Reproductive and sexual health care in oncology: current practice and challenges

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PART III

Discussion and Summaries

Chapter 13

General discussion and future perspectives

GENERAL DISCUSSION AND FUTURE PERSPECTIVES

The impact of cancer and its treatments on a person's sexual and reproductive function has been deliberated on to a great extent in existing literature. With the studies presented in this thesis, we aimed to make a step forward in identifying current practice and barriers in discussing sexual functioning and fertility concerns in medical and surgical oncology in the Netherlands. A retrospective Canadian study of medical records from cancer survivors of childbearing age showed a significant association between reproductive and sexual health counselling. Those who engaged in a dialogue around one topic were significantly more likely to be counselled by their medical provider about the other (1). This finding emphasizes the coherence between the two main subjects of this thesis, the counselling of sexual and reproductive health in oncology practice.

Part I Sexual health communication between cancer patients and oncology clinicians

The first part of this thesis demonstrated the existing obstacles among the majority of the surveyed respondents in discussing sexual adverse effects and function during daily practice. In general, among oncology health care providers in the Netherlands, consensus exists regarding responsibility for addressing (potential) sexual dysfunction pre- and post-treatment. Despite this sense of responsibility, the implementation of discussing sexual function as a standard of care is not carried out structural. Knowledge regarding how to initiate a discussion concerning sexual function, how to treat sexual dysfunction and possible adverse effects of anti-cancer drugs is limited, and a need for training is expressed by a significant number of nurses and physicians. Furthermore, referral possibilities, patient information materials and department protocols seem to be lacking; updates could benefit both patients and medical professionals in daily practice.

Common barriers, factors influencing practice patterns and existing opinions

In the surveys described in part one, the common failure of clinicians and nurses to address sexual health concerns of cancer patients is apparent. Assessments of sexual function are not regularly performed by health professionals in the clinical oncology setting. By identifying barriers for addressing sexual function, strategies could be accomplished to resolve current barriers keeping clinicians from providing sexual health care. Most mentioned barriers among Dutch oncology care providers were lack of training and lack of time, no angle or motive for initiating a discussion, advanced age of patients, presence of a third party and too ill patients. In comparison to literature, similar obstacles were found among health professionals discussing sexual issues with cancer patients, although cultural differences can be identified. In our surveys, lack of time was a repeatedly mentioned limitation in relation to the counselling on sexual function. In a qualitative study from White et al. among patients, partners and health professionals performed at two cancer centres in the UK, time restraints were mentioned as well by both patients and health professionals (2). Both real and perceived time constraints existed, like patient workload and attitudes of health professionals during consultations. Health professionals considered addressing sexual function to be more time consuming because of its sensitive nature and time needed to determine the individual context for clinical intervention (2).

A lack of training was one of the most mentioned barriers among the variety of disciplines that were evaluated. Besides, a wish for additional training was expressed by a significant number of respondents from all evaluated professions. It was a general agreement that sexual counselling should be a regular component of medical speciality residency training in the field of oncology as well. However, the effect of educational training for oncology health care providers remains debatable. Grondhuis Palacios et al. evaluated the effect of a symposium on sexual health care in prostate cancer, but found no significant influence on knowledge, competence and referral rate after the symposium (3).

In contrast to a study performed by Faulder et al., which showed that teaching peer-led sex education improved medical students' confidence in dealing with sexual issues (4). The study conducted by Jonsdottir et al. depicted that a two year educational intervention for healthcare professionals resulted in higher knowledge scores and fewer perceived barriers. However, no significant reported changes in practice and frequency of discussing sexual issues were detected (5). In our surveys, self-reported knowledge relating to changes in sexual function during and after cancer treatment was limited as for most health professionals. In regards to adverse effects on sexual function of anti-cancer drugs, knowledge also seemed to vary widely. With a lack of training as the major barrier for counselling on sexual concerns, poor knowledge remains a factor that must be considered. In order to provide this component of care, awareness and knowledge of potential ramifications are indispensable.

