

Psychological aspects of fertility preservation in men and women affected by cancer and other life-threatening diseases

Sibil Tschudin¹ and Johannes Bitzer

Department of Obstetrics and Gynecology, University Hospital Basel, Spitalstrasse 21, 4031 Basel, Switzerland

¹Correspondence address. E-mail: stschudin@uhbs.ch

TABLE OF CONTENTS

- Background
- Methods
- Results and discussion
 - Characteristics of the included studies
 - Impact of fertility issues in cancer patients
 - Attitudes towards fertility preservation
 - Experiences with counselling
 - Implications for counselling
- Conclusions and implications for future research

BACKGROUND: With advances in treatment, the number of young cancer survivors who may benefit from fertility preservation is growing. The aim of this study was to review the literature investigating psychological aspects of fertility issues and fertility preservation in patients undergoing fertility-compromising therapy for cancer or other life-threatening diseases, previous to or during their reproductive lifespan.

METHODS: Articles were identified in PubMed, Embase and PsycLIT as well as manually retrieved from literature citations for the time period from 1999 to 2008. Inclusion criteria were (i) qualitative or quantitative design, (ii) focus on patients previous to or during their reproductive lifespan and (iii) dealing with aspects such as (1) impact of fertility issues in cancer patients or (2) health professionals' and/or patients' attitudes towards fertility preservation or (3) counselling.

RESULTS: Twenty-four studies were identified. According to the studies on aspect (1), fertility is an important issue for cancer patients. Health professionals as well as patients and parents consider fertility preservation as an important option for young cancer patients; all parties involved, however, were noted to have knowledge and information deficits. Patients recalling counselling about the impact of cancer treatment on fertility ranged from 34% to 72%. Counselling is far from being offered globally to all patients at risk, and providing information seems to be selective.

CONCLUSIONS: The existing literature demonstrates the need for and the limits of current counselling. Future research should target the means to facilitate the decision-making process for patients and health professionals.

Key words: counselling / cryopreservation / psychology

Background

Recent advances in cancer therapy have resulted in an increased number of long-term cancer survivors (Donnez *et al.*, 2006; Maltaris

et al., 2006). Currently, the 5-year survival of childhood cancer lies between 75% and 80% (Wallace *et al.*, 2005) and the cure rates for certain malignancies may exceed 90% (Jemal *et al.*, 2004). Estimates suggest that by 2010, every 250th adult will be a survivor of childhood

cancer (Blatt *et al.*, 1999; Maltaris *et al.*, 2006). Depending on the type of cancer, fertility might be impaired by the disease itself, or through gonadal damage as a consequence of aggressive chemo- and/or radiotherapy regimens, as well as bone marrow transplantation (BMT) (Wallace *et al.*, 2005). The resulting infertility might be temporary or permanent. Furthermore, an increasing number of patients with non-malignant autoimmune and haematological diseases are being successfully treated with chemo- or radiotherapy (Maltaris *et al.*, 2007). For all patients affected by a disease that could impair fertility before or during the reproductive lifespan, strategies to preserve their fertility and the ability to bear their own children may be of utmost importance. Most of the currently available strategies to preserve fertility, however, are far from well established and have inherent associated risks (ovarian stimulation and surgical risk, when removing testicles or ovaries) and an impact on cancer risk (ovarian stimulation in the case of hormone-sensitive cancer) (Sonmezer *et al.*, 2005; Kim, 2006; Pacey, 2007). All patients concerned, as well as their families and the medical staff responsible for their care, are confronted with a unique and challenging situation that demands special considerations and research with regard to the psychological impact and consequences.

The aim of the present article is to review the studies published during the last decade (1999–2008) investigating the psychological aspects of fertility issues and fertility preservation in patients affected by cancer or other life-threatening diseases previous to or during their reproductive lifespan. These are summarized and discussed in three sections focusing on (1) the impact of fertility issues in cancer patients, (2) attitudes towards fertility preservation from the health professionals' and/or patients' perspective and (3) experiences with, as well as implications for, counselling.

Methods

An initial search in PubMed, Embase and PsycLIT for the time period from 1999 to 2008 using the terms 'fertility', 'fertility preservation', 'infertility', 'cancer', 'cancer survivors', 'psychology' and 'counselling' was performed; additional articles cited in the identified papers were retrieved manually.

Papers were defined as eligible when the study design was either qualitative or quantitative and dealt with cancer patients previous to or during their reproductive lifespan. In addition, the study had to focus on one of the following aspects:

- (1) the impact of fertility issues in cancer patients;
- (2) attitudes towards fertility preservation from the health professionals' and/or patients' perspective;
- (3) experiences with counselling or implications for counselling.

The articles that covered more than one of the chosen aspects were reviewed for each of them separately and are discussed in the corresponding paragraphs. Furthermore, the discussion was complemented by underlying theoretical considerations and models, where appropriate.

Results and discussion

Characteristics of the included studies

In total, 24 studies were identified, which fulfilled the eligibility criteria; 8 with a qualitative and 16 with a quantitative approach. Ten papers focused predominantly on the impact of fertility issues in cancer patients. Three of these papers and another eight concerned the

opinions and attitudes of health professionals (five studies) and of cancer patients and their families (six studies). Five of the aforementioned papers and six additional ones dealt with current counselling practices. The age range of the included patients differed between studies and ranged from a minimum of 10 years to a maximum of 47 years. In Table I, all studies included are listed and the chosen design, methods and sample characteristics as well as the main focuses of the study indicated.

