so overwhelming that an individual's ability to receive and process fact-based information (central route) may be impaired (Petty and Cacioppo, 1986). In such cases, the theory predicts that health promotion will be more successful if presented by a communicator perceived as appealing to the individual (peripheral route).

As mentioned by both survivors and HCPs, when SB is presented as part of standard care and patients are sufficiently

receptive, SB is facilitated. When patients were told accurate infertility information, they were likely to have banked sperm. In addition, there were survivors who clearly stated they were glad their doctor had insisted for them to bank their sperm, whereas others wished their HCP had been more clear in presenting the risk of infertility and the need for SB. These comments were of particular interest to us, given the larger context of our investigation, which is geared towards improving communication around infertility and promoting access to SB.

Parents and partners may also help communicate facts and help decision-making around SB. This may explain why the involvement of the patient's parents or significant others in the discussion around SB can act as a facilitator. These results are in line with those of Schover *et al.* (2002a), who observed that 17% of male cancer survivors believed that a family member, either a wife, a parent or a bother, had very much influenced their decision to cryopreserve their sperm.

The feedback we received from HCPs suggests that younger patients may be especially at risk of being overwhelmed by the shock of their diagnosis, therefore putting them at risk of being less perceptive to fact-based information about SB and more likely to be influenced by their impression of the communicator. Although individuals vary in the degree to which they wish to be involved in treatment decisions, male patients and patients with a severe or life-threatening illness generally prefer less involvement in treatment decision-making (Degner and Sloan, 1992; Robinson and Thomson, 2001) or wish not to carry the burden of making an informed choice about treatment, especially when they have limited emotional resources (Schneider, 1998). However, even when patients are not actively involved in the choice of their treatment, they want to be informed about the treatment and its consequences (Vick and Scott, 1998). This suggests that in the context of decision-making about gonadotoxic cancer treatment, where patients become overwhelmed by their diagnosis and the prospect of treatment, HCPs need to assume a directive role and appeal to patients in warning them about their personal risk of infertility and the need to bank sperm. Especially during the crucial period around diagnosis, young male patients are likely to want to rely more on the guidance of their physician to make decisions about SB, and this guidance will be more effective if provided by someone who is perceived to be an expert.

We believe these two models are fitting and complementary. The Health Belief Model emphasizes how to tailor the content of the information to be given to patients about infertility and SB to improve likelihood of sperm cryopreservation. The Elaboration Likelihood Model brings attention to features of the communicator (i.e. HCPs' need to come across as appealing) and features of the recipient (i.e. need to assess patient's level of distress while SB is discussed). Both suggest interesting avenues for future research on communication and how to promote SB.

## Conclusions and implications

In light of the above findings, it is our opinion that SB should be promoted among young male cancer patients about to undergo gonadotoxic treatment, and improving practice and

doctor-patient communication around fertility-related issues are necessary steps towards achieving this goal. Accurate and personalized information about the high risk of infertility associated with treatment for testicular cancer and Hodgkin's disease should be provided to all patients in a timely manner (early) and with sufficient guidance to emphasize the benefits of the procedure in preserving future fertility potential and options for fatherhood. Possible obstacles such as high preoccupation with survival, cost, lack of support and perceived complexity or inefficacy of the procedure should be addressed proactively. Particular attention is warranted in the case of young patients, who may be at increased risk for feeling overwhelmed by the diagnosis, for not having considered fatherhood seriously or for lacking sufficient financial resources. HCPs will be more effective in promoting SB if they come across as appealing communicators.

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