

# Children After Cancer? Meeting Male Patients' Fertility Needs During Cancer Care

**EDITOR'S  
PICK**

My Editor's Pick for this edition focusses on an important hot topic. Young men (and, I would add, women) affected by cancer should always have the possibility to preserve their future fertility and receive appropriate counselling. Being responsible for the male gamete cryopreservation bank at the University Hospital of Careggi, Florence, Italy, I am aware that, all too often, consultants in a variety of fields forget to provide appropriate counselling to young male cancer patients regarding the possibility of fertility preservation before initiating any therapy that may affect testicular function. This article analyses the perceptions of all the stakeholders regarding fertility and cancer, remarking that banking spermatozoa reassures patients and helps them to face the battle against cancer. The article also analyses the main obstacles to fertility preservation, giving insights on how to surmount them. I found this article a very helpful read.

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## Abstract

The prospect of cancer survivorship has changed significantly in the past decades. Cancer patients are now living longer and healthcare professionals are increasingly aware of the concerns of survivors with regard to quality of life. It is well known that psychological and social problems are created or exacerbated by cancer. At any stage of cancer survivorship, individuals may experience depression, a high sense of vulnerability, fear for the future, and other types of worries, such as changes in sexual function and reproductive ability. For many survivors, the ability to conceive and deliver a healthy baby is of paramount importance. However, in many circumstances, and for a variety of complex reasons, the importance of fertility is under-addressed and sometimes disregarded by the healthcare team. This article describes the significance of addressing fertility as a psychosocial need in male cancer patients, followed by a discussion on cancer patients' and family members' perceptions about the importance of fertility preservation. The authors also present practical strategies to improve the quality of services for cancer patients to address their fertility needs.

## INFERTILITY AS A CAUSE OF PSYCHOSOCIAL DISTRESS IN MALE CANCER PATIENTS

Imagine if every healthcare professional would routinely ask “what matters to you?” when meeting with patients and their family members. In 2012, Barry and Edgman-Levitan<sup>1</sup> introduced the concept of asking “what matters to you?” in addition to “what is the matter?” to emphasise the need for healthcare providers to implement shared decision-making with patients and families regarding care plans. Using this patient-centred care approach, clinicians can inquire more deeply about what is really important to their patients and become more responsive to patients’ values and preferences during the course of their illnesses.<sup>1</sup> In recent decades, a shift has occurred regarding cancer care, and research has clearly shown the importance of identifying, understanding, and addressing cancer patients’ needs beyond those related to managing the cancer.<sup>2,3</sup> According to Zebrack et al.<sup>4</sup> and Gupta et al.,<sup>5</sup> three needs were identified as important to young adults with cancer: information on treatment and risk of recurrence of their specific malignancy, the effects of cancer treatment on fertility, and information on healthy diets and exercise during cancer treatment. Similarly, Klosky et al.<sup>6</sup> noted that good health and fertility were among the three top life goals in adolescent and young adult (AYA) cancer patients. In another study, 50% of men with cancer valued parenthood and expressed a wish to preserve their fertility.<sup>7</sup> Indeed, men who banked sperm prior to treatment felt more reassured and less worried about their fertility than patients who did not bank sperm, which helped them in the emotional battle against cancer.<sup>8</sup> Therefore, patients’ concerns and uncertainty regarding fertility and parenthood are common forms of psychological stress, not only before or at the beginning of cancer treatment<sup>9,10</sup> but also during the post-therapy phase in the cancer survivorship trajectory, particularly for those cancer survivors who do not become parents.<sup>7,11</sup>

The National Comprehensive Cancer Network (NCCN) has defined distress as ‘a multifactorial unpleasant emotional experience of a psychological (i.e., cognitive, behavioural, emotional), social, and/or spiritual nature that

may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment’.<sup>12</sup> The NCCN also state that all patients with cancer and their families should be able to expect and receive cancer care that ensures the delivery of appropriate psychosocial health services, which are recognised as an essential component of quality of care.<sup>12-14</sup> Similarly, the American Society of Clinical Oncology (ASCO),<sup>15</sup> the American Academy of Pediatrics (AAP),<sup>16</sup> the European Society for Medical Oncology (ESMO),<sup>17</sup> and the American Society for Reproductive Medicine (ASRM)<sup>18</sup> have recommended clinicians to discuss with all newly diagnosed cancer patients the potential impact of cancer treatments on future fertility and to present options for fertility preservation. Despite the recognition by multiple professional organisations and medical groups that fertility preservation is an essential part of comprehensive cancer care, recent studies have indicated that proper pretreatment fertility counselling was disseminated to only a minority of newly diagnosed cancer patients.<sup>19,20</sup>