Impact of fertility issues in cancer patients

General consideration

Young individuals affected by cancer are confronted with a life crisis in two respects: the cancer diagnosis itself and the threat of impaired fertility. Cancer is a life-threatening disease and can evoke fear of death (Hockenberry-Eaton *et al.*, 1995; De Graves and Aranda, 2008); furthermore, infertility might compromise self-esteem, identity, sexuality and self-image. The inability to procreate can be experienced as a narcissistic wound resulting in feelings of emptiness and defeat, and being deprived of parenting tasks can evoke feelings of loss (Dunkel-Schetter and Lobel, 1991; Hammer Burns, 2000; Oppenheim *et al.*, 2005). These are theoretical considerations that have been and still have to be further evaluated with regard to cancer survivors. In a review of the existing literature from 1986 to 1998 on fertility issues in cancer patients, Schover focused on particular aspects such as infertility distress, concerns about health risks for the patients and/or offspring, attitude towards adoption and third party donation, and attitudes towards parenting in cancer survivors. From her findings, she formulated the following eight hypotheses: (1) cancer survivors might have higher infertility distress, with (2) adolescents being more distressed than adults, (3) women more often distressed than men, and (4) those with inheritable cancers more frequently distressed than those with non-inheritable cancers. (5) Lower quality of life might be associated with less concern with regard to infertility. (6) Cancer survivors might see the relationship with children more positively and (7) be more likely to prefer adoption or third party donation. (8) Overall, they may lack accurate risk knowledge (Schover, 1999). We felt that an analysis of the more recent literature might be able to better confirm or refute some of these hypotheses, and therefore examined the studies subsequent to Schover's review.

Study findings

Significance of fertility issues. The studies reviewed were aimed at investigating the impact of fertility issues in male and female cancer patients; four are qualitative studies and six are cross-sectional surveys and they focus on experiences, attitudes and emotions regarding cancer-related infertility. The results of Dunn and Steginga's qualitative study of 23 breast cancer patients suggested future fertility to be an important consideration at the time of treatment planning (Dunn and Steginga, 2000). The findings of an exploratory study by Green *et al.* on 15 male cancer survivors illustrated that men also found the prospect of infertility disturbing (Green *et al.*, 2003). Furthermore, these authors, as well as those of another qualitative study on young men recently diagnosed and treated for cancer, found that feelings about possible infertility seemed to be variable over time and to depend on the current life period (Chapple *et al.*, 2007). In a convenience sample of 32 (14 female and 18 male) childhood cancer survivors, most of the

Table 1 All reviewed studies, the chosen design, methods and sample characteristics, as well as the studies' main focuses.

Reference	Type of study	Objectives			Methods	Sample	
		Cancer and fertility	Fertility preservation (attitudes and needs)	Counselling practices		Size	Characteristics
Schover <i>et al.</i> (1999)	Pilot survey	✓		✓	Purpose-built postal questionnaire including SF-36 for quality of life	132/283 eligible patients (47%): females: 89 (49.7%) males: 43 (41.2%)	Patients from a tumour registry Inclusion criteria: cancer free for at least 15 months diagnosed between 18 and 35 years
Zapzalka <i>et al.</i> (1999)	Survey		✓		Postal questionnaire	46/165 contacted oncologists Return rate: 28%	All members of the American Society of Clinical Oncology in Minnesota
Dunn and Steginga (2000)	Qualitative study	✓			Multi-angulated method including: literature review 2 focus groups 4 in-depth interviews -a three-round iterative survey	23 patients	Women with breast cancer: age range: 31–47 years 1 months to 7 years post-treatment
Schover <i>et al.</i> (2002b)	Survey		✓		Postal questionnaire	162/690 contacted oncologists Return rate: 24%	Oncologists from two cancer centres including 26 allied sites
Schover <i>et al.</i> (2002a)	Two-centre survey	✓	✓	✓	Purpose-built postal questionnaire	201/904 contacted patients Return rate: 27%	Patients from tumour registries of two centres Inclusion criteria: new diagnosis of cancer, age 14–40 years, treatment potentially impairing fertility
Green <i>et al.</i> (2003)	Qualitative exploratory study	✓			One-hour semi-structured interview	15 patients	Young male cancer survivors attending one oncology centre
Thewes <i>et al.</i> (2003)	Qualitative study			✓	Four 1 1/2 hour focus groups 8 individual semi-structure telephone interviews Quantitative ranking of information tools	24/36 eligible patients (66%)	Early stage breast cancer patients Inclusion criteria: 18–45 years, commenced or completed adjuvant therapy, English speaking
Crawshaw <i>et al.</i> (2004)	Qualitative		✓		Semi-structured interviews with selective transcription	22 health and social work professionals	10 doctors, 6 nurses, 4 scientists and 2 social workers from 2 regional paediatric oncology centres and the affiliated assisted conception units
Zebrack <i>et al.</i> (2004)	Qualitative exploratory study	✓			Semi-structured telephone interviews transcription and data coding by two reviewers	Convenience sample 32/86 contacted childhood cancer survivors	Patients from a database over last 20 years Inclusion criteria: ≥ 18 years, 5 years from diagnosis, chemo-, radiotherapy and/or surgery, English or Spanish speaking, US residents

Continued

Table I Continued

Reference	Type of study	Objectives		Counselling practices	Methods	Sample Size	Characteristics
		Cancer and fertility	Fertility preservation (attitudes and needs)				
Partridge <i>et al.</i> (2004)	Web-based survey	✓		✓	One-time survey with piloted questionnaire including HADS and Lasry Fear of Recurrence Scale	657/1702 invited members of Young Survival Coalition (YCS)	Breast cancer patients Inclusion criteria: premenopausal, ≤40 years at diagnosis
Duffy <i>et al.</i> (2005)	Survey			✓	Telephone interviews and postal questionnaire including validated instruments MHI-5, IES, CARES*	164/183 eligible patients (89.6%)	Young women undergoing chemotherapy for breast cancer (144 premenopausal, 107 ≤ 45 years)
Saito <i>et al.</i> (2005)	Survey	✓	✓		Postal questionnaire	51/66 eligible patients (77.3%)	Cancer patients from one centre with cryopreserved sperm Inclusion criteria: age > 20 years, chemotherapy with or without BMT, cryopreservation > 1 year
Thewes <i>et al.</i> (2005)	Survey			✓	Postal self-report questionnaire on fertility- and menopause-related information, decision-making, HADS, STAI-short form, GCS and FACT-B*	228/275 eligible breast cancer patients (83%)	Early stage breast cancer patients recruited at 12 urban and 7 rural Australian oncology clinics Inclusion criteria: 18–40 years at the time of diagnosis, diagnosed 6 months to 5 years previously, treated with adjuvant systemic therapies Exclusion criteria: metastatic disease/no English
Zanagnolo <i>et al.</i> (2005)	Survey	✓			Postal questionnaire	68/75 patients	Patients with malignant ovarian tumours Inclusion criteria: conservative treatment ≥ 15 years
Achille <i>et al.</i> (2006)	Qualitative study			✓	In-depth interview	20 patients 18 health professionals	Male patients from two university hospitals Inclusion criteria: ≥ 18 years at diagnosis, having received chemotherapy, 1–10 years post-treatment Health professionals Inclusion criteria: male or female, having experience treating testicular cancer or Hodgkin's disease patients

