

Cancer and fertility preservation in Puerto Rico: a qualitative study of healthcare provider perceptions

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Abstract

Purpose This study aims to examine healthcare provider perceptions of cancer-related infertility and fertility preservation (FP) in an underserved population and to highlight cognitive and structural barriers to use.

Methods In-depth, semi-structured interviews were conducted with a sample of 16 healthcare providers participating in a larger ethnographic study on cancer survivorship and cancer-related infertility in Puerto Rico, an unincorporated US territory. Interviews were conducted in-person, audio-recorded, transcribed verbatim, and coded using the constant comparative method.

Results Providers identified several barriers to FP in Puerto Rico: high cost in relation to income levels, lack of insurance

coverage, gaps in provider knowledge of fertility clinics and financial assistance, lower prioritization of quality-of-life needs leading to inconsistent physician disclosure of fertility risks, geographical location of fertility clinics, and logistical challenges to maintaining FP offerings. Two factors act as facilitators: a high value placed on patient-provider communication and relationships and the formation of local alliances between the oncology and reproductive medicine fields, potentially leading to increased cross-specialty communication and referral.

Conclusions Infertility is a continuing source of distress for cancer patients and survivors, and barriers to FP vary cross-culturally. In Puerto Rico, context-specific factors indicate potential areas of intervention. Greater awareness of fertility risks and

Relevance for research, policies, and programs Steep inequalities in access to infertility treatments are evident both in the USA and worldwide. Social scientists have argued that emerging disparities in access to fertility preservation are likely to parallel documented class- and race-based disparities in cancer incidence, mortality, and treatment. Few studies have examined fertility preservation outside of the mainland USA and high-income Western European countries, especially in more resource-limited settings like Puerto Rico. This gap has limited our knowledge about how cancer patients are able to use these critical supportive care resources and what specific infrastructural and contextual factors are most important in influencing access. While it is intuitive that barriers and challenges do vary cross-culturally and cross-nationally, there are likely some shared barriers and challenges across settings worldwide. The identification of such barriers is the essential first step in conceptualizing effective, broadly applicable interventions.

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options can be fostered through physician training in conjunction with organizational measures targeting cost barriers.

Keywords Cancer · Infertility · Fertility preservation · Puerto Rico · Healthcare providers

Introduction

Cancer incidence rates are increasing in Puerto Rico (PR) at the same time that mortality rates are declining [1]. Coinciding with these trends in PR and elsewhere is an increased emphasis on long-term quality-of-life concerns such as infertility, a common side effect of cancer treatment in reproductive-aged individuals. Depending upon the type of treatment and the patient's age, women face a 40–80 % risk and men a 30–70 % risk of infertility [2]. Studies conducted in the USA and other Western countries have demonstrated the importance of fertility and future parenthood to newly diagnosed patients [3–6]. One study found that both male and female survivors rated the ability to have children as a chief concern [4], while others have shown that infertility can be a significant and lingering source of distress for both newly diagnosed patients and post-treatment survivors [7, 8].

For individuals who desire genetically related children after cancer treatment, an increasing number of pre-treatment fertility preservation (FP) options exist. These include egg, embryo, and sperm freezing (cryopreservation) [9]. These technologies do, however, come with significant access challenges. US studies have demonstrated that many newly diagnosed patients are unaware of the effects of cancer treatment on their reproductive abilities [5, 10]. Corresponding research has documented low levels of patient-provider communication about infertility [6], FP techniques [11], and referrals to fertility-related services [12]. Many survivors learn about their fertility status years later after attempts at having children have failed. Healthcare providers are often the gateway for information about cancer treatment side effects, including long-term side effects such as infertility [13]. Thus, it is critical to gain their perspectives on the issue.

Studies on FP and cancer-related infertility have primarily been conducted in Western countries and with White/Caucasian populations, limiting our knowledge of the infrastructural, cultural, and contextual factors influencing access to these important supportive care resources. Socioeconomic and race-based disparities in outcomes and utilization rates of assisted reproductive technologies (ARTs) have been documented in the USA and other developed countries [14–16]. In addition, studies have demonstrated cultural variation in beliefs about and use of ARTs both globally [17, 18] and within the USA [19–23]. While little research has been conducted to date on disparities specific to FP, studies thus far have highlighted differences in counseling and/or referral

patterns according to ethnicity and certain socioeconomic factors such as insurance status and educational attainment [24–27].

