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Oncologists' confidence in knowledge of fertility issues for young women with cancer

Christine Duffy,

Department of Biology and Medicine, Warren Alpert School of Medicine, Brown University

Susan M. Allen,

Program in Public Health, 121 S Main Street, 6th floor, Brown University, Providence, RI 02912

Catherine Dube, and

Department of Community Health, Brown University, Centers for Behavioral and Preventative Medicine, Coro West Suite 314, One Hoppin St, Providence, RI 02901

Kay Dickersin

Johns Hopkins Bloomberg School of Public Health, 615 N. Wolfe St, Rm W5010, Baltimore, MD 21205

Introduction

There are nearly 800,000 women diagnosed yearly with cancer [1] and nearly 100,000 of these cancers will occur in women younger than age 45 [2]. Despite the importance of fertility issues for young female cancer survivors, research suggests that many women do not receive adequate education and counseling regarding how cancer may affect their fertility [3]. To address this failure in communication between oncologists and their patients, the American Society of Clinical Oncology published recommendations in 2006 urging oncologists to inform all individuals of the risks to fertility from cancer treatments, and to begin such discussions as soon as possible in the management and treatment of their cancer [4].

Lack of knowledge regarding treatment-related risks to fertility and fertility preservation options has been identified as a barrier to discussions about these issues between women and their doctors [5, 6]. Failure to discuss fertility issues may result in some women initiating treatment unaware of associated risks to fertility until it is too late to pursue fertility-preserving options. However, fertility risks associated with cancer treatment and options to preserve or protect fertility are complicated clinical issues. The risk of infertility due to cancer treatment varies widely based on the type of cancer treatment and age of the woman [7]. Fertility preservation options range from the well-established embryo cryopreservation, to less-established modified surgical, radiologic, or medical treatment strategies designed to preserve or protect gynecologic organs [8], to emerging technologies such as in vitro maturation or ovarian tissue cryopreservation that hold the promise of future fertility [9]. Given the rapidly advancing field of onco-fertility, a substantial amount of effort to stay abreast of this complex field may be required for oncologists to feel confident in their knowledge and develop sufficient expertise to educate their young female patients regarding fertility issues, and address their' questions and concerns.

Some oncologists may be reluctant to invest the time required to gain necessary knowledge regarding fertility issues, believing it is not their responsibility to develop sufficient expertise to discuss these issues. These physicians may feel that their primary responsibility to the patient is to treat the cancer and that expertise in the area of fertility preservation is in the domain of the reproductive specialist [5, 6]. Lack of perceived responsibility to discuss fertility issues among oncologists may result in avoidance, failure to disclose, and failure to educate female cancer patients about changes in their fertility related to cancer treatment. It has been shown that a sense of responsibility to counsel patients regarding a particular health issue is associated with greater knowledge and actual patient education practices for that issue [10, 11]. A sense among oncologists that discussing fertility issues is not their responsibility is particularly problematic because women are unlikely to raise the topic themselves, or to seek referral to a reproductive endocrinologist for information if they are unaware of the risks of infertility due to cancer treatment.

Even among oncologists who take responsibility to educate young women about fertility issues and who want to increase their knowledge of fertility and cancer, much of the information regarding fertility preservation is disseminated in journals or at meetings geared toward reproductive specialists. Therefore, many oncologists may be unaware of opportunities to acquire information regarding current and emerging options in this rapidly advancing field. In fact, difficulty in accessing information resources has been shown to impact whether and how physicians choose to address complex clinical issues or questions [12, 13].

In summary, perceptions of personal responsibility for acquiring expertise regarding cancer-related risk of infertility and fertility preservation options, as well as awareness of and access to opportunities to acquire this knowledge are likely to undermine oncologists' confidence in their own knowledge about these important issues. We sought to explore, in a national sample, oncologists' confidence in their knowledge of cancer-related fertility risks and options to preserve fertility. We also investigated associations between their confidence in this knowledge and their perceptions of personal responsibility, information use, and information availability. Understanding these issues is an important first step to implementing interventions to ensure high quality patient education regarding threats to fertility associated with cancer and its treatment.