## STAKEHOLDERS’ PERCEPTIONS OF FERTILITY AND CANCER

Why then is fertility not always part of the conversation between clinicians and patients? How can healthcare providers make a positive healthcare experience for male patients with cancer as they transition from patient to survivor? Although there is no simple, universal answer or solution to these important questions, one approach is to first evaluate and understand stakeholders’ perceptions about fertility. These stakeholders include cancer patients and their family members, as well as clinicians. While the bulk of the existing literature has focussed on cancer survivors’ needs after their treatments, recent studies have explored patients’ needs at the time of diagnosis, especially those of AYA cancer patients. Male AYA are as susceptible to the adverse effects of cancer treatment as fully mature men and are considered a vulnerable population because cancer diagnosis and treatment can be particularly disruptive to their social maturation, a process by which young people develop self-identity and social awareness that will guide them throughout their lives.<sup>21</sup> This unique cancer

population, which includes patients between the ages of 15 and 39 years, encounters challenges that differ from those of children and older adults with cancer.<sup>2,22</sup> Feeling different from their peers as a result of the cancer diagnosis is a source of stress for AYA cancer patients, who often report feelings of isolation. These feelings could be due to missing out on important social activities, such as sports and school dances, or experiencing stigma and unfair treatment due to changes in their appearance, adding to the fact that their peers often have little familiarity with illness and do not know how to extend their support to a friend with cancer.<sup>2</sup>

Since perceptions may differ from the time of cancer diagnosis to the various stages along the trajectory of survivorship, it is important to analyse all of these points of view. Thus, the different stakeholders' opinions regarding fertility of AYA cancer patients are briefly summarised in the following sections.

**Adolescent and Young Adult Cancer Patients' Points of View at Time of Diagnosis:** Patients diagnosed with cancer are often worried about not being able to have children and have highlighted the need for access to high-quality information about sexuality and fertility.<sup>23</sup>

**Adolescent and Young Adult Cancer Survivors' Points of View:** One of the various themes discussed by AYA cancer survivors is the fact that infertility often comes as a surprise to cancer survivors, and patients have voiced regret about fertility risks not being addressed at the time of cancer diagnosis.<sup>23</sup> Cancer experience increases the value many patients place on family, therefore, increasing their desire to have children.<sup>3,6</sup> Moreover, cancer survivors have expressed desire that oncology healthcare providers and fertility specialists have a proactive involvement with patient fertility.

**Cancer Patients' Parents' Points of View at Time of Diagnosis:** Parents play a key role in the co-ordination and execution of care for adolescents. For many parents of cancer patients, the prompt initiation of treatment, rather than fertility preservation, is the primary concern. Moreover, they often do not feel at ease or equipped to discuss the subject of fertility with their children following a new cancer diagnosis. Nevertheless, many parents are interested in

receiving information related to fertility and are concerned about the negative consequences of infertility in regard to its impact on relationships.<sup>24</sup>

**Cancer Survivors' Parents' Points of View:** Many parents have expressed similar regrets regarding fertility, as well as a strong sense of guilt.<sup>23</sup> In contrast to parents of newly diagnosed cancer patients, parents of cancer survivors reported that their children should have been involved in fertility discussions regardless of the patient's age at diagnosis and expressed that discussing fertility issues with the oncology healthcare provider would have fostered a feeling of optimism.<sup>23</sup>

