



Reflective Practice

Thinking about white bears: Fertility issues in young breast cancer survivors[☆]Vânia Gonçalves^{a,*}, Nicholas Tarrier^b, Gwendolyn Quinn^c^a Faculty of Psychology and Educational Sciences, University of Coimbra, Coimbra, Portugal^b Department of Psychology, King's College London, Institute of Psychiatry, London, UK^c H. Lee Moffitt Cancer and Research Institute, Department of Health Outcomes & Behavior, Tampa, USA

ARTICLE INFO

Article history:

Received 25 February 2014

Received in revised form 27 July 2014

Accepted 18 August 2014

Keywords:

Young survivors

Breast cancer

Fertility

Parenthood

Health care providers

Patient education

Psychological counseling

A meeting with an oncologist from a specialist cancer center to discuss a possible collaboration in a study about fertility issues in young breast cancer survivors made an indelible impression on me (VG). After a quick look through the protocol and questionnaires, the physician stared at me and said with strong conviction: “Pregnancy? Forget it... we do not even want them [the patients] to think about it, and we [doctors] tell them not to get pregnant and we do not talk about it, we do not want them to remember [the option of pregnancy]...” I replied, “but..., we are not telling patients to get pregnant, we just want to understand young women attitudes toward fertility after a breast cancer diagnosis, so we can then be able to provide them support for their needs”. The physicians’ subsequent arguments were based on the premise that the only concern someone diagnosed with such a life-threatening illness has, is being alive. I left the office thinking certainly the physician was right – individuals diagnosed with a life-threatening illness do want to be alive; but is it their only concern? I thought about my own children, and how much they mean to me. Yes, life continues

after cancer, but that life has to be more than just being alive. Life is about hopes and dreams. I started to wonder if women who learn they have breast cancer would give up the dreams and plans for children? Even if it is not biologically possible for a woman to have a child after cancer treatment would not she still wish to discuss this with her physician? Is it an appropriate clinical choice to describe the cancer and the treatment in great details but simply tell the patient not to get pregnant and not discuss with her dreams and plans for motherhood? I remember a woman I met once in the chemotherapy suite. She told me, “I have cancer, but cancer does not have me, does not have what I am as a person, I continue to be the same, with my beliefs, my wishes”. Her eyes sparkled to tell me that this “me” goes much beyond “just being alive”. These two exchanges brought to my mind a classic experiment done by Wegner and colleagues [1] 26 years ago that I learned about when I was still a college student. Could subjects avoid thinking about white bears when they were told not to do so? The answer is no [1]. Patients cannot avoid thinking about fertility just like they cannot erase white bears from their mind when they are told to do so. This aspect of quality of life is particularly significant for patients who consider fertility issues to be very important to them. Some patients have said “I have wanted to be a mother for as long as I can remember. This is the reason I want to be alive”. This left me wondering if patients of reproductive age are getting the necessary support from their health care professionals on fertility related matters.

According to the literature, which is primarily based on health care experiences from the United States, the response to my concern is probably “no”. And, if US patients are not getting this information, it is likely those in smaller European countries, where the episode described above occurred, are not getting fundamental support on fertility issues. Therefore, my “experience” with the physician does not come as a surprise. Unfortunately, the attention paid to this subject by many health care professionals is not proportional to the importance fertility issues may have to the quality of life and emotional well-being of many patients [2]. Are there vital reasons to avoid discussing fertility issues in the consultation room? No, just as there are equally important reasons to include it in the consultation agenda.

Consistent with our own clinical experiences, when young women are diagnosed with breast cancer, research suggests most had a life plan that included having (more) children [3]. Given the

[☆] For more information on the Reflective Practice section please see: Hatem D, Rider EA. Sharing stories: narrative medicine in an evidence-based world. Patient Education and Counseling 2004;54:251–253.

* Corresponding author at: Faculty of Psychology and Educational Sciences, University of Coimbra, Rua do Colégio Novo, Apartado 6153, 3001-802 Coimbra, Portugal. Tel.: +351 239851450; fax: +351 239 851465.

E-mail address: vmo.goncalves@hotmail.com (V. Gonçalves).

potential for cancer treatments and the disease to pose temporary or permanent infertility, these life plans, dreams and wishes are, as a result, impacted. From a psychological perspective, infertility can be devastating for young survivors [4]. High levels of psychological distress, poor adjustment [5,6], depressive symptoms, anxiety, anger, grief, relationship disruptions and lower quality of life [7] have been reported. Unfortunately, in many cases, this distress does not dissipate with time [8]. Given this scenario, it seems rudimentary not to acknowledge the value of fertility for these women and providers are remiss if they ignore, the subject. Furthermore, merely avoiding an issue as important to women as fertility is unlikely to be effective in reducing its importance to the women involved. Out of sight is not necessarily out of mind! A comprehensive care plan, including screening for distress, identification of those patients at high risk and implementation of adequate psychological interventions should be offered.