Thus, access to FP options in developed countries may be particularly difficult for low-income and cultural minority populations, such as cancer patients in the unincorporated US territory of Puerto Rico, a Caribbean island of four million. We believe it is critically important to extend research on FP to diverse populations and settings to examine variation in beliefs, practices, and access to reproductive technology with the ultimate goal of alleviating context-specific barriers to FP. Little is known about factors influencing access to FP in Puerto Rico, which is available through only four clinics on the island, and no known studies have been conducted to date. This paper describes an examination of cancer-related infertility and cognitive and structural barriers to FP use in an underserved population.

Materials and methods

This paper is based upon a sample of 16 healthcare providers in a larger ethnographic study on cancer survivorship and cancer-related infertility in PR. The original study included key informant interviews with ten cancer researchers and 50 in-depth, semi-structured interviews with cancer survivors, healthcare providers, and advocates/support group leaders. The sub-sample described in this paper consists of four types of healthcare professionals who have regular clinical contact with cancer patients/survivors: fertility specialists, oncologists, oncology nurses, and gynecologists. These providers were purposively selected [28] to represent certain specialties and because of their reputations addressing these topics (for example, having previously worked on oncofertility issues). Providers were identified for possible inclusion through a referral by one of the key informants, who were all cancer researchers employed at medical schools or universities. Providers were contacted via telephone or email and invited to participate. Inclusion criteria consisted of the following: (1) a specialization in gynecology, oncology, oncology nursing, reproductive endocrinology, or andrology; (2) a medical or nursing degree; (3) serving the profession in PR at the time of the interview (i.e., not retired); and (4) routine clinical contact with cancer patients or survivors.

All interviews were conducted using a semi-structured, open-ended interview guide that was developed using input from key informants, a media analysis, and a literature review. Interview questions focused on the following topics: providers' assessment of their patient's long-term medical and social issues, knowledge of fertility problems following cancer treatment and available FP options, perspectives on patient-provider communication related to infertility and FP, perceptions of barriers and facilitators to patients' use of FP,

and the importance they as providers accord to issues of cancer-related infertility.

Interviews lasted 22–65 min with an average of 43 min and were conducted in providers' clinics or offices. It was determined by the authors that saturation was reached when no new themes or insights emerged [29]; recruitment was halted after 16 interviews. All interviews were audio-recorded and transcribed verbatim. Transcripts and notes were entered into MaxQDA [30], a qualitative analysis software program, and coded using the constant comparative method [31]. An initial codebook that captured inductively generated open codes was developed by the first author (a medical anthropologist) and by a Puerto Rican cultural anthropologist. Related codes were then combined into broader, more inclusive categories and analyzed for commonly expressed themes. Transcripts were dually coded and differences were resolved through meetings and dialog.

Twelve male providers and four female providers participated in this study. Thirteen were located in the capital city of San Juan, while the other three were located in the southern part of the island, a 2-h drive from San Juan, or the west, a 3-to-4-h drive. Participants were between 34 and 67 years old, with a mean age of 46.8 years. Most had attended medical school in PR. While eight received the totality of their medical training on the island, six received some training in the mainland USA and two others attended medical school internationally. Mean time since medical school graduation was 17.6 years.

Results

The main themes emerging from interviews related to providers' perceptions of four issues: (1) the importance of the issue of infertility to their patients; (2) socioeconomic, geographic, and health system barriers to fertility preservation; (3) provider relationship and communication factors; and (4) challenges specific to the delivery of fertility services in PR.

Perceived importance of issue to patients

In general, providers believed patients' desires about parenthood did not change after cancer diagnosis. However, oncologists noted that fertility and desire for future parenthood take a backstage to other concerns at that time: patients are overwhelmed, afraid or concerned by a multitude of other immediate details. As time goes on, though, they believed their childless survivors begin thinking about fertility again, as the following quote demonstrates:

I think patients are very distracted about their diagnosis, and the association that cancer has with death.

Everything else goes to a secondary level...But I know that once their treatment is over and they are cured or fall into surveillance, then those issues are going to be brought up, and they are going to ask me why I didn't tell them (oncologist, male).