Advanced age of patients as a barrier for bringing up sexual functioning is a rational barrier, though it should be reconsidered. In the survey of Lindau et al., among a sample of 3005 adults, sexual activity was reported by 73% among respondents who were 57 to 64 years of age, 53% among respondents who were 65 to 74 years of age, and 26% among respondents who were 75 to 85 years of age (6). Much as the prevalence of sexual activity declined with age, with a quarter of plus 75 years old reporting sexual activity, older adults' sexual function should not be neglected.

Other aspects were also demonstrated to influence current practice significantly. Younger aged respondents were less likely to discuss sexual function, likewise for less experienced professionals in the field of oncology and professionals with a self-reported lack of knowledge regarding sexual dysfunction. The presence of a department protocol addressing sexuality was also significantly influencing practice patterns. As for the surgical oncologists, men were more likely to discuss the topic. Male and older participants were also more likely to provide sexual health care in a study performed in South Korea, which assessed oncology nurses' and physicians' attitudes relating to cancer patients (7).

On the subject of accountability for addressing sexual concerns in daily practice, the majority of all surveyed clinicians agreed that it is their responsibility to raise the matter (75-99%). This is with the exception of physicians working in the field of plastic surgery, of which 49.1% stated that plastic surgeons have the responsibility to discuss sexuality-related issues with their patients (however, most breast- and cosmetic surgeons agreed to their responsibility). Agreeance on responsibility for discussing sexual health with oncology patients was also seen among 94% of South Korean nurses and physicians (7). In a qualitative study performed in the Netherlands among patients, partners and health care professionals examining sexual health care needs in colorectal cancer care, health care professionals had a debate on whose responsibility it is to discuss sexual health (8). Patients and partners considered discussing sexuality a shared responsibility of health care professionals of each discipline, and possible consequences of their treatment should be discussed and evaluated during follow-up. Health care professionals assumed responsibility is an "and and" situation, meaning patients should feel free to ask questions regarding sexual health care if needed. They believed a professional network could intensify awareness that sexual health care is an essential aspect of cancer care (8). In general, oncology health care professionals feel responsible. However, translation to practice suggests that although a large amount of responsibility is felt for sexual concerns, responsibility for actually bringing up the subject is partly being left at the patients initiative.

Coping with sexual concerns during and after cancer

Late treatment effects in sexual functioning are prevalent among long-term cancer survivors and are strongly associated with reduced quality of life and high degrees of depression (9). Accordingly, it is of utmost importance for all involved clinicians to be aware of this overall burden and its impact. Strategies for dealing with sexual concerns during and after cancer treatment have been investigated widely and are still evolving continually. For many cancer patients seeking information becomes a convenient way of coping with a cancer diagnosis (10, 11). Accordingly, adequate information provision is an essential strategy for addressing sexual health as a part of integrative cancer care. Coping efforts frequently occur within the context of a relationship. They often include adjusting a couple's concept of sexual function and activity to behaviour that concentrates on intimacy and sexual activities rather than actual intercourse (a phenomenon called 'flexible coping') (12). Coping strategies for individuals have been researched less extensive in comparison to couple-based efforts (12). Psychosocial interventions were proven moderately helpful at improving sexual outcomes following cancer treatment (13). Physiological approaches may be helpful for specific indications, like vaginal dilator therapy for women after pelvic radiation, use of vaginal moisturizers or hormone replacement therapy for women who entered early menopause (14, 15). For men, physiological approaches may consist of the prescription of PDE5 inhibitors, vacuum constriction devices, intraurethral alprostadil, intracavernous injections or penile prostheses (16). Online self-help intervention for sexual problems after cancer may also be an exciting option to explore. A recent study showed that an online intervention for women with cancer, including interactive cognitive-behavioural exercises, in-depth information for most cancer sites and guidance on finding professional help, led to increased sexual activity at follow up, improved sexual function, improved lubrication and decreased genital discomfort after three months (17). However, it is believed that men are less likely to search for health information on the internet and may also be less likely to utilize online health interventions (17-19).