Burns <i>et al.</i> (2006)	Cross-sectional survey	✓		Purpose-built questionnaire	50/54 approached families	Convenience sample: 53% leukaemia, 47% various other childhood cancers Inclusion criteria: 10–21 years of age Exclusion criteria: known infertility/non-English/endstage
Chapple <i>et al.</i> (2007)	Qualitative study	✓	✓	Narrative interviews analysed by qualitative interpretive approach	21 patients	Young male patients in the UK diagnosed with different types of cancer Aged 16–26 years
Goodwin <i>et al.</i> (2007)	Survey	✓		36-item questionnaire	30/32 eligible health-care professionals Return rate: 93.8%	55.3% physicians, 46.6% nurses and nurse practitioners of a Paediatric Haematology/Oncology Division
Quinn <i>et al.</i> (2007a)	Qualitative study	✓	✓	Open-ended, in-depth face-to-face interviews	16 oncologists (13 males, 3 females)	Oncologists from one cancer centre
Van den Berg <i>et al.</i> (2007)	Survey	✓		Postal questionnaire	117/159 eligible families	Parents of boys surviving childhood cancer between 1993 and 2003 at one children's hospital
Zebrack <i>et al.</i> (2007)	Web-based survey		✓	Online questionnaire	1088 patients recruited via Lymphoma Research Foundation's website: females 823 (76.2%) males 257 (23.8%)	Young adult cancer patients Inclusion criteria: age 18–39 at the time of study, age 15–35 at the time of cancer diagnosis
Oosterhuis <i>et al.</i> (2008)	Survey	✓	✓	Piloted questionnaire	40/45 eligible adolescent patients (88.8%) 129/163 eligible parents (79.1%)	Paediatric cancer patients of one centre Inclusion criteria: ≥ 14 years, routine follow-up visit
Van den Berg and Langeveld (2008)	Survey		✓	Questionnaire	117/159 families returning 202/234 questionnaires	Parents of chemotherapy treated childhood cancer survivors at one centre
Ginsberg <i>et al.</i> (2008)	Survey	✓		Eleven-item questionnaire	45/53 patients intending to bank sperm and 5/8 not intending to bank sperm 46/50 parents	Cancer patients and their parents approached for sperm banking at one centre Inclusion criteria: disorder requiring cancer therapy, scheduled for chemotherapy, ≥ Tanner Stage III

*MHI-5, Mental Health Inventory for emotional distress; IES, Impact of Event Scale for post-traumatic stress disorder symptoms; CARES, Cancer Rehabilitation Evaluation System; HADS, Hospital Anxiety and Depression Scale; STAI, State-Trait Anxiety Inventory; GCS, green Climacteric Scale; FACT-B: functional Assessment of Cancer Therapy-Breast.

participants expressed a desire to have children in the future, although almost 60% were uncertain about their fertility, and judged family and parenting as very important (Zebrack *et al.*, 2004). The percentage of patients with concerns about future fertility differed from one survey to the other, with 25% in a sample consisting of male and female patients from a tumour registry (Schover *et al.*, 1999), 32% in a sample of male patients from a tumour registry (Schover *et al.*, 2002a), 51% in a sample of patients with ovarian cancer (Zanagnolo *et al.*, 2005), 57% in breast cancer survivors (Partridge *et al.*, 2004) and 60% in male cancer patients, in spite of having their sperm cryopreserved (Saito *et al.*, 2005).

Factors influencing fertility concerns. Oosterhuis *et al.* could confirm these findings in their survey on 37 adolescent cancer patients and 97 parents of paediatric patients, but they also revealed the above mentioned knowledge deficits and misperceptions about the risk of infertility relative to treatment received (Oosterhuis *et al.*, 2008). This points out that the degree of concerns about fertility seems to depend on factors other than evidence based risk-estimation as well. The concerns were more pronounced in patients who did not have children prior to cancer diagnosis, and were 31% and 76% for women with and without children, and 26% and 76% for men with and without children, respectively (Schover *et al.*, 1999, 2002a). In breast cancer patients, greater concerns about infertility were associated with the wish for a child, lower number of prior pregnancies and prior difficulty in conceiving (Partridge *et al.*, 2004). Cancer did not influence the desire for pregnancy in 71% of women and 68% of men, and in 70% of patients with ovarian cancer, respectively (Schover *et al.*, 1999, 2002a; Zanagnolo *et al.*, 2005). Twenty-nine per cent of breast cancer survivors claimed that concerns about future fertility had an impact on their decision with regard to therapy (Partridge *et al.*, 2004).

Generally speaking, the existing literature shows that fertility is an important issue for cancer patients and that there is considerable concern regarding the fertility impairment due to cancer and its treatment.