Approximately half of the sample felt infertility was an important issue to their young patients, with some noting that parenthood is deeply valued in Puerto Rican culture. Others, especially those who worked with acute leukemia patients, described how their patients did not necessarily consider it to be important:

All of them, they don't care [...] They're in the inpatient [unit], they're sick, there are other things on their mind (oncologist, female).

Providers drew distinctions between men and women regarding the impact of treatment and available FP options.

I think it's easier to orient males for future fertility and that's probably because of the ease or how simple it is to preserve sperm before chemotherapy. It's probably less expensive, less invasive, and it's been available for more time than female treatments or female fertility preservation (fertility specialist, male).

Oncologists also identified gender differences in their patients' priorities about having children: women were perceived as being more pro-active about finding fertility solutions and generally placing more value on discussing fertility and future childbearing. They were seen by many providers to be inherently maternal and to strongly desire children, which they believed translated into greater interest in FP. As one oncologist noted, "in Puerto Rico, 96% of the women want to be mothers."

On the other hand, providers regarded men as "not caring" about infertility; rather, they were seen to be chiefly concerned about providing for their families after their cancer diagnosis. Several participants drew linkages between traditional notions of masculinity and men's reaction to discussions about infertility risks and options. Commonly noted by oncologists was men's tendency to focus on sexuality over infertility:

I think that women are more open to [voicing fertility concerns]. They clearly say, 'Am I going to be able to have kids or not?' Boys are not that open, but they kind of say 'can I have a girlfriend? Can I be sexually active?' Some men ask about impotence problems (oncologist, female).

Factors affecting access to FP

Nearly all interviewees pointed to high cost and/or lack of insurance coverage as the principal barriers to FP, particularly for the costlier female options. Several oncologists noted they had never had a patient undergo FP because it was too expensive and not covered by insurance, particularly when combined with the cost of cancer treatment, the loss of work days and sometimes jobs, and the generally low salaries and high cost of living that is the current economic reality in PR.

The other day I had a young man who was 24 years old, was planning on getting married soon—which he did a year later—who had Hodgkin’s lymphoma, and it was a huge tumor. So instead of giving him the routine therapy I gave him a German protocol, which is highly spermatotoxic, because it’s very aggressive. I sent him for sperm banking, and he talked to his fiancé, and he said ‘listen Doc, I just can’t pay that’ (oncologist, male).

All oncologists believed that treatment delays created significant obstacles. Because egg or embryo cryopreservation can delay cancer treatment for several weeks (and sperm banking for several days), providers were hesitant to take what they perceived as a risk in putting off treatment, a sense of urgency they believed patients too experienced.

Sometimes the younger people think about it, but if they cannot do it, they prefer the cure more than having children in the future. Usually they want to start treatment quickly, so sending them for an evaluation for fertility preservation would take time, especially here in Puerto Rico. That’s a problem here (oncologist, male).

All of the fertility clinics are located in San Juan, the capital city, which can be a 3-to-4-h drive from distant parts of the island. Some saw this as a major impediment for those with inflexible jobs or no transportation. For example, an oncologist located 2 h from San Juan noted the following:

We don’t have many [fertility clinics], so most of the people don’t have much access to them. Many are poor, or they have [transportation] issues. I’m new here; I’ve been in the area for one year, and none of my patients are willing to go. When I was in San Juan, my younger patients went sometimes because the fertility clinic was closer. But here, it’s not that accessible (oncologist, male).

While these providers did cite distance as a major barrier (three of whom practiced outside of San Juan), others disagreed, insisting that PR is a small island and distance is

irrelevant. As a fertility specialist in San Juan noted: “Where there’s a will, there’s a way.”

Provider relationship and communication factors

Many cited obstacles concerned patient-provider relationships and communication. Oncologists and oncology nurses pointed to providers’ lack of disclosure about fertility risks and options and voiced the importance of informing patients.

The best policy is not to judge anybody, so I tell everybody of childbearing age. If they are a nun, I would say, ‘Listen you can’t get pregnant during chemotherapy, and you’re at risk of infertility.’ Because people make changes in their lives. So you pretty much have to tell everybody (oncologist, male).

However, there was consensus among providers that, on the whole in PR, newly diagnosed patients are not systematically informed about infertility by their oncology team. They agreed that lack of disclosure constituted the major barrier after high cost and lack of insurance coverage.