The questions “*Shall I have children after cancer?*” or “*Can I have children after cancer?*” certainly are asked by many cancer patients. The subject is complex and involves several factors, including uncertainty. To address infertility concerns, fertility preservation techniques hold promising options for some women. Adoption and third-party reproduction are other options for those unable to have biological children. Reproductive decisions are difficult in the context of cancer. Although the milieu is surrounded by uncertainty, there is one thing that is certain: the important role health care providers have in helping patients find answers to questions about fertility and sexuality. Providing information is a crucial aspect of high-quality health care, resulting in well informed patients, better adjusted to their circumstances and compliant with their treatment [9]. There are clinical practice guidelines about fertility preservation for adults and children with cancer, acknowledging the medical and psychosocial significance of fertility. In the USA for example, in 2006, the American Society of Clinical Oncology (ASCO) published clinical practice guidelines on fertility and, in 2013, the guidelines were updated [10]. ASCO states, amongst other issues, that health care providers (medical oncologists, radiation oncologists, gynecologic oncologists, urologists, hematologists, pediatric oncologists, surgeons, as well as nurses, social workers, psychologists, and other non-physician providers) should discuss fertility preservation with all patients of reproductive age if infertility is a potential risk of therapy, refer patients interested in fertility preservation to reproductive specialists, address fertility preservation as early as possible, before treatment starts and refer patients to mental health professionals if they experience distress about potential infertility.

We understand that discussing fertility related issues with cancer patients is often a challenge for providers. Fertility preservation is surrounded by medical and ethical controversies, which may make some clinicians wish they could avoid these issues. There are a multitude of reasons for the lack of communication between providers and patients on this matter. These include lack of knowledge about where to refer patients for fertility counseling, patients not bringing up the subject, medical reasons, personal reasons and lack of time [11]. However, several studies have identified effective ways to overcome these communication and structural barriers [12,13]. These include providing training for clinicians, developing a systematic referral process, and offering patient decision aids. Communication barriers need to

be overcome to improve patients' quality of life. This may mean providers need to update their education on this matter, engage in multidisciplinary teamwork and expand their clinical networks.

The episode we describe with the oncologist is reminiscent of the “white bear” experiment. The premise of that study was that “attempted thought suppression has paradoxical effects as a self-control strategy, perhaps even producing the very obsession or preoccupation that it is directed against”. It is not likely that fertility issues and parenthood wishes will vanish from the mind of the patient, especially for those who were expecting motherhood in their future. Patients told not to think about fertility and pregnancy will likely fixate on it even more, and more importantly, the lack of discussion could have a serious psychological impact on the patient's quality of life. We look forward to day when health care professionals are providing the appropriate support to target women's fertility needs, or at least, helping them to cope with a possible infertility due to cancer. Is sweeping the information under the rug the solution ... Certainly not!

Conflict of interest

The authors disclose no conflicts of interest.

Acknowledgements

This work was supported by funding from the European Union Seventh Framework Program (FP7/2007–2013) under Grant agreement no. PCOFUND-GA-2009-246542 and from the Foundation for Science and Technology of Portugal.

References

- [1] Wegner DM, Schneider DJ, Carter 3rd SR, White TL. Paradoxical effects of thought suppression. *J Personal Soc Psychol* 1987;53:5–13.
- [2] Gonçalves V, Sehic I, Quinn G. Childbearing attitudes and decisions of young breast cancer survivors: a systematic review. *Hum Reprod Update* 2014;20:279–92.
- [3] Quinn GP, Vadaparampil ST. More research, more responsibility: the expansion of duty to warn in cancer patients considering fertility preservation. *Am J Obstet Gynecol* 2013;209:98–102.
- [4] Camp-Sorrell D. Cancer and its treatment effect on young breast cancer survivors. *Semin Oncol Nurs* 2009;25:251–8.
- [5] Penrose R, Beatty L, Mattiske J, Koczwara B. The psychosocial impact of cancer-related infertility on women. *Clin J Oncol Nurs* 2013;17:188–93.
- [6] Carter J, Chi DS, Brown CL, Abu-Rustum NR, Sonoda Y, Aghajanian C, et al. Cancer-related infertility in survivorship. *Int J Gynecol Cancer* 2010;20:2–8.
- [7] Duffy C, Allen S. Medical and psychological aspects of fertility after cancer. *Cancer J* 2009;15:27–33.
- [8] Crawshaw MA, Sloper P. ‘Swimming against the tide’ – the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer. *Eur J Cancer Care* 2010;19:610–20.
- [9] Mounce G. An overview of information giving in fertility clinics. *Hum Fertil (Camb)* 2013;16:8–12.
- [10] Loren A, Mangu P, Beck L, Brennan L, Magdalinski AJ, Partridge AH, et al. Fertility preservation for patients with cancer: America Society of Clinical Oncology Clinical Practice Guideline Update. *J Clin Oncol* 2013;31:2500–11.
- [11] Quinn GP, Vadaparampil ST, King L, Miree CA, Wilson C, Raj O, et al. Impact of physicians' personal discomfort and patient prognosis on discussion of fertility preservation with young cancer patients. *Patient Educ Couns* 2009;77:338–43.
- [12] Clayman ML, Harper MM, Quinn GP, Reinecke J, Shah S. Oncofertility resources at NCI-designated comprehensive cancer centers. *J Natl Compr Canc Netw* 2013;11:1504–9.
- [13] Woodruff TK, Clayman ML, Waimey KE, editors. *Oncofertility communication: sharing information and building relationships across disciplines*. Springer; 2014.