Attitudes towards fertility preservation

General considerations

Nowadays, patients affected by cancer, prior to or during the reproductive lifespan, and their physicians have to make decisions not only with regard to the best cancer treatment option but also with regard to fertility preservation should the cancer be successfully overcome. Cancer is life threatening, and may evoke fear of death; furthermore, it has implications of individual suffering, pain, dependence, loss and a challenge to self-confidence and self-esteem (Bodurka-Bevers *et al.*, 2000; Ganz *et al.*, 2002; Trask *et al.*, 2002; Brown *et al.*, 2003). To the contrary, fertility is associated with new life, hope, joy, pride, strength, optimism, sense in life and growth (Hammer Burns, 2000). Therefore, fertility preservation represents, in many respects, the opposite of cancer. At first glance, fertility preservation is a promising option. The fact, however, that most methods are far from being well established or are even still experimental and no method guarantees success requires ethical considerations before being undertaken. These recommendations are discussed elsewhere (ESHRE Task Force on Ethics and Law, 2004).

The health professionals' and patients' perspective

When considering not only the ethical but also the psychological impact of decision-making in fertility preservation, insight into the opinions, attitudes and needs of all parties involved (health professionals, patients and their families) is of utmost importance. Only a few studies have focused on these aspects. Five of these studies dealt with health professionals, whereas six others with patients and their parents, and are briefly summarized below.

Health professionals. The return rate of two postal questionnaires to oncologists was low, at 28% and 24%, respectively (Zapzalka *et al.*, 1999; Schover *et al.*, 2002b). This low return rate might have led to a bias towards more interested physicians. The study conducted by Schover *et al.* showed that as many as 91% of health professionals felt that sperm banking should be offered to all patients at risk, but 48% of them state that they either never bring up the topic or do so in <25% of instances. This and other surveys on professionals revealed some important knowledge deficiencies (Crawshaw *et al.*, 2004). In the study of Zapzalka *et al.*, only 26% of oncologists knew about intracytoplasmic sperm injection (Zapzalka *et al.*, 1999). The study by Goodwin *et al.* assessing paediatric health professionals' knowledge and attitudes on fertility preservation showed deficits in knowledge with regard to advanced fertility preservation techniques, limited interdisciplinary interchange, e.g. with infertility specialists, and 64.3% reported difficulties with regard to access to centres providing fertility preservation. Most parents (85.7%) and more than half of the patients (57.2%), especially those with more advanced age, were concerned about fertility impairment and broached the issue themselves (Goodwin *et al.*, 2007). Similarly, a qualitative study on oncologists of adult patients also revealed a lack of knowledge on fertility preservation resources as a major barrier to discussion (Quinn *et al.*, 2007a).

Patients' and their parents' attitudes. A two-centre survey conducted by Schover *et al.* was aimed at determining the knowledge, attitude and experience of male cancer patients regarding cancer-related infertility and sperm banking (Schover *et al.*, 2002a). The return rate was low (27%), and even though a comparison with the non-responders showed no differences with regard to institution, age, ethnicity and type of cancer, the authors point out that there might be a bias towards higher education of the responders and suggest an overestimation of distress, knowledge and the use of sperm banking when compared with cancer survivors across the USA in general. Fifty-one per cent of the respondents wanted children in the future, and the same percentage of them had been offered sperm banking. Only 24% of men, however, eventually banked sperm. They were significantly ($P < 0.001$) more often childless, had a greater desire for future children, had more current anxiety about the impact of cancer treatment on fertility and were younger in age. Lack of information was the most common reason for failing to bank sperm. Burns *et al.* conducted an exploratory cross-sectional survey on a convenience sample of 50 female adolescent cancer patients and their parents by means of a questionnaire specifically developed for this purpose (Burns *et al.*, 2006). More than 80% were interested in pursuing research-based fertility preservation techniques, but only 30% would be willing to wait one month or more to start cancer treatment due to any fertility preservation procedure. Adults and adolescents had >70% agreement in their responses and there was no statistically significant disagreement between them. In accordance with these results, Ginsberg *et al.* could demonstrate a high agreement

between patients and parents in their survey on adolescent patients' and their parents' perspective on sperm banking (Ginsberg *et al.*, 2008). More parents of patients than patients themselves, however, were concerned about future fertility of their sons at diagnosis (65.9% and 40.1%, respectively, $P = 0.04$) and more of them were very positive about the idea of sperm cryopreservation as well (80.4% and 55.1%, respectively, $P = 0.01$).

Factors influencing decision-making. When comparing 25 male cancer survivors who had banked sperm on their own initiative with 26 patients who had banked sperm on their physician's instructions, Saito *et al.* could demonstrate that the former felt significantly more invigorated by the fact of having cryopreserved sperm (Saito *et al.*, 2005). Chapple *et al.* illustrated the importance of choice and involvement in the decision-making process in a qualitative study with narrative interviews with young men recently diagnosed and treated for cancer (Chapple *et al.*, 2007). Van den Berg *et al.* surveyed the parents of all boys surviving childhood cancer during an 8-year period at a Dutch children's hospital (Van den Berg *et al.*, 2007). Their hypothetical desire and acceptance of the idea of spermatogonial stem cell (SSC) cryopreservation were assessed. The response rate was 74% (117 of 159 eligible families). Sixty-two per cent of parents from prepubertal boys would have given consent to collect SSCs by testicular biopsy at the time of initial diagnosis, and 34% if hemicastration would have been necessary for the collection. Parents from pubertal boys would have given consent in 60% and 27% of cases, respectively. In comparison, the collection of sperm by masturbation or electrostimulation was approved by 70%. The acceptability of hemicastration was significantly lower than all other forms of SSC/sperm collection (at least $P < 0.013$). There were no significant differences when comparing responses from mothers with those from fathers.

Summary

In conclusion, health professionals as well as patients and their parents consider fertility preservation an important option for young cancer patients, although for the patients themselves, the perceived relevance seems to depend on factors such as the stage of life at cancer diagnosis. All parties involved were shown to have knowledge and information deficits. On the basis of the available study results, one can suggest that parental support is important and required regarding this issue, and that patients and parents are usually in agreement.

