

# Oncofertility Resources at NCI-Designated Comprehensive Cancer Centers

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## Abstract

NCI-designated comprehensive cancer centers (CCCs) set the standard for providing exemplary patient care. Quality cancer care includes discussions about fertility and referrals to fertility specialists for patients at risk for sterility. This study sought to determine what fertility preservation (FP) resources are available in CCCs and how well those are integrated into patient care. Leaders at each CCC received a letter requesting a short telephone interview with individuals who could provide information about the institution's FP resources. A semi-structured interview guide was used and responses were audio-recorded. Data were analyzed using content and thematic analysis. Interviews were conducted with 30 of the 39 CCCs that see adult patients (77%). The remaining institutions included 4 nonresponders, 3 that referred the interviewers to childhood cancer survivorship clinics, 1 that refused, and 1 that could not identify any FP resources. Participants were primarily affiliated with reproductive endocrinology (n=15) or hematology/oncology divisions (n=10). Institutional policies regarding consistent provision of FP information were rare (n=4), although most sites (n=20) either had some services on-site or had referral programs (n=8). However, only 13 had some experimental services, such as ovarian tissue cryopreservation. Respondents reported barriers to provision of FP, including oncologists' identification of patients at risk, low referral rates, and perceptions of patient prognosis. Only 8 (27%) sites had staff with time dedicated to FP. CCCs vary widely in implementing FP-recommended practice to their patients. CCCs are positioned to provide exemplary oncofertility care, but most need to better integrate FP information and referral into practice. (*JNCCN* 2013;11:1504–1509)

Increasing interest has recently been shown in quality-of-life issues for cancer survivors, including fertility preservation (FP).<sup>1–12</sup> Following the publication of the American Society of Reproductive Medicine's guidelines on FP,<sup>13</sup> in 2006 ASCO published FP guidelines, stating that oncologists should be prepared to discuss risks to patients' fertility and make appropriate referrals.<sup>14</sup> Despite these professional guidelines, current evidence indicates that numerous barriers exist to patients' receipt of information about fertility options and referrals to appropriate clinical resources.<sup>8,11,15</sup>

The Competing Demands Model,<sup>16</sup> which examines the offer of preventive services in a clinical setting, provides an excellent framework for examining discussions and offering FP. Because oncologists have multiple roles and must prioritize demands, such as adherence to guidelines and regulations and time required for patient visits, it has been argued that “rational physicians could be forgiven for despairing over yet another demand.”<sup>17</sup> The Competing Demands Model explicitly considers these tensions.<sup>18</sup> As noted by Williams,<sup>17</sup> “the model describes 3 domains that directly influence the outcome of each clinical encounter: the clinician, the patient, and the practice ecosystem. The services delivered are the result of the competition between these demands. The model is useful because it highlights the need to consider all 3 factors in any attempt to improve care.” However, to date, the examination of barriers has only been conducted within patient populations or physician groups. Because no research to date has reviewed the institutional setting or practice ecosystem, this article potentially contributes novel information that will help advance health services research to improve FP communication.

At the time of this study, 39 NCI-designated comprehensive cancer centers (CCC) throughout the United States were treating adult patients. For a cancer cen-

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Submitted December 27, 2012; accepted for publication October 10, 2013.

This work was supported by funding to the Oncofertility Consortium, 5-UL1DE019587-05. The authors have disclosed that they have no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors. Parts of this work were presented as posters at the 2011 ASCO Annual Meeting and the 2012 Cancer Survivorship Research Conference.

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ter to achieve the “comprehensive” designation, it must demonstrate “reasonable depth and breadth of research activities in each of three major areas: laboratory, clinical, and population-based research.”<sup>19</sup> Furthermore, NCI documents express an expectation for these CCCs to be leaders in progress against cancer and its sequelae.<sup>20</sup> Because of their leadership in many areas of cancer treatment and survivorship, the authors expected these institutions would also be at the vanguard of addressing patients’ FP needs.

Notably, only 8 CCCs mentioned fertility and/or FP among their own survivorship activities in the 2006 report of the Cancer Center Directors Working Group.<sup>21</sup> Although some may not consider FP a survivorship activity, the NCI uses the definition of *survivor* that begins at the time of diagnosis. Given the evolving landscape of basic and clinical science regarding FP<sup>22</sup> and the interest in survivorship for young adults with cancer,<sup>23–25</sup> the goal of this study was to examine institutional policies related to the provision of clinical FP resources and the availability of these services.