Closing the gap

As a result of our efforts and commitment to create awareness for omissions in the current health care system regarding addressing sexual function, a variety of collaborations and initiatives have been carried out. To start with the establishment of the Sick and Sex foundation, an organization aiming for accessible healthcare in the field of sexuality, intimacy and relationship for anyone facing an illness (http://www.sickandsex.nl). The purpose of the foundation is to bridge the gap between care providers and patients. Scientific research is fundamental to the foundation's working method. The key feature is an informative website for both patients and clinicians and the development of informative apps plus videos addressing issues concerning disease and sexual functioning. We have heard from colleagues working all over the country that more and more care providers are finding their way to the Sick and Sex platform. Likewise, patients are easily referred to the website for additional information. Next, collaborations with the AYA network (established for adolescents and young adults with cancer), the Dutch Federation of Cancer patients (NFK) and several other specific cancer patient representative organizations have been established. These collaborations have resulted in the developments of a podcast ("De Bespreekkamer"), an animated movie for partners of men with prostate cancer in collaboration with the Prostate cancer foundation (Prostaatkankerstichting), the development of the website https://kankerenseks.nl and the 'Pink Elephant' project (Roze Olifant). The Pink Elephant project is a toolbox developed for breast cancer care teams to discuss sexuality and intimacy with their patients (https://www.seksinjegesprek.nl). To resume, in the past few years, considerable efforts have been taken to create awareness on the subject of cancer and sexuality. Through all these collaborations, we feel a sense of optimism for the future, striving to further optimize sexual health care in oncology practice, above all for every person facing an illness.

Recommendations for clinical practice

Patients will scarcely express issues with their sexual functioning to a health care professional spontaneously. Hence, it is essential that sexual concerns are addressed in a routine, matter-of-fact approach. Factors within the institution, such as insufficient re-discussion of sexuality during follow-up consultations and inadequate referral systems, have been proven to impede sexual health care (8). As we have been able to demonstrate that the presence of a department protocol addressing sexual health as a standard of care significantly influences practice patterns, it is recommended that every oncology practice incorporates sexual function as an item in its protocols. With a majority of our respondents expressing interest in educational training on sexual functioning and how to address it, providing training will undoubtedly be appreciated and raise awareness. Standardizations of informed consent provision with adverse effects of surgeries, radiation, and anti-cancer drugs mentioned, may help to improve information provision and contribute to patients' expectations management. In line with the informed consent provision, one can also consider implementing possible sexual side effects in treatment decision aids, which are increasingly used according to the shared decision-making developments in cancer care. Brief counselling could be provided by one specialized affiliated health professionals on an oncology treatment team, for example, a nurse specialist. A minority of patients will require specialized, intensive medical or psychological treatment for sexual concerns. In a large cancer centre, such treatment could be provided as part of a psychological recovery program serving the unique needs of cancer patients. In smaller settings, members of the oncology treatment team should build a referral network of specialists in the region.

During the compiling and progressing of the survey among oncologists about sexual adverse effects of cancer drugs, accessible information describing actual adverse effects to sexual function was not easy to uncover. This was substantiated by the considerably varying reported knowledge on adverse effects from our responding oncologists. A widely available overview of sexual side effects that may result from the admission of anti-cancer drugs would be beneficial.

Future research

A growing body of literature reveals the omissions in the current oncology practice regarding consideration of impaired sexual function as a result of cancer and its treatment. Although responsibility was felt, practice was highly varying and depending on multiple factors. The majority of our clinical working respondents expressed a wish for additional educational training. This conclusion could support new study designs to unravel the actual effect of different varieties of educational training for oncology health care providers. One has to bear in mind that educational programs may not be the solution for introducing sexual function into the daily oncology practice and other measures have to be taken to ensure necessary care will be incorporated in the future. For example, efforts to integrate sexual function into every practice by introducing access to sexologists or any other person who is comfortable in discussing sexual concerns may be more useful. Moreover, strategies on how to identify existing sexual concerns in a subtle way, the effect of screening patients who are at risk and the effect of offering sexual counselling routinely is yet to be evaluated. Empirical research should focus on how to manage information provision, counselling and follow up for sexual function disorders in cancer patients. A closer look to the specific needs of particular cancer types is recommended. Suitable guidance for partners is also to be evaluated. Particularly should be examined which coping strategies are effective for sexual concerns during and after cancer for both single patients and couples of all ages. Research questions should specifically address how to offer targeted interventions and how to improve the current infrastructure about referral networks within organizations. However, the added value and efficacy of targeted interventions and specific infrastructure is still to be identified. The role of adequate information provided should not be underestimated. By this means, one can think of tailored information suiting a patients' level of understanding, literacy and preferred extensiveness. Some patients may profit more from digital apps and animated movies, others from personal counselling, stories of fellow sufferers or simply very factual, written information.