Experiences with counselling

General considerations

Guidelines on fertility preservation underline the importance of informing patients affected by cancer, prior to or during the reproductive lifespan, about possible fertility impairment due to cancer treatment and the available options to preserve fertility (Royal College of Obstetrics and Gynaecologists, 2000; Lass *et al.*, 2001; Practice Committee of the American Society for Reproductive Medicine, 2004; Lee *et al.*, 2006; American Society of Clinical Oncology, 2006). In reality, however, many patients seem to lack sufficient information on this topic.

The eight studies presented below focused on current counselling practices and patients' recollections of having been informed about fertility and the options to preserve it.

Recall of counselling

The percentage of patients recalling counselling about the impact of cancer treatment on fertility ranges from 34% to 72%. In the study by Schover *et al.*, the percentage was significantly higher in patients who had had at least one treatment likely to impair fertility ($P < 0.001$) (Schover *et al.*, 1999). The cross-sectional survey by Duffy *et al.* including 107 patients younger than 45 years under chemotherapy for breast cancer showed a lower odds ratio for counselling with more advanced age and higher anxiety level (Duffy *et al.*, 2005). In another study by Schover *et al.* published in 2002, 60% of male cancer survivors ($n = 201$) who recalled counselling cited the most common health professionals to discuss cancer-related infertility as the treating physicians (55%), followed by nurses (21%) or family physicians (8%) (Schover *et al.*, 2002a, b). For the 51% recalling counselling on sperm banking, the most common health professionals to discuss this issue were the oncology physicians (40%), followed by nurses (14%).

Effects of counselling

Men who had no recollection of being told by a health provider about sperm banking were significantly less likely to have chosen to cryopreserve sperm than those who had been informed (11% and 36%, respectively, $P < 0.001$). The most frequent reason not to bank sperm was that they had not been given the information they needed by the health-care team. Men who had been informed about the potential for cancer-related infertility and men who chose to bank sperm scored higher on knowledge regarding this area ($P = 0.017$ and 0.002 , respectively) (Schover *et al.*, 2002a). In the study by Partridge *et al.* including 657 breast cancer survivors, 72% of women reported that they had discussed fertility concerns with a doctor and 17% had discussed the issue with a fertility specialist (Partridge *et al.*, 2004). Half of the women felt that their concerns about fertility were adequately addressed, but a substantial minority of women (26%) reported that their concerns had not been adequately addressed at the time of diagnosis. The majority of respondents (86%) reported knowing at diagnosis that adjuvant chemotherapy might affect fertility. Women who were diagnosed more recently were more likely to know about the impact of treatment on fertility than those who were diagnosed several years ago ($P = 0.0028$). The results of a study by Thewes *et al.* of 228 early stage breast cancer patients are in line with Partridge *et al.*'s findings (Thewes *et al.*, 2005). Seventy-one per cent reported that they had discussed fertility-related information with a health professional. Bivariate analysis revealed that younger women were significantly more likely to rate this information as extremely important ($P < 0.001$) and in the final model of an ordinal logistic regression analysis of correlates of perceived importance of fertility-related information, three variables remained significant: women who had plans to have children at the time of diagnosis ($P < 0.01$; OR = 16.94, 95% CI, 7.10–40.45), women without children at diagnosis ($P = 0.04$; OR = 1.07, 95% CI, 0.29–1.36) and women who desired more information ($P = 0.02$; OR = 1.55, 95% CI, 1.07–2.25).

Patients' needs

Zebrack *et al.* recruited 1088 young cancer patients and survivors via the Lymphoma Research Foundation's website to take part in an online survey to assess their supportive care needs (Zebrack *et al.*,

2007). For younger patients, counselling and information around fertility were more important and females ranked counselling about fertility, reproductive problems and options for having children significantly higher than males ($P = 0.006$). In contrast with Patridge *et al.* who found that 26% of women were not satisfied by the counselling received, in Oosterhuis *et al.*'s study of 97 parents of paediatric cancer patients and 37 adolescent patients themselves, as little as 29.9% of the parents and a similar proportion of patients were satisfied with the amount of information received (Oosterhuis *et al.*, 2008). A lack of recall of discussion does not necessarily mean that no information had been provided, which could be demonstrated by Van den Berg *et al.* In his study, all 202 parents of 117 male childhood cancer patients had been informed on the fertility issue at the consent procedure, but only 50% of them recalled statements on the effect on fertility and 36% indicated that this had not been the case (Van den Berg and Langeveld, 2008).

In conclusion, counselling regarding fertility issues is far from being offered globally to all patients at risk, and the provision of information by health professionals as well as patient and parental recall of having been informed seems to be selective.

Implications for counselling

Current practice and requirements

As demonstrated above, not all physicians discuss fertility preservation with every cancer patient of childbearing age. This might be due to their partly insufficient knowledge, lack of accessible resources for fertility preservation and the particularly challenging counselling setting (Crawshaw *et al.*, 2004; Quinn *et al.*, 2007a, b). As counselling has to be offered within the small time period between diagnosis and treatment start, there is time pressure. Besides decisions concerning treatment strategies, the patients concerned have to make additional decisions with regard to fertility preservation, and this in a moment that is experienced as a life crisis and considerable challenge by most of them (Bodurka-Bevers *et al.*, 2000; Ganz *et al.*, 2002; Trask *et al.*, 2002; Brown *et al.*, 2003). This requires specific communication strategies and skills. Ethical and legal considerations build the framework within which health professionals have to offer their counselling. As mentioned above, various expert groups have formulated guidelines for counselling prior to infertility preservation. In addition, health professionals counselling in the context of fertility preservation should have profound knowledge of current strategies and their efficiency, and should make an effort to keep themselves up to date on this issue. To be able to meet the patients' needs and to alleviate possible barriers, contextual information about the patients' individual situations is indispensable.

Factors influencing the use of fertility preservation

In a qualitative study consisting of in-depth interviews of 20 male cancer survivors and 18 health professionals designed to examine their perspectives on factors that facilitate or hinder sperm banking, eight factors were identified as having an impact on sperm banking (Achille *et al.*, 2006). The results of the study were conceptually consistent with the health belief model (Hochbaum, 1958; Rosenstock, 1966) and the elaboration likelihood model of health promotion (Petty and Cacioppo, 1986).