## Methods

### Sample and Recruitment

A letter, signed by the director of the Robert H. Lurie Comprehensive Cancer, was sent via e-mail attachment to the cancer center director of each of the 39 CCCs that treat adult patients. The letter requested a short telephone interview with a person or persons within each institution who could provide information about the institution’s FP resources and procedures. If no response was received after 3 business days, a second e-mail was sent stating that the researchers would follow-up with a phone call.

Based on the recognition that people within the same institution may play different roles within an FP program, respondents could nominate other colleagues at the institution or those with whom they partner to provide fertility resources and services to complete the interview. When more than one interview at the same institution was conducted, data from one interview was included in frequency distributions and the second interview served to add qualitative detail.

### Interview Format

Interviews were conducted by one of the authors (M.L.C., M.M.H., S.S.) using a semi-structured in-

terview guide and responses were audio-recorded. Content analysis was used to organize responses into deductive categories, and discrete, inductive codes were applied after discussion with the research team. In addition, site visits were conducted with institutions that had programs that were particularly well established or innovative. To identify those sites, the authors focused on LIVESTRONG Fertile Hope Centers of Excellence, which are institutions that have been recognized for implementing fertility processes into clinical care, including provision of patient and health care provider education and referrals to fertility specialists.<sup>26</sup> All participants provided verbal consent for study, which was approved as exempt by the Northwestern University Institutional Review Board.

### Data Analysis

Content analysis of the audio files was completed through entering interview responses into Snap Survey software (version 9; Snap Surveys Ltd, Portsmouth, NH). Frequent responses to open-ended questions were consolidated into categories. When no appropriate response was listed, the category “other” was used. Explanations of processes or illustrative quotations were entered into a free-text category. Thematic analysis/inductive coding of the audio files was completed by having 2 authors listen to the files and identify recurrent themes.

## Results

Interviews were conducted between June 2010 and November 2011 with respondents at 30 of the 39 CCCs. Of the remaining CCCs, 4 did not respond to repeated requests, 3 referred the authors to childhood cancer survivorship clinics, 1 refused, and 1 could not identify any FP resources. Participants mainly worked in divisions of reproductive endocrinology/infertility (REI; n=15) or hematology/oncology (n=10), with the others affiliated with other departments (n=3) or in nonclinical positions (n=2).

### Institutional Policies

Four sites reported having institutional policies or formal procedures in place or in development for referral to FP services or provision of FP information, whereas 25 had none and the respondent for 1 site was unsure. Regarding the development of policies, 1 participant stated, “There’s definitely resistance to

kind of mandating things...There's this real strong belief that as physicians they should have autonomy to make decisions about what's in their patient's best interest." To the contrary, however, a respondent working at a site with policies in place felt that, in addition to increasing uptake of FP services, the institution was able to keep better data about the interest in and use of these services. More common were reports of no formal process to ensure that the topic was discussed, despite the availability of electronic health records that could incorporate relevant prompts or reminders.

### **Institutional Resources**

Most centers (n=20) had some mix of fertility services available to patients on-site, with 13 having established services, such as sperm banking, plus some experimental protocols (eg, ovarian tissue cryopreservation). Several centers (n=9) had no services available on-site, although all but one of these referred out to other clinics. One respondent did not know of services available or referral sites.

Several centers (n=8) reported that at least one health care provider had dedicated time or a position description that included FP. The training and role of this person varied widely among sites, ranging from physicians to mid-level providers to patient navigators. In addition, these centers tended to have formal FP programs in place. Administratively, however, these programs were also varied, because they could be housed within REI divisions, survivorship clinics, or hematology/oncology departments.

### **Barriers to Providing Information and Services**

Interviewees mentioned several barriers to timely provision of fertility-related information. A common theme was that it was difficult to identify which patients needed FP services. That is, mechanisms to determine if a patient is at risk for impaired or damaged fertility and also desires to have biological children in the future were described as being difficult to implement. Without knowing the denominator of "patients at risk," institutions cannot reasonably say what proportion of patients they are reaching. A participant in an REI division noted, "We see the cancer patients that are referred, that want to come here, and are interested in it. But how many patients have fertility issues and cancer?"