Part II Discussion of fertility concerns with cancer patients of reproductive age

Part two of this thesis describes self-reported practice routines concerning the counselling on impaired fertility and the possibility of fertility preservation for patients of reproductive age facing cancer. Furthermore, for testicular cancer patients we reported on specific items concerning the discussion, referral and process of semen cryopreservation. Long term reproductive concerns were identified among these testicular cancer survivors. Lastly, knowledge of medical oncologists was evaluated regarding anti-cancer drugs side effects in relation to sexual function and reproductive capacity.

Current practice, barriers, knowledge and responsibility

Medical oncologists and oncology nurses both reported discussing the impact of cancer treatment on fertility. However, it was not performed in all cases and depending on several factors like educational level, working experience, type of hospital, patients' prognosis and chances of fertility recovery. The most important indicated reasons for not discussing fertility-related issues by medical oncologists were poor prognosis, unlikely survival of treatment and the high chance of fertility recovery after treatment. As for nurses, these reasons were a lack of knowledge, a poor prognosis and a lack of time during consultations. For both oncology team members, especially prognosis seemed to play a major role in whether or not to discuss the subject of fertility. This is comparable to the opinions from oncologists working in Sweden (20), Germany (21), Canada (22), the United Kingdom (23) and the United States (24). Instinctively, the prognosis seems an important factor in counselling about future fertility. However, one must remember that under certain circumstances, post-mortem reproduction using preserved semen, embryo's, oocytes or ovarian tissue is considered by either partners or family members (25). Therefore, even in the palliative setting, the subject should not be ignored. Half of the surveyed Dutch oncologists believed posthumous reproduction is acceptable; more than a third stated this should not be acceptable, and others were not aware of this possibility. Knowledge concerning fertility preservation options was limited among both nurses and medical oncologists. Three-quarters of the oncologists stated that current residency training is lacking education about fertility issues and expressed a wish for additional training. Responsibility for discussing fertility issues was felt by the majority of oncology nurses (73%) and medical oncologists (93%).

Information provision regarding impaired fertility and preservation options

Self-reported practice of medical providers with regards to fertility counselling showed that 68.3% of medical oncologists and 32.3% of oncology nurses often or always discussed fertility issues with their patients. Referral to fertility specialists by medical oncologists was reported to be performed for 44.6% of reproductive men and 28.9% of reproductive women. A Canadian study retrospectively reviewed medical records of 427 patients aged 20-39 diagnosed with solid tumors between 2008-2010 who survived ≥ two years. Records showed that only 58% received counselling on reproductive health at their initial oncology consultation, most of which were led by medical oncologists. By 6 months, an additional 7% had undergone counselling about fertility (1). Data imply that the lack of referral for reproductive issues in oncology practice is a worldwide matter.

In this thesis, referral was evaluated for semen preservation in male facing testicular cancer. Our results showed that 1 out of 10 men were not informed about possible impaired fertility, and the possibility of fertility preservation was mentioned according to 77% of the respondents. When comparing to literature, in a sample of 201 male cancer survivors, only 60% recalled being informed about infertility as a side effect of cancer treatment, and 51% had been offered sperm banking (26). The men who discussed infertility with their physicians possessed more knowledge about cancer-related infertility and were significantly more likely to bank sperm (26). Adequate information provision seems to be of major importance to make a decision about whether or not to bank sperm after being diagnosed with cancer. Among our sample of testicular cancer survivors, written information materials regarding fertility issues were provided in less than a quarter of the respondents. This corresponds to an American survey among oncologists, where only 13.5% reported 'always or often' giving their patients educational materials about fertility preservation (27). Development and the broad availability of educational materials are essential to facilitate communication between oncology care professionals and patients on this important topic.

