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Has oncofertility information for male patients improved? Objective assessment of internet-based fertility preservation resources at NCI cancer centers from 2015 to 2020

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Abstract

Purpose Fertility preservation is a critical patient counseling component following cancer diagnosis. The aim of this study was to compare change and quality of fertility preservation information available to patients on the websites of National Cancer Institute (NCI)-designated cancer centers over 5 years (2015 to 2020) for both women and men.

Methods All NCI-designated cancer center websites were queried for information on oncofertility in 2020 publicly available to patients using the methodology and rubric previously employed in 2015. Data was evaluated based on each center's city, county, and state by demographic data obtained from the US Census. Additionally, the yearly number of in vitro fertilization (IVF) cycles performed in the city, county, and state of each NCICC was included using websites of clinics reporting data to the Society for Assisted Reproductive Technology.

Results Significantly NCICCs have a standalone pages for fertility preservation in 2020 compared with 2015 ($p=0.004$). There is a statistically significant association between discussion of male fertility and the number of fertility centers in the county and state of the NCICC ($p=0.04$ and $p=0.001$). NCICCs in counties in the highest quartile of per capita income were significantly more likely to address male fertility ($p=0.03$).

Conclusions Oncofertility information on NCICC websites has improved between 2015 and 2020. The impact of cancer treatment on male fertility, while improved, is still limited, particularly in counties with lower per capita income.

Keywords Oncofertility · Fertility preservation · Gestational carrier · Donor oocyte · Donor sperm · Donor embryo

Introduction

Loss of fertility potential is a serious side effect of cancer treatment and has been shown to negatively impact quality of life [1, 2]. The negative psychological effects of infertility

after cancer treatment and unmet informational needs for patients have been well [3–5]. The American Society for Reproductive Medicine recommends starting fertility preservation discussions as early as possible in planning of cancer treatment [6]. The American Society for Clinical Oncology (ASCO) first proposed standard guidelines for fertility preservation in 2006, and these guidelines were revised in 2013 and 2018 [7–9]. The recommendations include discussion of possible infertility from the gonadotoxicity of treatment and fertility preservation as part of education and informed consent before cancer therapy [7]. The most recent revision of the ASCO guidelines includes changes on who is responsible for discussing fertility preservation with cancer patients. The original language used by ASCO has been revised to replace the word “oncologist” with “health care provider” to include other physicians, psychologists, nurses, and social workers [7]. This broader definition recognizes

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the importance of a team-based approach to cancer care and increasing awareness on the impact of cancer treatment on fertility.

The barriers patients seeking fertility preservation are faced with include uncertainty about their individual risk of infertility, fear of delaying cancer treatments, and the cost of fertility preservation [10]. A cancer diagnosis can result in significant financial distress, even among insured patients. A systematic review of 25 studies found that 16 to 78% of survivors experienced financial hardship as a result of their cancer [11]. The ASCO guidelines discuss that race and ethnic disparities in health care, as well as geographic location, are barriers to equal access to fertility preservation [9].

The role of electronically accessible health information in clinical care has been the focus of discussion nationally for the past decade [12]. The National Cancer Institute reports up to 55% of patients used the internet as their first resource — a tendency that increased between the years 2003 and 2008 [13–15]. Hospital websites are seen as a trusted source of web-based resources to supplement the knowledge of patients and their families regarding diagnoses, treatments, and survivorship from malignancy [16].

As current guidelines recommend that cancer patients of reproductive age should be counseled and educated on fertility preservation, oncofertility information should be readily available to patients and their families^{6,9}. However, there is no information on the quality of information available on these sites. The aim of this study was to objectively assess the quality of fertility preservation information available to female and male patients on the websites of National Cancer Institute (NCI)-designated cancer centers and the Cleveland Clinic. The assessment focused on discussion of the effects on cancer treatment on fertility, options for fertility preservation, parenting-related survivorship resources, and specific discussion about male fertility. This study also looked at the objective effect of time on availability of oncofertility information comparing the same data points from 2015 to 2020.

Methods

All websites of NCICC were evaluated; there were 62 centers in 2015 and 65 in 2020. Two investigators collected the data from NCICC's websites and a third member from a separate institution reviewed discrepancies. Using the information from NCI-designated cancer center websites, a rubric was employed to establish minimum content quality standards for the validation process. The methodology and rubric were previously employed in 2015 to establish minimum content quality standards for the validation process [17, 18]. This is publicly available information and exempt from Institutional Review Board approval.

Data were then evaluated based on each cancer center's city, county, and state by data obtained from the US Census (2010 and 2014–2018) for demographic information including race, income/poverty, and insurance status to estimate demographic variables within the population. Various socioeconomic factors were included such as population density, income per capita, percent population without insurance, median household income, percent college degree, percent with a high school degree, and percent other language spoken at home.

Additionally, we investigated the association between volume and presence of fertility centers in the catchment area of NCICCs as they relate to patient oncofertility information on NCICC websites. Data was evaluated based on the number of fertility clinics in the city and the county that each NCICC is located in. Additionally, the yearly number of in vitro fertilization cycles performed in the city and county of each NCICC was included. Websites of clinics reporting data to the Society for Assisted Reproductive Technology (SART) from the most recent complete year (2017) were queried for this information [19]. Descriptive statistical analysis and chi-square analyses of the top and bottom quartiles (Q1 vs. Q4) of various socioeconomic factors such as population density, income per capita, percent population without insurance, median household income, percent college degree, percent with a high school degree, and percent other language spoken at home.