The health belief model. In the health belief model, the likelihood that an individual engages in an action or behaviour depends on four factors: (i) the perceived health threat that might be avoided by the behaviour, (ii) the personal risk for the health threat, (iii) the benefits when engaging in a behaviour and (iv) obstacles or barriers that may impede engaging in the behaviour. Survivors emphasized the need for health professionals to be clear and directive in addressing the risk for infertility associated with cancer treatment regimens (severity), the need to make this information personally relevant (susceptibility) and the need to promote sperm banking as a fertility-sparing intervention (benefit). The authors point out that although the desire to parent is not equally salient for all patients at the time of diagnosis and treatment, the existing literature suggests that most cancer survivors desire children at a later time and that many consider that the experience of having cancer would make them better parents (Achille *et al.*, 2006; Schover *et al.*, 1999). They therefore conclude that it is desirable for health professionals to remind patients that their desire for parenthood may increase, especially in very young patients, and to encourage them to keep their options open by using fertility preservation offers.

The elaboration likelihood model. The elaboration likelihood model of persuasion predicts that people's attitudes can be influenced either by the use of logic, facts and reason (central route of persuasion) or by an appeal to emotion and impressions about the communicator (peripheral route). In certain 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, and the promotion of a certain behaviour might be more successful if presented by a communicator perceived as appealing to the individual (peripheral route). As shown in the study of Schover *et al.*, patients were more likely to bank sperm when they had received accurate information and clear presentation of the risks by a doctor who insisted on the importance of banking sperm. At the same time, possible obstacles such as high preoccupation with survival, cost, lack of support and perceived complexity, as well as the potential inefficacy of the procedure, should be addressed proactively. Considering the emotional impact of experiencing cancer, the patients' knowledge that their fertility potential is secured might help to cope with and overcome this serious disease. In the survey by Schover *et al.*, feeling healthy enough to be a good parent after cancer was the strongest predictor of emotional well-being (Schover *et al.*, 1999). On the other hand, however, patients' expectations with regard to the success of the more or less established or even experimental fertility preservation techniques may be far too high and false hopes leading to deception may be evoked.

Counselling options and limitations

Most studies on experiences with fertility preservation present and discuss findings in the context of sperm banking. This is—even if sometimes distressing, especially for younger boys—a simple method, in comparison with procedures necessary for oocyte freezing or the cryopreservation of ovarian tissue. Reports of pregnancies and deliveries after such procedures have been published during the recent years and cancer survivor websites such as fertilehope.org report individual success stories, but no studies exist to systematically examine the emotional impact and effects of these procedures (Donnez *et al.*, 2004, 2006; Davis, 2006; Yang *et al.*, 2007). Furthermore, depending on the course of cancer therapy, undergoing a fertility

Table II Information exchange: basic principles (Miller and Rollnick, 2002)

Elicit	Patient's pre-existing knowledge and questions
Provide	Give information in small units and short sentences
Elicit	Patient's understanding and evaluation of the information. 'What does this information mean to you?'

Table III Patient-centred approach: principles of reflective listening (Rogers and Farson, 1979)

More listening than talking
Responding to what is personal rather than to what is impersonal, distant or abstract
Restating and clarifying what the other has said, not asking questions or telling what the listener feels, believes or wants
Trying to understand the feelings contained in what the other is saying, not just the facts or ideas
Working to develop the best possible sense of the other's frame of reference while avoiding the temptation to respond from the listener's frame of reference
Responding with acceptance and empathy, not with indifference, pure objectivity or fake concern

preservation strategy may not always be in the best interest of a patient. Besides this, a promising technique may not be available for all patients who could profit from it. Therefore, many patients will ultimately have to adjust to the fact that they will not be able to produce a biological child, and will need support and assistance to grieve this loss.

Counselling strategies

In summary, counselling should take into account the patient's individual background and context, be provided in a timely, clear, transparent and accurate manner, and address the patient's emotional needs. A helpful strategy is to apply the well-established model developed by Miller and Rollnick and the communication skills of active listening typically used in a patient-centred approach (Rogers and Farson, 1979; Miller and Rollnick, 2002) (Tables II and III). When considering by which means such information should be provided, Thewes *et al.* found in their retrospective qualitative study published in 2003, as well as in their more recent quantitative study, that medical oncologists and fertility specialists ranked higher than other health professionals as well as other various types of information sources (decision aids, leaflets and internet) (Thewes *et al.*, 2003, 2005).

Conclusions and implications for future research

With advances in the treatment of cancer and other life-threatening diseases, the number of young survivors with impaired fertility is growing. As the existing literature based on surveys as well as qualitative and exploratory studies has revealed, fertility is a clear issue for cancer patients. Affected patients and their families are interested in information about fertility issues. Many of them state that they are

in favour of fertility preservation. At present, however, only some of them receive information prior to treatment for various reasons. Fertility preservation is far from being accessible to all, and not all health professionals have adequate knowledge and sufficient communication skills to counsel the concerned patients in a timely and supportive manner. Information transfer is challenging in this situation, and emotional support is demanding in this ethically and emotionally complex field, in which various meaningful issues have to be broached in the short time period between diagnosis and commencement of treatment. Future research should target the means to facilitate the decision-making process for patients as well as health professionals. With deeper insight into patients' needs and decisional conflicts, and through more thorough behavioural and communication research, the tools and resources for shared decision-making in fertility issues and fertility preservation for cancer patients can be further developed to the benefit of both the patients and their medical caretakers.