For women, Bastings et al. showed that only 9.8% of all potential women (aged 0-39 years) were referred to a fertility specialist in 2011, although the absolute number of patients receiving fertility preservation counselling increased over time (28). Among a sample of 166 young women undergoing chemotherapy for breast cancer, 34% of women reported recalling a discussion with a physician regarding fertility (29). In a young adult female cancer survivor survey, 43% to 62% of participants reported an unmet information need regarding fertility topics (30). Given the rapidly expanding treatment options for fertility preservation in women facing cancer in the past decade, it is no surprise that physicians are not entirely familiar with all these options and women are often poorly informed. Besides patient educational materials, physicians also require regular updates on fertility preservation developments and availability within their own clinic, region or country. This corresponds to oncologists stating that the topic is lacking in current residency, with an expressed need for additional training.

Children born to cancer survivors

One of the most significant reproductive concerns of cancer patients and survivors, concerns the health of future offspring (30). Although rare, unexpected health problems may occur during pregnancy due to damage to heart or lung function (31). Birth complications for female cancer survivors may include low birth weight infants, premature birth or miscarriage, particularly after pelvic radiation (32, 33). Congenital anomalies are not increased among either female or male cancer survivors' offspring (32, 34, 35). Children who have been exposed to chemotherapy in utero due to maternal cancer treatment are likely to be healthy unless chemotherapy was administered after the first trimester of pregnancy (36). Becoming pregnant after completing cancer treatment does not appear to enhance the possibility of recurrence, even in women with hormone-positive breast cancer (37).

Psychosocial impact of fertility concerns among cancer survivors

Several instruments have been developed to measure reproductive concerns of female cancer survivors, like the Reproductive Concerns After Cancer scale (RCAC) and the Reproductive Concerns Scale (RCS) (38, 39). The RCAC scale has also recently been modified for the use of male cancer survivors (RCAC-M scale) (40). The INDICATE data showed that long-term reproductive concerns, grief and less satisfaction in life occurred among men who survived testicular cancer. Correspondingly, a recent survey among testicular cancer survivors reported 28% of the sample had a high level of reproductive concerns in ≥1 dimension of the RCAC (41). In female cancer survivors, significant distress about infertility and avoidance is reported when reminded of infertility (42). Prevalence of reproductive concerns reported by women after cancer is much higher when compared to men (58-65% with moderate to high scores), and associated with severe depression (43, 44). Reproductive concerns are well known to be significantly associated with lower quality of life (39). Reproductive concern scales may help screen for concerns among cancer survivors of reproductive age and lead to a timely referral for psychosocial support.

Recommendations for clinical practice

A vital component of comprehensive care for cancer patients is addressing potential threats to their reproductive health. Referral for counselling about fertility preservation options is associated with less regret and greater quality of life (45). Men and women of reproductive age should receive expert counselling and should be given the opportunity to make active decisions about preserving fertility, despite their prognosis, partner status or possible treatment delay. Prompt referral to reproductive specialists allows patients to explore options for fertility preservation prior to the receipt of cancer-directed therapies. There is an urgent need for improvements in oncology care to ensure all patients of reproductive age are well informed about infertility risks and fertility preservation options and to support them in their reproductive decision-making prior to treatment. Enhancing shared decision making has the potential to prevent later-life grief, unmet reproductive wishes and irreversible damage to reproductive organs. Oncofertility referral pathways should be implemented in every centre providing cancer care, with optimal collaboration between clinicians, nurses, psychologists and fertility departments. It is recommended that patients at risk are referred for psychological support when needed. In particular, patients with a history of psychopathology are at risk for psychological distress during fertility preservation decisions (46).

Improvements in patient and oncology clinician education, as well as coordinated referral within cancer care centres are crucial to secure fertility preservation as a priority pre-treatment. Figure 1 depicts a proposed model of care for patients eligible for fertility preservation, as extracted from the European Society of Human Reproduction and Embryology (ESHRE) female fertility preservation guideline. Interventions should be developed for cancer survivors in order to improve coping with unresolved grief due to cancer-related infertility. For medical oncologists, a comprehensive overview of fertility diminishing effects that may result from the admission of specific anti-cancer drugs would be advantageous.