Results

Among NCICC centers, 92% were affiliated with academic institutions. The risk of cancer treatment on fertility was mentioned by 86% of centers and 83% discussed fertility preservation, which were not significantly different from 2015. Among NCICC's, significantly more cancer centers have a standalone pages for fertility preservation in 2020 compared with 2015 ($p=0.004$). Survivorship information on family building after cancer significantly increased from 32% in 2015 to 82% in 2020 ($p=0.008$). Among all cancer centers, there was a significant increase in information on fertility preservation specifically directed toward men, such as sperm cryopreservation which is increased from only 60% in 2015 to 70% in 2020 ($p=0.014$). Among NCICCs, there was a statistically significant increase in standalone web pages for fertility preservation, survivorship information, and information on fertility preservation specifically directed toward men (Fig. 1). Among all cancer centers, there was a significant increase in information on fertility preservation specifically directed toward men, such as sperm cryopreservation which is increased from 60% in 2015 to 70% in 2020 ($p=0.014$). NCICCs in states with more fertility centers were significantly more likely to discuss the risk of cancer

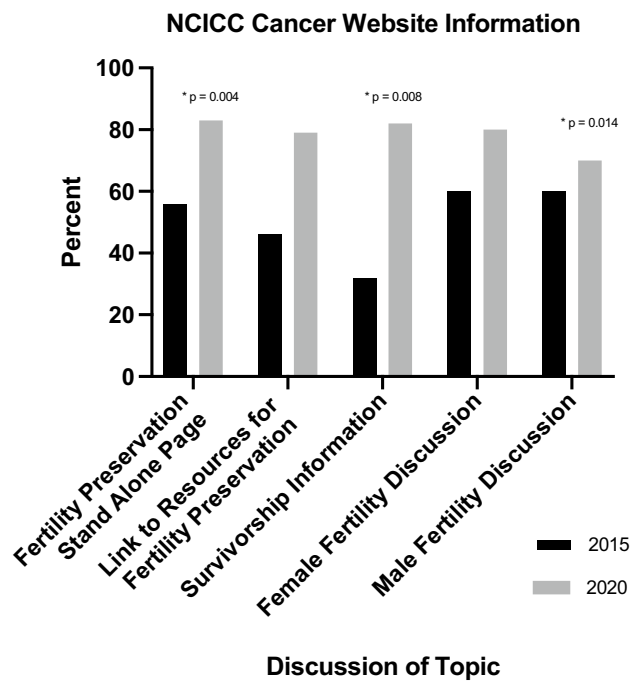


Fig. 1 NCICC cancer website information for men oncofertility

treatment on fertility and fertility preservation ($p=0.01$ and $p=0.04$, respectively). NCICCs in counties in the highest quartile of per capita income were significantly more likely to address male fertility ($p=0.03$). Geographic location in a city, county, and state with a higher volume of IVF cycles was also significantly associated with increased discussion of the effects of cancer on male fertility ($p=0.04$, $p=0.01$, $p=0.01$).

Discussion

The negative psychological effects of infertility after cancer treatment and unmet informational needs for patients have been well documented [3–5]. This study demonstrates that nationwide improvements have been made between 2015 and 2020, with statistically significant increases in standalone web pages for fertility preservation, survivorship information, and information on fertility preservation specifically directed toward men on NCICC websites. The ASCO guidelines discuss that race and ethnic disparities in health care, as well as geographic location, are barriers to equal access to fertility preservation³. In this study, male oncofertility information was less available in counties with lower per capita income. No other statistically significant associations were observed between web-based oncofertility content and income, insurance status, college education, and non-English language spoken at home. Presence of oncofertility information was, however, associated with access to fertility care,

as NCICCs in states with more fertility centers and higher IVF volumes did offer this information. Additionally, there may be a bias given NCICCs are located in cities and counties with a higher than average per capita incomes. Given the increasing recognition of the importance of oncofertility in cancer survivorship, more education should be available about options for fertility preservation for all persons, particularly for men in lower income counties.

Conclusion

Oncofertility information on NCICC websites has improved between 2015 and 2020. The impact of cancer treatment on male fertility, while improved, is still less than that of females, and is particularly limited in counties with lower per capita income. NCICCs in areas with lower rates of insurance and education or higher rates of speaking a foreign language were less likely to discuss the effect of cancer treatment on male fertility on their websites. This highlights an opportunity for health care providers to improve the education on male infertility for the underserved and underinsured populations. Given the increasing recognition of the importance of oncofertility in cancer survivorship, more education should be available about options for fertility preservation for all persons, particularly for men in lower income counties.

Data Availability Requests for data can be made to melody.rasouli@unlv.edu.

Code availability Not applicable.

Declarations

Ethics approval Not applicable.

Consent to participate Not applicable.

Consent for publication Not applicable.

Conflict of interest The authors declare no competing interests.

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