References

- Achille MA, Rosberger Z, Robitaille R, Lebel S, Gouin JP, Bultz BD, Chan PT. Facilitators and obstacles to sperm banking in young men receiving gonadotoxic chemotherapy for cancer: the perspective of survivors and health care professionals. *Hum Reprod* 2006;**21**:3206–3216.
- American Society of Clinical Oncology. Recommendations on fertility preservation in cancer patients. *J Clin Oncol* 2006;**24**:2917–2931.
- Blatt J. Pregnancy outcome in long-term survivors of childhood cancer. *Med Pediatr Oncol* 1999;**33**:29–33.
- Bodurka-Beyers D, Basen-Engquist K, Carmack CL, Fitzgerald MA, Wolf JK, de Moor C, Gershenson DM. Depression, anxiety, and quality of life in patients with epithelial ovarian cancer. *Gynecol Oncol* 2000;**78**:302–308.
- Brown KW, Levy AR, Rosberger Z, Edgar L. Psychological distress and cancer survival: a follow-up 10 years after diagnosis. *Psychosom Med* 2003;**65**:636–643.
- Burns KC, Boudreau C, Panepinto JA. Attitudes regarding fertility preservation in female adolescent cancer patients. *J Pediatr Hematol Oncol* 2006;**28**:350–354.
- Chapple A, Salinas M, Ziebland S, McPherson A, MacFarlane A. Fertility issues: the perceptions and experiences of young men recently diagnosed and treated for cancer. *J Adolesc Health* 2007;**40**:69–75.
- Crawshaw M, Glaser A, Hale J, Sloper P. Professionals' views on the issues and challenges arising from providing a fertility preservation service through sperm banking to teenage males with cancer. *Hum Fertil* 2004;**7**:23–30.
- Davis VJ. Female gamete preservation. *Cancer* 2006;**107**(Suppl 7):1690–1694.
- De Graves S, Aranda S. Living with hope and fear—the uncertainty of childhood cancer after relapse. *Cancer Nurs* 2008;**31**:292–301.
- Donnez J, Dolmans MM, Demylle D, Jadoul P, Pirard C, Squifflet J, Martinez-Madrid B, van Langendonck A. Livebirth after orthotopic transplantation of cryopreserved ovarian tissue. *Lancet* 2004;**364**:1405–1410.
- Donnez J, Martinez-Madrid B, Jadoul P, Van Langendonck A, Demylle D, Dolmans MM. Ovarian tissue cryopreservation and transplantation: a review. *Hum Reprod Update* 2006;**12**:519–535.
- Duffy CM, Allen SM, Clark MA. Discussions regarding reproductive health for young women with breast cancer undergoing chemotherapy. *J Clin Oncol* 2005;**23**:766–773.