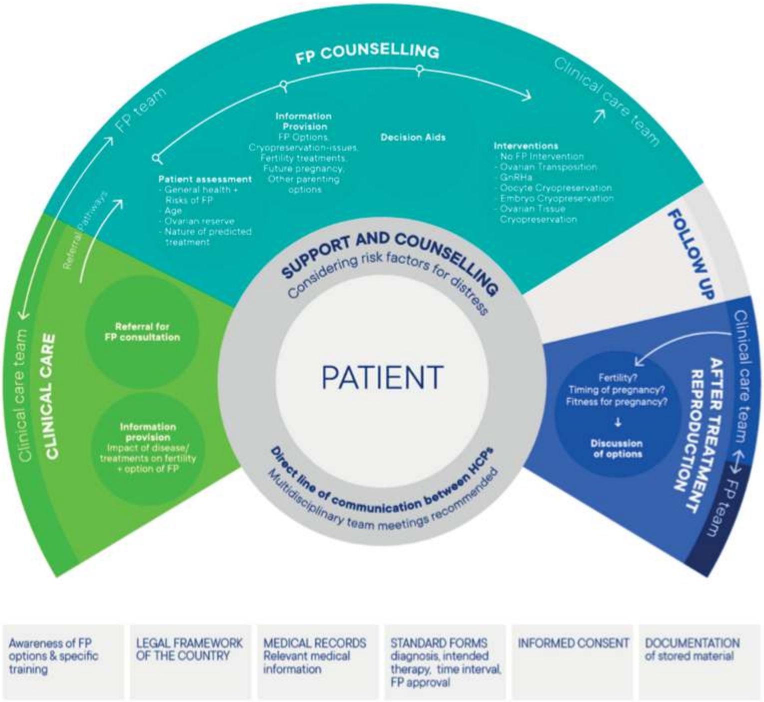

Figure 1. Model of care for patients eligible for fertility preservation.

Source Preservation TEGGoFF, Anderson RA, Amant F, Braat D, D'Angelo A, Chuva de Sousa Lopes SM, et al. ESHRE guideline: female fertility preservation†. Human Reproduction Open. 2020;2020(4). (46).

Future research

Current literature demonstrates the need for and the limits of current fertility counselling in cancer care. Future research should mainly target methods to improve access to care by facilitating reliable referral pathways and decision-making processes for patients, survivors and oncology health professionals. Religious and cultural constraints, as well as costs and insurance issues, should be taken into account. Furthermore, existing uncertainties regarding the exact treatment risks of cancer-related infertility should be investigated. As our survey among oncologists showed, estimations of fertility impact from cancer drugs are highly variable and, in many cases, insecure.

With an expected increasing number of oncofertility practice due to the growing number of fertility preservation options, a corresponding increase of need for education will emerge. Incorporation of oncofertility education in medical school, residency and fellowship curricula should be undertaken. Furthermore, nurses, nurse practitioners and physician assistants can assist medical doctors in the process of counselling and referral for fertility preservation and should be involved in educational initiatives. With a proven, strong willingness to engage in educational activities among medical providers in the oncological community, we are urged to incorporate education. An example may be taken from the American Society for Reproductive Medicine's Air Learning platform, which created numerous educational tools in various formats, including a oncofertility textbook, educational training videos and a free online certificate course (47).

Research should be performed to identify optimal learning strategies, timing and content. Adequate patient information provision on fertility risks and fertility preservation options is identified as a critical component of oncofertility care, should be improved in quality and available in different formats (48). Scientific progress can be made in identifying optimal patient information services.

Psychological distress due to fertility concerns is prevalent and persistent in cancer patients and survivors. Virtually all patients and survivors would benefit from fertility-related psychological support implemented into standard practice from diagnosis through to survivorship. Instruments measuring reproductive concerns may be helpful in screening. Currently, there is a lack of studies examining these concerns in men diagnosed with cancer.

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