Methods

Sampling Frame

A national sample of 2000 medical oncologists, hematology/oncologists, radiation oncologists and gynecologic oncologists was drawn randomly by a third party vendor from the American Medical Association Master File, the most comprehensive listing of physicians in the United States. Physicians in the US are added to the AMA Master File list upon graduation from medical school, and it is updated annually from over 2000 different resources including state licensing boards, residency programs, hospitals, specialty certification boards, medical societies, and the Physicians' Professional Activities (PPA) Survey. The number drawn for each specialty reflected their representation in the AMA Master File, except for gynecologic oncology, whose subspecialty numbers were relatively small (n=454), and hence all were sampled. In addition, 32 oncologists from New England, California and Texas were contacted to participate in the survey pilot, and these responses were added to the sample pool. Only those physicians who were currently practicing clinical medicine, and who reported treating > 5 women aged 21 – 45 in the past year, were eligible to participate.

Data Collection

Physician addresses and phone numbers were provided by the AMA. Since email addresses were not available for all physicians, study personnel searched the internet to find as many email addresses as possible. Hard copies of the survey, each accompanied by a cover letter and a stamped and addressed return envelope, were mailed to sampled physicians, who were offered the option of completing a hard copy of the survey and returning it by mail, or of completing an identical Web-based version of the survey on-line. This mixed method option approach was designed to maximize our study response rate, given oncologists' low response to previous national surveys[14].

A total of four follow-up contacts were attempted (via valid e-mail address or phone number) before the case was considered a "passive refusal". Those with unavailable or undeliverable emails were contacted by phone. An Excel database was used to track the return of questionnaires by mail and completion of surveys on the Internet, as well as the timing of repeat mailings. Respondents were sent a \$20 gift certificate upon completion of survey. The Brown University Institutional Review Board approved the study and all participants completed an on-line consent process.

Survey Development

Survey questions regarding confidence in knowledge of fertility issues and resources most often used were developed by authors based on qualitative studies with oncologists, and Schover and colleagues' survey of fertility issues for men with cancer [15], adapted for a female cancer population. Input from a national advisory panel of experts in survivorship and reproductive technologies was obtained to provide feedback on survey question wording and ease of administration, and their recommendations incorporated.

Measures

Dependent Variable—The dependent variable "confidence in knowledge" was based on responses to eight knowledge questions. Physicians were asked "Please indicate your confidence in your knowledge about each topic below on a scale from 1, "not at all confident" to 5, "very confident". Topics included risks of infertility associated with chemotherapy agents typically used, options for fertility preservation (including surgical techniques to preserve the uterus and ovaries and cryopreservation of eggs and ovarian tissue), and health risks to mother and child. A summary scale "confidence in knowledge" was generated based on the responses to these questions. Each question was allotted 1–5 points based on response ("not at all confident"=1 to "very confident" =5). Higher scores reflect more confidence in knowledge. The summary scale was normally distributed and had good internal consistency (alpha coefficient = 0.84; Range 10–40, mean=23.8 SD 6.43).

Independent Variables—The variable "sense of responsibility" was based on physician response to the question: "To what extent do you feel it is your responsibility to discuss *infertility* with women of child-bearing age (i.e., 18–45) facing cancer treatment?" and a second similar question, for which *fertility preservation options* was substituted for *infertility*. Responses to each of these questions included: "not at all", "somewhat", "mostly", and "entirely". Those who answered "mostly" or "entirely" to both questions were considered to have a "high" sense of personal responsibility for discussing fertility issues, while those who reported "not at all" or "somewhat" to both questions were considered to have a "low" sense of responsibility. Responders with "mostly" or "entirely" on one item but "not at all" or "somewhat" on the other item were considered to have a "moderate" sense of responsibility for fertility discussions.

To capture current oncologist information sources, an “information sources” summary score was generated based on responses to two survey questions; the first regarding oncologists’ sources of knowledge about fertility preservation options; the second for sources of knowledge about potential benefits and harms of fertility preservation options. Potential sources included personal experiences, professional guidelines, peer reviewed literature, fertility specialists, continuing medical education, patient education materials, and “other”. Respondents could check multiple sources. One point was allotted for each resource checked off, and an “information resources” score was generated (possible scores 0–14; Range 2–14, $X=6.6$ SD 2.62).

Because reported availability of patient information resources in respondents’ practices was low in our survey (72% reported no resources), we created a dichotomous “patient resource variable” (“yes” = any resource, and “no” = no resource), reflecting access to patient resources.

Sociodemographic and practice characteristics—Demographic variables including age, sex and specialty of physicians were obtained from the AMA masterfile. Physician practice type was self-reported (University-based, non-University based, and private practice).

