Availability of Male and Female Sexual Health and Fertility Information on National Cancer Institute—Designated Cancer Center Websites

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ABSTRACT

Introduction: For the estimated 15 million cancer survivors in the United States, access to accurate information regarding quality of life issues such as sexual health and fertility preservation is a very important part of cancer recovery.

Aim: Because National Cancer Institute (NCI)—designated cancer centers (CCs) are leaders of cancer care, we sought to determine the prevalence and quality of information relating to male and female sexual health and fertility on all NCI-designated CC websites.

Methods: A total of 70 NCI-designated CC websites listed on www.cancer.gov and divided by geographic regions were carefully analyzed for the presence and quality of male and female sexual health and fertility information. Fisher’s exact test was performed to assess for differences between websites.

Main Outcome Measure: We determined the number and percentage of NCI-designated CC websites with sexual health and/or fertility information, availability of information by region, and information available for each gender.

Results: Sexual health and/or fertility information was accessible on 43 of 63 (68.3%) CC websites and was more prevalent on comprehensive CC compared with non-comprehensive CC websites (37 of 49 [75.5%] vs 6 of 14 [42.9%] websites, respectively; \( P < .05 \)). NCI-designated CC websites had less information on sexual health compared with that on fertility (24 of 63 [38.1%] vs 41 of 63 [65.1%] websites, respectively; \( P < .01 \)). Access to data was less available for men compared with women (35 of 41 [85.4%] vs 41 of 41 [100%] websites, respectively; \( P < .05 \)) on CC websites providing fertility preservation information. Fifteen CCs in the South Atlantic (11) and East South Central (4) regions did not offer sexual health information on their respective websites.

Conclusion: Information regarding sexual health and fertility preservation after cancer treatment is not common and less available for men compared with women on NCI-designated CC websites. The aforementioned data highlight the need to improve the quality and accessibility of sexual health and fertility preservation information for all NCI-designated CC websites. Shah T, Shin D. Availability of Male and Female Sexual Health and Fertility Information on National Cancer Institute—Designated Cancer Center Websites. J Sex Med 2020;8:315–317.

INTRODUCTION

In 2018 alone, there are estimated to be more than 1.7 million new cancer diagnoses in the United States.1 The diagnosis of cancer is life altering, changing the trajectory of one’s life. Moreover, cancer treatment and rehabilitation is emotionally and physically exhausting, leaving patients with a bleak outlook.2 With improving medical research, technology, and treatments, an increasing number of patients are successfully battling all types of cancer. Once cancer diagnosis and treatment are completed, it is imperative for patients to be provided with information and support regarding life after cancer treatment.3

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treatment. For the estimated 15 million cancer survivors in the United States, access to accurate information regarding quality of life issues such as sexual health and fertility preservation is a very important part of cancer recovery.

National Cancer Institute (NCI)—designated cancer centers (CCs) are institutions recognized for their scientific leadership, research initiatives, and dedication toward developing more effective approaches to prevent, diagnose, and treat cancer. As treatments improve, survivorship after cancer becomes an equally important aspect of cancer care. Because NCI-designated CCs are leaders of cancer care, survivors and healthcare providers use these CC websites as reliable sources of web-based information for all things related to cancer. We sought to determine the prevalence and quality of information relating to male and female sexual health and fertility on all NCI-designated CC websites.

MATERIALS AND METHODS

Seventy NCI-designated CC websites publicly listed on www.cancer.gov as of June 24, 2018, were evaluated. Non-clinical basic laboratory CCs (7) were excluded. Comprehensive CCs (49) defined by NCI as CCs that demonstrate an added depth and breadth of research were compared with non-comprehensive CCs (14). Each website was carefully analyzed for the presence and quality of male and female sexual health and fertility information. The number of clicks to reach topic specific webpages regarding male and female sexual health and fertility information was recorded. Geographic regions as established by NCI (New England, Mid-Atlantic, East North Central, West North Central, South Atlantic, East South Central, West South Central, Mountain, Pacific) were compared for the percentage of websites with information. Quality of information as determined by content present on websites vs external links and outsourcing of information was reviewed. Fisher’s exact test was performed to assess for differences between websites.

RESULTS

Sexual health and/or fertility information was accessible on 43 of 63 (68.3%) CC websites and was more prevalent on comprehensive CC compared with non-comprehensive CC websites (37/49 [75.5%] vs 6/14 [42.9%], P < .05). Of the 43 CC websites, 34 (79.1%) had sexual health and/or fertility information specifically for patients with cancer. Sexual health and/or fertility information was embedded on 27/43 (62.8%) websites with a median number of 4 clicks needed to access content (range 2—6). NCI-designated CC websites had less information on sexual health compared with fertility (24/63 [38.1%] vs 41/63 [65.1%], P < .01). South Atlantic (11) and East South Central (4) regions had no information on sexual health, whereas all 9 regions had at least 1 CC website with fertility information (See Table 1). On websites providing fertility preservation information, access to data was less available for men compared with women (35/41 [85.4%] vs 41/41 [100%], vs P < .05). Furthermore, male sexual health information was only 87.5% present compared with female sexual health information being 100% present when available.

DISCUSSION

With improving cancer care and treatments, more patients are surviving cancer. Although surviving cancer is the initial goal of both the patient and physicians, a return to normalcy after surviving cancer is critical. Because life after cancer treatment can be very difficult, it is important to provide patients with support groups, information, and other resources regarding all aspects of cancer survivorship. One area of cancer survivorship is sexual health and return to sexual intimacy and another is postcancer fertility, primarily a concern for younger patients. Individual providers may have some information regarding cancer survivorship and sexual health/fertility, and a quick online search can yield several articles; however, patients with cancer need reliable, evidence-based information to help guide them during the challenging road to cancer recovery.

NCI-designated CC are institutions recognized for their scientific leadership, research initiatives, and dedication toward developing more effective approaches to prevent, diagnose, and treat cancer. Because NCI-designated CC are leaders of cancer care, survivors and healthcare providers use these CC websites as reliable sources of web-based information for all things related to...
cancer. The aforementioned results demonstrate that sexual health and/or fertility information is accessible on only 43 of 63 (68.3%) CC websites and was more prevalent on comprehensive CC compared with non-comprehensive CC websites. Although this is a good start, such information should be provided on all NCI websites, with each website having specific details embedded onto the website itself. A goal should be made to provide standardized information with region- or center-specific information as well. Sexual health and/or fertility information was embedded on 27 of 43 (62.8%) websites with a median number of 4 clicks needed to access content (range 2–6), demonstrating that even when information was present, it was not always clearly present or not directly embedded on the website itself. Moreover, we found that sexual health information and fertility information was more prevalent for women compared with men as such the desired information should be modified to be equally available for both genders. The strength of the study is that all websites were reviewed in 1 day to avoid changes in information available, whereas a weakness is that the websites were assessed by only one reviewer.

CONCLUSIONS

Information regarding sexual health after cancer treatment is not common and can be difficult to access NCI-designated CC websites when available. Although sexual health and fertility may not immediately be a concern for patients with cancer, it is important for cancer survivorship return to normalcy. The aforementioned data highlight the need to improve the quality and accessibility of sexual health and fertility preservation information for all NCI-designated CC websites.

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