**Oncologists' Points of View:** Practitioners have expressed concern about the inadequacy of time for conversations regarding fertility preservation at the time of cancer diagnosis, since there is often a short time period between cancer diagnosis and initiation of treatment, and they perceive that fertility preservation could potentially delay cancer treatment. Furthermore, many oncologists also feel unequipped and uneasy discussing fertility preservation with patients due to their lack of knowledge on the effect of fertility and cancer, the difficulty finding convenient fertility clinics for referral, their perceptions on ethical issues regarding conversations with minors, and the uncertainty on how to approach the topic of fertility preservation in patients with poor prognosis or developmental delay.<sup>25-27</sup> Practitioners have also expressed concerns regarding the out-of-pocket cost to patients and the possible resulting inequity of service delivery based on income.<sup>27</sup>

Taken together, infertility is a cause of concern and anxiety among cancer patients and their parents. Contrary to the common assumption of clinicians and parents that cancer patients are too overwhelmed to handle information regarding risks of infertility due to cancer treatments, patients want to receive information on their current reproductive status and future reproductive risks.<sup>23,28,29</sup> Moreover, cancer survivors and their parents share a sense of regret for not considering fertility preservation at the time of cancer diagnosis. Discussing infertility with AYA cancer patients during diagnosis is therefore needed to prevent the issue from becoming a silent concern and to minimise negative future effects.

## IMPLEMENTATION OF SUCCESSFUL FERTILITY PRESERVATION PROGRAMMES

These perceptions are not unique to AYA cancer patients; fertility is important to all males newly diagnosed with cancer, regardless of age and situation. For example, older, married, or homosexual men who are not informed about the option of preserving sperm often manifest high levels of confusion and anger towards healthcare professionals.<sup>30</sup> With recent dramatic progress in the access to assisted reproductive technologies, open and timely communication followed by a referral process from the oncology team to the fertility specialists is essential to ensure quality of care to all males newly diagnosed with cancer and to minimise unnecessary distress and litigation. A study by García et al.<sup>31</sup> demonstrated that male cancer survivors who previously cryopreserved sperm and later on in life sought assisted reproduction using their frozen sperm, presented comparable reproductive outcomes to a non-cancer population undergoing *in vitro* fertilisation (IVF) treatment; this finding supports the notion that sperm banking or cryopreservation for cancer patients is a highly valued service that should be encouraged for all male cancer patients prior to gonadotoxic cancer treatment.<sup>31</sup>

Finally, as previously mentioned, for young cancer patients, cost could be a barrier to pursue fertility preservation.<sup>27,32</sup> Moreover, since cryopreserved sperm are of finite quantity, the more sessions of sperm cryopreservation carried out the lower the risk of sperm quantity limiting the success of future assisted reproduction. In 2010, the province of Quebec, Canada became the first North American jurisdiction to offer full financial coverage, through provincially funded Medicare programme, for 5 years of sperm cryopreservation and storage for cancer patients. It has been shown that there has been a significant increase in the number of sperm banking sessions per cancer patient after the provincial implementation of the sperm banking coverage, when the practice pattern of oncologists was constant,<sup>33</sup> suggesting that once cancer patients are aware of the option of freezing sperm, and when cost is no longer a barrier, they are interested in banking sperm and quality of care is improved. Based on the research described, it is important that oncology care providers, who are at the front-line to counsel cancer patients, are aware of the availability, accessibility, and reproductive success of fertility preservation.

What are the challenges encountered when establishing a successful fertility preservation programme? Although sperm freezing is a relatively accessible clinical procedure that is accepted as part of the standard of care when managing male cancer patients, there are several challenges inherent to the decision-making process in fertility preservation. Firstly, since sperm banking is most effective before cancer treatment begins, gathering and assimilation of information about fertility preservation need to be accomplished within a relatively short timeframe, usually within days but often hours.<sup>15</sup> Secondly, sperm banking requires the involvement of a multidisciplinary team, such as oncology healthcare professionals, urologists, mental health professionals, and fertility specialists, with continuous interaction, open communication, and knowledge-sharing being essential to bridge the gap between specialities. Thirdly, as previously mentioned, cost may be a significant financial burden for patients at cancer diagnosis. Therefore, the establishment of a successful fertility preservation programme should be equipped to address many of these potential hurdles regarding decision-making in fertility preservation.

The goal of a clinical fertility preservation programme is to help patients and their physicians evaluate the impact of cancer treatment on fertility and to facilitate fertility preservation options in a timely manner.<sup>34</sup> When developing a successful fertility preservation programme, there are several key considerations, some of which are outlined in the following sections.