Analysis

We performed descriptive statistics on all variables and chi-square analyses were first performed to determine unadjusted relationships between our independent variables and reported confidence in knowledge (categorized as low, moderate and high) of various fertility issues and options. These variables were examined for inclusion in our model based on our study hypothesis and the existing literature at the time. We performed multiple linear regression to determine the relationship between our outcome variable, total confidence in knowledge summary scale score, and our predictor (independent) variables. Variables which were significantly correlated with confidence in knowledge ($p < .10$) were included in our final model (specialty, practice setting, physician and patient information resource scores, and physician sense of responsibility to discuss these issues), as well as the demographic variables age and sex. STATA 6.0 software was used for all analysis.

Results

We calculated the survey response rate using AAPOR’s Response Rate 4, in which a proportion of cases of unknown eligibility are estimated to be ineligible based on available scientific information [16]. Of the 2032 oncologists in our sampling pool, 194 physicians (9.5%) were not located (i.e., letter returned with no forwarding address, no valid phone number or e-mail address), and 141 (6.9%) responses indicated ineligibility due to death, retirement or for treating less than 5 premenopausal women in the previous year. An additional 609 (30%) persons did not respond to at least four follow-up e-mail or phone contacts and were estimated to be ineligible based on demographic data of practicing oncologists [17]. Of the 1088 estimated to be eligible for the survey a total of 344 participated, a response rate of 31.6%.

Respondents’ average age was 48.5 and they were predominantly male (75.3%) (Table 1). Representation from Medical Oncology, Hematology Oncology and Radiation Oncology, was approximately equal (29.3%, 28.1% and 30.9% respectively), but gynecologic oncology representation was lower, consistent with their lower representation in the AMA Masterfile (11.7% of respondents). Respondents to the survey were younger than the sample pool (48.5 v 51.2 $p < 0.01$), but there were no meaningful differences observed between respondents and sample pool based on gender or specialty.

Sense of responsibility to discuss fertility issues

More oncologists' reported that it was their responsibility to discuss fertility issues than reported it was their responsibility to discuss fertility preservation options (77.7% versus 60.1% respectively). For our composite measure of sense of responsibility which combined these variables, well over half of oncologists reported a high sense of responsibility (58%), twenty percent were categorized as low responsibility, and the remainder characterized as moderate (22%).

Oncologists information sources

The most prevalent source of information on fertility preservation options was the scientific literature (71.5%), followed by professional guidelines (65.4%) and discussion with fertility specialists (63.6%). Slightly more than half reported using their own clinical experience (54.3%). Less commonly used sources were continuing medical education (41.7%) and patient education materials. Sources of information on the potential benefits and harms of fertility preservation options were similar. The average number of information sources was 6.6 (Range 2–14, SD 2.62).

Patient information sources

Only 18% of respondents reported having *any* patient resources available. Ten percent of oncologists reported access to printed brochures, the most common resource available. Approximately 5% reported having a nurse practitioner/social worker, or web-based materials/reference list as an information source for patients. Essentially no physicians reported using interactive web-based resources, CD-ROMS, or educational videos.

Oncologists' confidence in knowledge

Only about half of respondents reported moderate or high confidence in their knowledge about fertility and fertility preservation options (Table 2). These items included the risk of infertility with chemotherapy agents used most often, health risks to mother associated with pregnancy after cancer, surgical techniques to protect ovaries, and health risks to fetus from cancer treatments. Even fewer oncologists (<25%) reported confidence in their knowledge of new IVF protocols, cryopreservation of oocytes, cryopreservation of ovarian tissue, or radical trachelectomy.

Unadjusted analysis revealed confidence in knowledge of fertility issues was higher among respondents in University-based practices, in gynecologic oncology subspecialties, and among older physicians. Our multiple linear regression model exploring the association between "confidence in knowledge" score and our independent variables indicated that Gynecologic-Oncology subspecialty, greater information resource use, greater availability of information resources for patients, and a greater sense of responsibility to discuss fertility risks and preservation options, were all associated with higher confidence in knowledge scores. Physician age, gender, and practice setting were not significantly associated with knowledge scores (Table 3).

Discussion

Oncologists' confidence in knowledge regarding fertility preservation options in this study was moderate at best. Knowledge of newer options (such as low-estrogen exposure IVF protocols in women with estrogen sensitive tumors, and cryopreservation of ovarian tissue) was quite low in spite of the fact that options to preserve fertility are among the top information needs identified by cancer patients [3]. There was even low confidence in an area which one might *expect* oncologists to be knowledgeable --the infertility risks associated with various chemotherapeutic agents that study respondents prescribe most

often. More than one third of respondents were not confident in their knowledge about the fertility effects of these agents. The implications for women under their care are considerable since it is likely that at least some of these women may choose a regimen with lower infertility risk if given the option.