Several additional barriers were reported to have originated with the oncologists, because they often

failed to provide referrals for patients at risk. Several respondents felt that there was a (sometimes unwarranted) perception that the cancer diagnosis was an emergency: "There's a sense, sometimes more of a sense of urgency than need be, about getting people on treatment...The sense that we've got to do something like right away, when often it's really not a right-away kind of thing. It's something that could really wait 2 weeks." The referral was also subject to a lack of integration of FP into the clinical consciousness: "I'd get a lull where I didn't have any guys [referred for sperm banking] for like a month, then I'd run into one of the oncologists on the elevator, and say, 'hey what's going on,' and then I'd have 4 in the next day or two." In addition to the need to frequently remind oncologists that the services exist, the fact that the CCCs are also large teaching institutions with annual turnover among residents and fellows results in a need to continuously educate new individuals.

The level of knowledge, interest, or commitment of the oncologists was frequently referred to as an impediment: "So I think the biggest barrier there...is the lack of the knowledge about the type of patients that should or could be eligible for preservation techniques." For example, some felt that oncologists were unaware of recent advances in FP technology, such as oocyte freezing, which would help patients who might not have been eligible for FP even a few years ago.

Oncologists' personal judgments were also described: "There are some physicians that feel that it's their role to decide what's best for their patients. So when they have a really poor prognosis or they're really sick, I have to be honest, there are clinicians who choose not to discuss this. They feel it's not a priority. I think they mean well because they feel like they're sparing patients the stress, but it takes a lot of time to convince people otherwise."

Perceptions of patient resistance were also invoked as a barrier. The feeling was that patients are overwhelmed in the face of a cancer diagnosis and "want to be cured of cancer, and [therefore] the long-term outcomes and quality of life issues don't prevail all the time." Yet others felt that these perceptions actually provided a rationale for including survivorship care early in the treatment process: "What we find in the survivor mode is if you don't talk about [FP], patients get really [angry]. They come back and [say] they were involuntarily sterilized."

### Facilitators to Providing Information and Services

Several respondents mentioned systematic workflow patterns as a facilitator to providing FP information and services. Having a clear process for referral was deemed helpful, as was the use of prompts within the electronic health record. Two sites discussed the use of electronic prompts or patient intake questionnaires to raise questions about fertility, which would flag the need for discussion. However, these prompts were not perfect, and often required follow-up (eg, some patients may not know at intake if they have a need for FP).

Collecting and maintaining relevant data was also motivating: “When I went to each [division], I showed them the data of their [group] and how they compared to [the institution] as a whole, to start generating some discussion about where they were doing well and where they might be able to improve.”

### Who Informs Patients About Their Fertility Risks?

Oncologists were considered most likely (in 46% of responses) to inform patients of their risks of fertility loss. Some participants indicated that oncologists told patients about fertility risks within the context of the informed consent discussion conducted at the start of treatment. However, when oncologists spoke to their patients about FP, the extent and quality of that discussion was not clear to the participants: “We don’t have any idea if [the oncologists] talk for 10 minutes or they give [the patients] a handout...” Other institutions had a procedure of calling in a specialist, such as fertility navigator, to provide patients with the bulk of information about fertility loss and FP.

### The Oncologist’s Role in Providing Information

When asked to describe an ideal strategy for providing FP information, a widely held view was that the patient’s oncologist (or clinician who first sees the patient after diagnosis) should introduce the topics of fertility loss and FP, and then have the patient continue a more in-depth conversation with an REI expert or other person specifically prepared to conduct this conversation. This format was seen as ideal because of the time constraints involved in treating cancer and proactively treating infertility. This approach also allowed clinicians to specialize in their particular area of expertise. One REI expert said, “I wouldn’t know how to discuss cancer, and I wouldn’t assume they know how to discuss reproductive

health.” Through introducing the topic, the oncologist implicitly supports the idea that FP is a legitimate option that is not in conflict with the cancer treatment plan: “In a perfect world, I think it will always come from the first physician that [the patients are] seeing at their new patient visit...even if all that physician does is say ‘I want you to talk to my nurse about this.’ Because I think it goes back to the idea that [patients] need to know their oncologist or their surgeon is on board with this.”

### An Ethical Imperative

Some providers believed that delivering these services was an ethical and professional imperative. As one oncologist stated, “[A]s a comprehensive cancer center, you know, it should be something that’s integrated into everybody’s curriculum for their young cancer patients.” Another interviewee stated, “I think the most important thing we can do is to... make sure that the field as a whole has these discussions. And it isn’t the right of the doctor to withhold this information. And yes, at times it makes it more complicated to deliver care, but we owe it to every young adult patient and young girl who potentially can have therapy that could affect their fertility to at least tell them what their options are in [current year] and what we know about their risks, knowing that we don’t know everything about their risks.” In response to concerns that patients may not act on the information, one clinician stated, “You never go wrong with presenting the information. If they don’t want to hear it or they choose not to internalize it, then that’s their choice, but it’s your responsibility to at least present it to them.”

