Barriers to Adolescent Oncofertility Care

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Adolescent cancer patients experience parent, patient, and health care system barriers to developmentally appropriate oncofertility care.

oncofertility | fertility preservation | oocyte cryopreservation

1. Introduction

Oncofertility is an emerging discipline that is increasingly recognized as an essential component of adolescent cancer care [1]. The National Cancer Institute defines adolescence as patients 15–19 years of age [2]. High survival rates among adolescent cancer patients have shifted the medical focus to the long-term outcomes of cancer treatments [1]. For example, surgery, chemotherapy, and radiation increase the risk of infertility for adolescents in the years and decades following treatment [3]. Advances in oocyte cryopreservation techniques have created a viable fertility preservation (FP) option for post-pubertal female adolescents. Since 2006, the national and international cancer guidelines have advised that early fertility conversations should occur between health care providers (HCPs) and all cancer patients, and referrals to a fertility specialist should be offered to all interested patients [4]. Unfortunately, recent Canadian research [5][6][7] has shown that the majority of cancer patients do not receive the recommended standard of oncofertility care—a result of a combination of parent, patient, and health care system barriers to developmentally appropriate fertility care.

2. Parent Barriers

Oncofertility conversations and decisions occur within the clinician, parent, and adolescent triad [8]. Parents are an important part of the decision-making process. Parental concerns and attitudes influence the extent of FP discussions and the outcomes of fertility decisions [8][9]. After cancer diagnosis, parents commonly prioritize immediate initiation of cancer treatment over fertility considerations [10][9]. Some parents express the desire to wait to address fertility, with the attitude that ‘we will get to it when we get to it’ [11]. Parental hesitancy around discussing fertility is related to fears of overwhelming their child and exposing them to information that is not developmentally appropriate. Their views on FP are influenced by personal beliefs [12] and cultural values [13]. Certain cultures and religions place higher value on female reproduction and encourage parents to prioritize FP.

Studies have found that oncologists are receptive to parental cues, and that they consider parental attitudes when instigating or ending fertility conversations with patients [9]. Unfortunately, parental attitudes towards FP are often incongruent with adolescent patient attitudes. Quinn et al. [14] found that the majority of parents of female

adolescent cancer patients underestimated their daughter's fertility concerns, and incorrectly assumed that their daughter would be satisfied with survivorship only. Disagreements between parents and adolescents could create potential ethical dilemmas and dissuade teenagers from accessing FP services.

3. Patient Barriers

The patient-related barriers that inform fertility decisions include cognitive maturity, fertility knowledge, topic comfortability, and language [8][9][13][15]. Strong decision-making skills are required to navigate time-sensitive and complex fertility decisions. At diagnosis, fertility considerations compete with immediate concerns related to cancer treatment and survival [11]. Decisions are based on uncertainty, as there is no guarantee that oocyte cryopreservation will result in a successful future pregnancy. Adolescents may be less competent decision makers because their prefrontal cortex, which is the primary brain region involved in decision making, is not fully developed [16]. HCPs should consider the cognitive maturity of cancer patients during fertility discussions, to ensure that they are offering accessible and developmentally appropriate fertility information.

Fertility discussions between adolescents and HCPs are influenced by the patient's health literacy and subject matter comfortability [8][9]. Adolescent baseline sexual and reproductive health knowledge is influenced by age and life experience. Many adolescent patients do not receive developmentally appropriate information from HCPs and institutions during their cancer experience [17]. Institutions also lack fertility resources and information in other languages [15]. HCPs are an important source of fertility information, but many adolescents are uncomfortable discussing their sexuality with clinicians, especially in the presence of their parents [8]. HCPs are receptive to the comfort levels of the patients, and may end fertility conversations prematurely if patients are embarrassed [9]. Although the guidelines recommend that all AYA cancer patients have fertility conversations with their HCPs, patient-related factors, such as limited health knowledge and embarrassment, can negatively influence the occurrence and length of fertility discussions at cancer appointments.

4. Health System Barriers

Insufficient HCP knowledge and inadequate institutional guidelines inhibit the ability of adolescents to receive adequate support for cancer-related fertility concerns [8][9][18]. HCPs identify that a lack of knowledge on FP technology and international oncofertility guidelines is a barrier to instigating fertility conversations with patients. Role confusion over which HCPs (surgeons, oncologists, or nurses) are responsible for fertility referrals is another barrier to oncofertility support [7]. In addition, many oncologists report having little knowledge of fertility clinics or specialists for patient referrals [18]. If HCPs are unaware of the fertility services in their city, they are unable to refer cancer patients to the proper support services. Appropriate fertility services may not be available for adolescents or LGBTQ2S+ patients [19].

The majority of pediatric health care providers desire standardized FP guidelines at their institutions [20]. Institutions can create clinical models of care (MOCs) to define institutional guidelines for fertility services, informational

resources, and referrals [21][22]. Unfortunately, many cancer centers do not have institutional MOCs for fertility preservation [23]. The absence of official institutional guidelines likely contributes to the low HCP compliance with national and local oncofertility guidelines. In addition, many cancer centers do not have standardized referral programs or pathways to fertility specialists [24]. Fertility referral pathways are already complicated for adolescent cancer patients because teenagers fall between the medical and psychosocial boundaries of childhood and adulthood [8]. Adolescents are usually treated at pediatric cancer hospitals, while fertility specialists are available at adult centers. Standardized referral processes could ensure that there are proper networks for adolescents to find an appropriate fertility counsellor or fertility clinic. Insufficient referral guidelines have a larger effect on rural patients, who experience additional barriers to accessing fertility services [13].

The high cost of FP is a widespread system-level barrier to service access [25]. FP is expensive, and there are high costs associated with oocyte extraction, medications, oocyte storage, and future use of the eggs. Female FP is significantly more expensive than male procedures. FP coverage varies widely between Canadian provinces, and some provinces, such as British Columbia, Alberta, and Saskatchewan, offer no coverage at all [26]. Even Ontario, which arguably has the most comprehensive FP coverage program in Canada, does not cover all costs associated with FP, such as medications and oocyte storage [27]. Most adolescents have not entered the full-time workforce, and may not have the economic means to pay for FP [1]. In addition, FP concerns can occur at a time when patients and families are already under financial stress. Although Canada has publicly funded provincial health care, cancer is expensive, with hidden costs of transportation, parking, and lost wages [28]. The high costs of FP create socioeconomic disparities in accessing fertility services. In summary, the interactions between multilevel barriers and oncofertility care prevent adolescent patients from receiving the recommended cancer care outlined in the national and local oncofertility guidelines.

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