The only other barrier would be not being aware because the doctor is not giving the appropriate advice. The doctors have either not made them aware, or the doctor does not want to offer the fertility preservation treatment to them [...] The doctor himself might be a barrier, you know? (fertility specialist, male).

Several fertility specialists noted the lack of time with which oncologists, urologists, or gynecologists referred their newly diagnosed cancer patients for FP. While they emphasized making every effort at accommodation, such as bringing sperm banking kits directly to male patients in the hospital versus asking them to visit the fertility clinic, the rushed nature of many referrals limited the available options:

The problem is that urologists usually tell the patients 2-3 days before the chemotherapy. It’s always in a hurry, and that’s something that the primary doctor—the oncologist—has to do more in advance. Because if you have chemotherapy tomorrow, what can I do? (fertility specialist, male).

Participants cited several reasons for this lack of communication. First, they voiced the idea that patients’ priorities were the children they had already and that they preferred to focus on them rather than consider FP. Second, providers may not personally think it is an important issue

or are singularly focused on the curative aspect. As one oncologist noted:

I don't think many oncologists have this type of conversation, unless it's obvious. [...] I think that we assume that maybe this is not as important as treating the cancer. It is like the utmost goal is to have you disease-free forever, no matter what the consequences. This is a feeling that patients bring to the table, and other physicians also. They think that this is a war against cancer, and sometimes they don't think about the consequences of treatment. I don't think [that view] is changing (oncologist, male).

The religious beliefs of patients and providers engendered varied responses from participants. Several personally knew other oncologists who refused to refer patients or survivors for fertility services based on a personal religious objection:

I know for a fact that [because of] the religious vision of a hematologist/oncologist [in the same building], he doesn't recommend either fertility preservation treatments or even fertility treatments in patients without any history of cancer. Because of [his] religious beliefs, he has been an advocate against fertility treatments (fertility specialist, male).

On the other hand, several providers dismissed this idea:

Luckily most religions will see [FP] as a medical issue, and the religions that usually have something to say about it are against birth control. So fertility preservation – I mean, 90% of Puerto Ricans are at least non-practicing Catholic, right. Catholics who never go to church; we have tons of those here. The Catholic Church opposes birth control, but they don't seem to have an opinion about fertility preservation (oncologist, male).

Providers more generally acknowledged that religious beliefs impacted the willingness of some patients and survivors to use infertility services.

It's something that is going to come up at a point of the discussion about whether we create embryos or not. And whether those embryos are going to be used at some point or not. Especially in Puerto Rico, being a population with a strong Christian or Catholic background, that's always an issue that is there. Some people discuss it openly and some don't (fertility specialist, male).

Some providers described the dilemma of discussing FP with patients with poor prognoses. They feared that these

patients might choose what they would consider suboptimal therapy in order to save their fertility.

That's a very delicate issue, and that is probably where it is hardest to guide a young woman, but where you really have to be honest. What is the likelihood of the cancer coming back? Do you really want to have a child if you have a 50% chance of recurrence? And that gets rough; that gets rough. Because it's a cold reality hitting you in the face, and saying 'do you really want to have a kid when there's a toss of a coin whether he's going to have a mom?' (oncologist, male).

Other themes relating to disclosure among oncologists were not as strongly manifested. For example, a well-developed theme in the US literature about barriers to FP is that of time—oncologists refrain from discussing fertility risks and options with newly diagnosed patients because they have limited time for patient consultation, and must prioritize topics of discussion [32]. While fertility specialists in the current study did voice concern about the frequent lateness of cancer patients' referral to FP services, only one physician, an oncologist, noted that lack of time may be a factor impinging on actual physician disclosure of fertility risks. Conversely, it was clear from the data that providers in general took great pains to nurture healthy, trusting relationships with their patients. These providers described in great detail the partnerships that evolved between the two parties that ultimately furthered their patients' recovery and healing. As a general trend, the providers in this study greatly valued time spent in discussion with their patients.

I'm so happy when they come to me and they say, 'I don't want to take this drug. I want to take this other drug.' [...] That's exactly what I would love patients to be able to do. To be really motivated, to learn about it, to make their own decisions and choices (gynecologist, female).