### Integrated Pathways

In institutions with formal FP programs, the authors identified common models of the pathway through which patients received services. In step 1, a provider is prompted to discuss fertility risk and options, such as through electronic means or a patient request. In step 2, FP information is provided by a clinician, not necessarily the oncologist. “I think [patients] should hear about their risks from their treating oncologist, but I think in terms of all the fertility preservation options and how does it work, or what is involved and what does it cost, I think that there’s a real ad-

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vantage to having somebody who is a point person. Somebody [for whom] it's part of their role and who has the time to come and spend the time with the families [to go] through all of the information that they need to hear."

In step 3, patients would receive a referral to an andrology laboratory or a reproductive endocrinologist. In this model, the mid-level provider was often reported to assist in scheduling and coordinating, among other clinical matters. An oncology clinician with this role stated that the model worked well for several reasons. First, it worked because the REI experts are "just seeing patients who really want to pursue some treatment option. That makes it a little bit easier for them so they can spend more time with patients who really want to pursue some option. [Second,] it's better for the patients because they can be seen internally here..., and promptly, to talk about options, and they're dealing with clinicians like myself who just see people with cancer. So that's good. And [third,] it's good for us as a [cancer] program because it also helps introduce the concept of survivorship and long-term issues such as fertility right up-front."

## Discussion

In this study of NCI-designated CCCs, wide variation was found in the provision of information about and access to FP resources. Although it is encouraging that most centers had clinical resources available or had relationships with outside clinics for referral, few CCCs seemed to be following ASCO guidelines to ensure provision of timely information and referrals to patients. These data were collected before the recently updated guidelines, which include egg freezing as standard rather than experimental.<sup>27</sup> Consistent with studies using national data,<sup>11,28</sup> respondents stated that oncologists' referral patterns were erratic and that biases existed about the types of patients that should be offered FP services. Although CCCs are resource-laden compared with many community clinics, the large size and decentralized nature of care in many CCCs may make it difficult to implement systematic procedures across cancer types for all patients.

The authors found that roughly one-fifth of CCCs had clinical personnel for whom FP was an official part of their job, such as fertility navigators or a team involved in a formal FP program. Their role seemed

to be to facilitate data collection regarding the need for FP, acquire oncologists' support, and, perhaps most importantly, provide timely access to information and services. Having these programs in place facilitates data collection that both demonstrates the unmet need and allows for benchmarking of progress.<sup>28,29</sup>

Accounts of how institutions have established FP programs have been published,<sup>29-32</sup> which can serve as guides for institutions that have not done so or are not doing so effectively. Although the CCCs in this study differ from one another in organizational structure, several independently implemented the concept of having dedicated staff to address FP. This model is in line with the LIVESTRONG Fertile Hope recommendations for systematically integrating reproductive health into cancer treatment.<sup>26</sup>

In line with the model suggesting that patients with cancer become survivors from the moment of diagnosis,<sup>23</sup> these data support the idea that planning for survivorship must also begin then. Planning for family building before treatment begins allows patients to become aware of fertility risks and potentially avoid the distress associated with infertility.<sup>33,34</sup>

That 3 of the CCCs approached referred the researchers to survivorship clinics for childhood cancer survivors deserves mention. These centers, along with the one that could not identify any resources, showed that FP was still not well-integrated into cancer care, and that family-building is often considered a posttreatment survivorship issue. The fact that almost half of the respondents each came from REI or oncology departments shows that FP is still seen as a chimera that does not fully belong in either discipline.

Although not all CCCs participated in this study, the response rate was approximately 75%, and the results are in line with those of prior work in this area.<sup>11,15,28,35-37</sup> However, unlike other studies, this research focuses exclusively on results from NCI-designated CCCs, which are best positioned to set the standard for providing exemplary oncofertility care.

## Conclusions

To provide truly comprehensive cancer care, each CCC that has not already done so should commit to the establishment of formal FP programs, with some portion of at least one clinician's time designated for serving as a fertility educator or fertility naviga-

tor. These institutions should implement procedures for obtaining data on the numbers of patients who might benefit from FP, perhaps using their existing electronic medical records systems. To be leaders in the provision of quality, evidence-based cancer care, CCCs need to better integrate FP information and referral into their cancer treatment and survivorship models.

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