According to Bandura's Social Cognitive Learning Theory, new behaviors are adopted based on both a person's self-efficacy and their outcome expectations. For many oncologists, the practice of educating and counseling young women regarding fertility issues will be new to them, and they will lack the necessary confidence in one's knowledge essential to developing self-efficacy for a new behavior [18]. Research among physicians has consistently shown that confidence and self-efficacy are important factors in whether physicians counsel patients about a number of difficult issues, including discussion of do not resuscitate orders [19] and prognosis in cancer [20].

Increasing opportunities for Continuing Medical Education (CME) classes that employ active learning strategies could not only fill knowledge gaps and improve confidence in knowledge through didactic instruction, but could also provide oncologists opportunities to gain skills associated with successful counseling practices. A recent Cochrane review suggested CME, particularly interactive CME workshops, could produce moderate changes in practice behavior among physicians [21]. Standard curricula in fellowship training in oncology should also include training in educating and counseling young cancer patients regarding changes in fertility related to cancer treatment, and relevant questions should be included in board examination for the oncology subspecialty. Such steps could help provide the needed training as well as provide a strong incentive to develop a knowledge base in fertility issues and hence increase oncologists' confidence in their knowledge.

The most common sources of information (peer-reviewed literature, professional guidelines and discussion with specialists), were consistent with prior literature [22, 13], including a recent review of physician information sources [23] and the Practitioner Information Needs Study which examined cancer information usage and needs among oncologists and other practitioners [24]. In this study, more respondents obtained information from personal experiences than from continuing education opportunities. While information from personal experiences may be readily available for a clinician to call upon, conclusions drawn from such information are likely to be highly biased because they are based on unique experiences and relatively small numbers of patients.

Our results indicate that oncologists in the US make few patient education resources available regarding fertility and cancer. Lack of such resources and information likely hinders fertility discussions between patient and physician. Providing resources to patients can help identify women who are particularly concerned about infertility, and open the door to initiate discussions regarding fertility risks and preservation options. There were excellent patient resources available in 2009, the time of our survey, via reputable online sources, including Fertile Hope (now part of Lance Armstrong Foundation), American Cancer Society and the NCI-funded Oncofertility Consortium websites. However, oncologists must be aware of these resources to refer their patients to them, so efforts to educate oncologists about available resources are much needed.

While there has been a call to develop multi-disciplinary programs to address fertility issues for cancer patients [25], and many cancer centers throughout the country have, or are developing, such programs for their own patients, most patients still receive cancer care in the community setting with limited access to these centers. Reliable on-line decision aids from trustworthy sources, free from professional or commercial bias, are important potential resources to develop for oncologists and their patients. These resources could provide much

needed information for more geographically isolated patients and providers, and help identify women for whom fertility issues are particularly important and who may benefit from further discussion and referral to reproductive endocrinologists.

As patients live longer after a cancer diagnosis, survivorship issues such as fertility must be considered and addressed by their providers. Our multivariate regression analysis results suggest that increasing an oncologists' sense that discussion of fertility options is in fact their own professional responsibility may indeed help increase physician confidence and knowledge. Physicians who feel a sense of responsibility likely seek out information and knowledge and hence improve their ability to address these issues with their patients. In 2006 ASCO recognized this need with the publication of guidelines outline the oncologist's role. Continued attention by ASCO and development and strengthening of links to other professional organizations focused on fertility such as the American Society for Reproductive Medicine can help keep this issue in the forefront.

Somewhat surprisingly, we found that oncologist gender and age were not associated with confidence in knowledge in our multivariate analysis. Female gender [26, 19, 27] and younger age [19, 27] have been associated with lower confidence in knowledge and abilities in medicine in a number of areas of counseling. It is possible that women, while traditionally reporting lower confidence in most areas, are relatively more aware of fertility issues in female cancer patients simply because of their gender, hence we see no difference. Similarly, although younger physicians are usually less confident in their knowledge and abilities, given that many of reproductive medicine's advancements are quite recent, younger physicians may have had more training in reproductive medicine during medical school or residency and hence may be more confident in their knowledge.

Strengths of our study include that it is the first national survey of oncologists regarding access to resources for fertility and cancer. It is also the first to explore the association between confidence in related knowledge and: 1) information access and use, and 2) sense of responsibility to address fertility issues. Previous survey studies have only addressed male infertility [15], or pediatric cancer [28], or focused on referral patterns to reproductive specialists [14],[29].