**Institutional Commitment for Fertility Preservation:** As with any other programme, to be successful it is essential that the organisation is supportive. For instance, in 2005 Fertile Hope/LIVESTRONG launched the Centers of Excellence (COE) programme to recognise cancer centres that had made an institutional commitment to meet their patients' reproductive needs in a deliberate, methodical way.<sup>35</sup> Among the suggested criteria to support institutional commitment are the issuance of formal hospital-wide policy and the

description of fertility preservation discussions as part of standard operating procedures on the hospital's intranet.<sup>36</sup>

#### **An Efficient Fertility Preservation Referral Process:**

It is important to recognise that patients are strongly influenced by the messages they receive from their oncologist and may be more likely to seek fertility preservation services if the clinician introduces this topic as a legitimate concern.<sup>28,37</sup> Therefore, it is essential for clinicians to feel comfortable initiating fertility discussions with their patients. In order to facilitate this task, clinicians need to know where and how to refer interested patients to reproductive specialists and be educated about the topic. It is important to cultivate a strong relationship between the oncology and fertility teams to facilitate a fertility preservation referral process and bridge the gap between these two specialities.

#### **Professional Education on Fertility Preservation:**

As previously mentioned, for patients to receive proper fertility preservation counselling, oncology healthcare providers need to feel comfortable conveying this information to patients. For this purpose, educational presentations could be delivered effectively through various, continued, medical education channels, including ground rounds, staff orientations, case presentations, and medical conferences.<sup>38-40</sup> Also, clinicians should be provided with access to resources at the time they encounter the patients. Printed resources, such as posters and brochures, as well as an internal website on fertility and cancer treatments, can aid clinicians with fertility counselling.

**Patient Education on Fertility Preservation:** The goal of patient education should be to provide helpful information to patients about the risks of cancer treatment on fertility. By increasing their knowledge, clinicians will empower patients to participate in the decision-making process, thus engaging them to adopt an active role in managing their care.<sup>40,41</sup>

In the USA and Canada, several institutions have developed strategies to formalise oncofertility programmes, with the goal of increasing the number of men receiving fertility preservation consultations, leading to larger percentages of patients opting to cryopreserve sperm.<sup>34,42-44</sup> These strategies include:

- The implementation of a standard process through a continuous process improvement approach, which was developed at Seattle Children's Hospital, Seattle, Washington, USA, where patient and staff education material was created.<sup>43</sup>
- A referral system incorporated at the Moffitt Cancer Center, Tampa, Florida, USA, in which, after educating clinicians on fertility preservation and generating a brochure for patients, an electronic system prompted the physician to distribute a brochure to interested patients on fertility during their initial visit.<sup>42</sup>
- An alert on medical electronic records that reminds the treating physician to discuss fertility preservation options with new cancer patients at Northwestern University, Evanston, Illinois, USA.<sup>44</sup>
- Resources for patients and clinicians, education of clinicians, and a consultation service incorporated in a comprehensive cancer and fertility programme at the Memorial Sloan Kettering Cancer Center, New York City, New York, USA.<sup>41</sup>
- The designation of a dedicated clinical nurse for pre and post-therapy counselling on infertility risks included in the AYA programme at the Princess Margaret Cancer Centre, Toronto, Canada.<sup>45</sup>
- The development of a suite of educational tools and materials for patients, such as brochures, frequently asked questions, and videos posted at the MUHC Reproductive Center's website, as well as educational talks on fertility preservation for health care providers at the McGill University Health Center, Jews General Hospital and St. Mary's Hospital Center, Montreal, Canada.<sup>46</sup>

## CONCLUSION

In conclusion, research has clearly demonstrated that cancer patients wish to receive information about fertility, that a large proportion of cancer patients informed about the infertility risk of cancer therapy choose to freeze their sperm, and that professional guidelines recognise the value of future fertility of cancer survivors. However, there are still persistent obstacles for oncology healthcare professionals to initiate a discussion on the reproductive risks and management options with their

patients. Both patients and clinicians should adopt a proactive approach towards fertility preservation, and the creation of institutional policies addressing fertility as a psychosocial need should be an integral part of cancer care.

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