- Dunkel-Schetter C, Lobel M. Psychological reactions to infertility. In: Stanton L, Dunkel-Schetter C (eds). *Infertility, Perspectives from Stress and Coping Research*. New York: Plenum Press, 1991, 29–57.
- Dunn J, Steginga SK. Young women's experience of breast cancer: defining young and identifying concerns. *Psychooncology* 2000;**9**:137–146.
- ESHRE Task Force on Ethics and Law. Taskforce 7: ethical considerations for the cryopreservation of gametes and reproductive tissues for self use. *Hum Reprod* 2004;**19**:460–462.
- Ganz PA, Desmond KA, Leedham B, Rowland JH, Meyerowitz BE, Belin TR. Quality of life in long-term, disease-free survivors of breast cancer: a follow-up study. *J Natl Cancer Inst* 2002;**94**:39–49.
- Ginsberg JP, Ogle SK, Tuchman LK, Carlson CA, Reilly MM, Hobbie WL, Rourke M, Zhao H, Meadows AT. Sperm banking for adolescent and young adult cancer patients: sperm quality, patient, and parent perspectives. *Pediatr Blood Cancer* 2008;**50**:594–598.
- Goodwin T, Elizabeth Oosterhuis B, Kiernan M, Hudson MM, Dahl GV. Attitudes and practices of pediatric oncology providers regarding fertility issues. *Pediatr Blood Cancer* 2007;**48**:80–85.
- Green D, Galvin H, Home B. The psycho-social impact of infertility on young male cancer survivors: a qualitative investigation. *Psychooncology* 2003;**12**:141–152.
- Hammer Burns L, Covington S (eds). *Infertility Counseling: A Comprehensive Handbook for Clinicians*, 2nd edn. New York: Cambridge University Press, 2000.
- Hochbaum G. *Public Participation in Medical Screening Programs*. DHEW Publication No. 572, Public Health Service. Washington, DC: US Government Printing Office, 1958.
- Hockenberry-Eaton M, Dilorio C, Kemp V. The relationship of illness longevity and relapse with self-perception, cancer stressors, anxiety, and coping strategies in children with cancer. *J Pediatr Oncol Nurs* 1995;**12**:71–79.
- Jemal A, Clegg LX, Ward E, Ries LA, Wu X, Jamison PM, Wingo PA, Howe HL, Anderson RN, Edwards BK. Annual report to the nation on the status of cancer, 1975–2001, with a special feature regarding survival. *Cancer* 2004;**101**:3–27.
- Kim SS. Fertility preservation in female cancer patients: current developments and future directions. *Fertil Steril* 2006;**85**:1–11.
- Lass A, Akagbosu F, Brinsden P. Sperm banking and assisted reproduction treatment for couples following cancer treatment of the male partner. *Hum Reprod Update* 2001;**7**:370–377.
- Lee SJ, Schover LR, Partridge AH, Patrizio P, Wallace WH, Hagerty K, Beck LN, Brennan LV, Oktay K. American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol* 2006;**24**:2917–2931.
- Maltaris T, Boehm D, Dittrich R, Seufert R, Koelbl H. Reproduction beyond cancer: a message of hope for young women. *Gynecol Oncol* 2006;**103**:1109–1121.
- Maltaris T, Seufert R, Fischl F, Schaffrath M, Pollow K, Koelbl H, Dittrich R. The effect of cancer treatment on female fertility and strategies for preserving fertility. *Eur J Obstet Gynecol Reprod Biol* 2007;**130**:148–155.
- Miller WR, Rollnick S. *Motivational Interviewing: Preparing People for Change*. New York: Guilford Press, 2002.
- Oppenheim D, Brugières L, Hartmann O. Adolescents treated for cancer and fertility preservation. Psychological aspects. *Gynecol Obstet Fertil* 2005;**33**:627–631.
- Oosterhuis BE, Goodwin T, Kiernan M, Hudson MM, Dahl GV. Concerns about infertility risks among pediatric oncology patients and their parents. *Pediatr Blood Cancer* 2008;**50**:85–89.
- Pacey AA. Fertility issues in survivors from adolescent cancers. *Cancer Treat Rev* 2007;**33**:646–655.
- Partridge AH, Gelber S, Peppercorn J, Sampson E, Knudsen K, Laufer M, Rosenberg R, Przepyszny M, Rein A, Winer EP. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol* 2004;**22**:4174–4183.
- Petty RE, Cacioppo JT. *Communication and Persuasion: Central and Peripheral Route to Attitude Change*. New York: Springer-Verlag, 1986.
- Practice Committee of the American Society for Reproductive Medicine. Ovarian tissue and oocyte cryopreservation. *Fertil Steril* 2004;**82**:993–998.
- Quinn GP, Vadaparampil ST, Gwede CK, Miree C, King LM, Clayton HB, Wilson C, Munster P. Discussion of fertility preservation with newly diagnosed patients: oncologists' views. *J Cancer Surviv* 2007a;**1**:146–155.
- Quinn GP, Vadaparampil ST, Bell-Ellison BA, Gwede CK, Albrecht TL. Patient–physician communication barriers regarding fertility preservation among newly diagnosed cancer patients. *Soc Sci Med* 2007b;**66**:784–789.
- Rogers C, Farson R. Active listening. In Kolb D, Rubin I, MacIntyre J (eds). *Organizational Psychology*, 3rd edn. New Jersey: Prentice Hall, 1979.
- Rosenstock IM. Why people use health services. In: Stone A, Cohen F, Adler NE (eds). *Health Psychology*. San Francisco: Jossey-Bass, 1966, 189–206.
- Royal College of Obstetrics and Gynaecologists. *Storage of Ovarian and Prepubertal Testicular Tissue—Report of A Working Party*. London: The RCOG bookshop, 2000.
- Saito K, Suzuki K, Iwasaki A, Yumura Y, Kubota Y. Sperm cryopreservation before cancer chemotherapy helps in the emotional battle against cancer. *Cancer* 2005;**104**:521–524.
- Schover LR. Psychosocial aspects of infertility and decisions about reproduction in young cancer survivors: a review. *Med Pediatr Oncol* 1999;**33**:53–59.
- Schover LR, Rybicki LA, Martin BA, Bringelsen KA. Having children after cancer. A pilot survey of survivors' attitudes and experiences. *Cancer* 1999;**86**:697–709.
- Schover LR, Brey K, Lichtin A, Lipshultz LI, Jeha S. Knowledge and experience regarding cancer, infertility, and sperm banking in younger male survivors. *J Clin Oncol* 2002a;**20**:1880–1889.
- Schover LR, Brey K, Lichtin A, Lipshultz LI, Jeha S. Oncologists' attitudes and practices regarding banking sperm before cancer treatment. *J Clin Oncol* 2002b;**20**:1890–1897.
- Sonmezer M, Shamonki MI, Oktay K. Ovarian tissue cryopreservation: benefits and risks. *Cell Tissue Res* 2005;**322**:125–132.
- Thewes B, Meiser B, Rickard J, Friedlander M. The fertility- and menopause-related information needs of younger women with a diagnosis of breast cancer: a qualitative study. *Psychooncology* 2003;**12**:500–511.
- Thewes B, Meiser B, Taylor A, Phillips KA, Pendlebury S, Capp A, Dalley D, Goldstein D, Baber R, Friedlander ML. Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *J Clin Oncol* 2005;**23**:5155–5165.
- Trask PC, Paterson A, Riba M, Brines B, Griffith K, Parker P, Weick J, Steele P, Kyro K, Ferrara J. Assessment of psychological distress in prospective bone marrow transplant patients. *Bone Marrow Transplant* 2002;**29**:917–925.
- Van den Berg H, Langeveld NE. Parental knowledge of fertility in male childhood cancer survivors. *Psychooncology* 2008;**17**:287–291.
- Van den Berg H, Repping S, van der Veen F. Parental desire and acceptability of spermatogonial stem cell cryopreservation in boys with cancer. *Hum Reprod* 2007;**22**:594–597.
- Wallace WH, Anderson RA, Irvine DS. Fertility preservation for young patients with cancer: who is at risk and what can be offered? *Lancet Oncol* 2005;**6**:209–218.
- Yang D, Brown SE, Nguyen K, Reddy V, Brubaker C, Winslow KL. Live birth after the transfer of human embryos developed from cryopreserved oocytes harvested before cancer treatment. *Fertil Steril* 2007;**87**:1469.e1–1469.e4.

- Zanagnolo V, Sartori E, Trussardi E, Pasinetti B, Maggino T. Preservation of ovarian function, reproductive ability and emotional attitudes in patients with malignant ovarian tumors. *Eur J Obstet Gynecol Reprod Biol* 2005; **123**:235–243.
- Zapzalka DM, Redmon JB, Pryor JL. A survey of oncologists regarding sperm cryopreservation and assisted reproductive techniques for male cancer patients. *Cancer* 1999;**86**:1812–1817.
- Zebrack BJ, Casillas J, Nohr L, Adams H, Zeltzer LK. Fertility issues for young adult survivors of childhood cancer. *Psychooncology* 2004; **13**:689–699.
- Zebrack BJ, Mills J, Weitzman TS. Health and supportive care needs of young adult cancer patients and survivors. *J Cancer Surviv* 2007;**1**:137–145.
- Submitted on November 6, 2008; resubmitted on March 26, 2009; accepted on April 6, 2009