Limitations of the current study include the relatively low response rate of 31.6%. It is possible that our response rate is an underestimation, because we were not able to determine the eligibility of all nonresponders. In addition, several previous national studies of oncologists have yielded similarly low response rates (18–32%) [15, 30, 31], and responders and non-responders in our study were highly similar in terms of demographic factors and specialty. Additionally, our response rate may partly reflect a low priority given to fertility issues by oncologists [32].

It is possible responders to our survey were more interested in the topic of fertility and cancer, and this may have biased our results, likely overestimating the use of resources and confidence in knowledge of this topic. A second potential limitation is that we did not measure knowledge directly. However, we chose to measure confidence in knowledge, rather than actual knowledge, for several reasons. First, because direct testing of knowledge may have been off-putting, especially in a population that may be less familiar with fertility issues. Second, fertility and cancer information changes rapidly, as it is an area of intense research and investigation. Information can easily have changed between survey development and implementation. Finally, in a previous analysis under review, we have shown that higher confidence in knowledge is associated with higher frequency of raising fertility issues in young women with cancer.

In sum, our results show that confidence in knowledge of fertility issues is moderate at best in the oncology community, but our results also point to a number of different avenues to pursue to raise that confidence and improve the quality of education and counseling regarding fertility issues provided to young women with cancer. Coordinated, comprehensive education in fertility and cancer issues for fellowship training, interactive CME opportunities for established practitioners, and encouraging a professional commitment to take responsibility for informing and guiding patients regarding fertility issues all warrant consideration as methods for improving confidence in knowledge. In addition, not just individual providers, but also national professional organizations must make this a priority. A concerted effort among oncologists and professional organizations can help ensure that oncologists develop and maintain the requisite knowledge and confidence in knowledge about fertility issues, have access to high-quality resources, and commit themselves to discussing fertility issues with all young women with cancer. Such effort can help ensure that young female cancer survivors have the broadest range of parenting options open to them.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Characteristics of respondents to survey

Sample Characteristics	Sample (%) N=324
Male	75.3
Female	24.7
Age (mean)	48.5 (8.9)
Practice	
University	44.7
Non-University Hospital	25.9
Private Practice	29.3
Sub-specialty	
Medical Oncology	29.3
Hematology Oncology	28.1
Radiation Oncology	30.9
Gynecologic Oncology	11.7
Email Address available	73.5

Table 2

Percentage of oncologists reporting moderate or high confidence in knowledge of fertility issues and options for preservation

Knowledge of: N=324	
The risk of infertility with chemotherapy you prescribe most often	61.4%
Health risks to the mother associated with pregnancy after cancer treatments	58.3%
Surgical techniques to protect the ovary from radiation damage	57.3%
Health risks to the fetus associated with the mother having received cancer treatments	54.9%
New IVF protocols with less delay of cancer treatment or less estrogen exposure?	22.8%
Cryopreservation of unfertilized oocytes	24.4%
Radical trachelectomy	20.1%
Cryopreservation of ovarian tissue	18.2%
Summary confidence in knowledge score [*](higher scores= greater confidence in knowledge)	23.8 (6.4)

^{*} Range 8–40, alpha reliability coefficient 0.84

Table 3

Factors associated with confidence in knowledge of fertility issues (N=324)

Variable	<i>b</i> (<i>se</i>)	<i>p</i> -value
MD age (<40) n=69		
40–49 n=127	–0.32 (0.82)	<i>p</i> =0.69
50+ n=128	–0.1.9(0.80)	<i>p</i> =0.81
Male n=245	0.11(0.72)	<i>p</i> =.88
Setting (reference university-based hospital n= 175)		
Non-university hospital n=76	–1.02(0.78)	<i>p</i> =0.19
Private practice n=99	0.35(0.72)	<i>p</i> =0.62
Specialty (reference medical oncologist n=97)		
Radiation oncologist n=99	–0.26(0.85)	<i>p</i> =0.79
Gynecologic oncologist n=38	6.71(1.09)	<i>p</i> <0.001
Hematologist/oncologist n=92	0.40(0.80)	<i>p</i> =0.62
No patient resources available n=267	–2.66(0.79)	<i>p</i> =0.001
Oncology information resources score n=324	0.84(0.12)	<i>p</i> <0.001
Sense of responsibility (reference low responsibility n=65)		
Moderate responsibility n=72	2.21(0.95)	<i>p</i> <0.05
High responsibility n=187	3.29(0.74)	<i>p</i> <0.001