Fertility specialists' perspective on barriers

While oncologists emphasized cost and insurance obstacles as the primary determinants of FP usage, fertility specialists focused instead on providers' lack of awareness of reproductive side effects and available FP services. They believed most oncologists were unaware of the existence of fertility specialists or the services they provide.

Probably on our side, we don't give more information to the physicians than whatever we have on the website. We assume that everybody is reading the website, but

that's not true. So that's our part (fertility specialist, male).

Fertility specialists discussed in detail potential strategies to more effectively "advertise" their services to PR oncologists.¹ The fertility specialist quoted above continued:

I think we are preparing ourselves, getting all the training and everything, and we know that eventually we will be ready for these two parts – the patients and the physicians. But we still need to do our own part, just to go out and tell them what we can do. Or get together and do two workshops per year, somewhere, sponsored by a university or a company. Like a retreat for oncologists (fertility specialist, male).

Fertility clinics in Puerto Rico themselves face difficulties in offering services, some of which are related to the island's unique relationship with the USA. Fertility specialists emphasized the expense of maintaining FP services for cancer patients given the high level of required manpower, materials, and technology, and comparatively small financial return. Because the average income in PR is significantly lower than in the mainland USA, they are forced to lower the cost of their services proportionately even though they purchase the same equipment. In addition, those materials are more expensive because they must be imported from the USA.

Cryopreservation itself presented significant logistical challenges, including maintaining high-level technical expertise (especially for newer procedures, such as egg freezing), and the storage facilities and procedures that would most effectively safeguard the samples. Because so few people in Puerto Rico use fertility preservation, two of the fertility specialists noted that a centralized cryopreservation and storage system would effectively allow clinics to pool their limited resources.

I think that in Puerto Rico, because we are a small community, the ideal thing would be to have one center dedicated to this type of process. Not every clinic has its own group of patients doing it, but if just one center decides that they're going to be the oncologic center, and that center would do the process and take charge of the oocytes, so that each individual clinic doesn't have the responsibility of keeping track of that. That center may have economic help from the government for that particular issue [FP]. And that center [would get more] experience [because of] more referrals, and make

everything cheaper, and it would be easier for the patients to do it (fertility specialist, male).

Discussion

Steep inequalities in access to infertility treatments are evident both in the USA and worldwide [33]. Social scientists have argued that emerging disparities in access to fertility preservation are likely to parallel documented class- and race-based disparities in cancer incidence, mortality, and treatment [34, 35]. Few studies have examined fertility preservation outside of the mainland USA and wealthy Western European countries, especially in more resource-limited settings like Puerto Rico. This gap has limited our knowledge about how cancer patients are able to use these critical supportive care resources and what specific infrastructural and contextual factors are most important in influencing access. While it is intuitive that barriers and challenges do vary cross-culturally and cross-nationally, as Linkeviciute and colleagues [36] note, there are likely some shared barriers and challenges across settings worldwide. The identification of such barriers is the essential first step in conceptualizing effective, broadly applicable interventions.

In Puerto Rico, fertility preservation and parenthood form part of emerging discussions in PR about quality-of-life following cancer. Analyses identified several barriers that providers believe impede access to FP in PR: high cost and lack of insurance coverage, especially in relation to income levels; gaps in provider knowledge of fertility clinics and financial assistance programs; lower prioritization of quality-of-life needs leading to inconsistent physician disclosure of fertility risks; geographical location of fertility clinics; and logistical challenges to maintaining FP offerings.

Some of these challenges are not unique to PR per se. For example, studies conducted in the mainland USA have found that rates of referral to fertility specialists are low and oncologists often lack knowledge of available options [11, 12]. Additionally, oncologists have been found to display a singular focus on survival to the exclusion of quality-of-life issues [32]. Puerto Ricans who do not reside in the metropolitan San Juan area face similar transportation and logistical challenges as cancer patients who live in rural or healthcare resource-poor settings.

However, other issues identified by this study point to how barriers to FP vary cross-culturally and according to a society's socioeconomic and political context. For example, while both this study and mainland US studies [12, 37] have identified cost and insurance as

¹ Since data collection concluded for this study, new collaborative initiatives have taken place: for example, fertility specialists were invited to present to the PR oncology/hematology professional association about the impact of cancer treatment on reproductive capacity and locally available fertility preservation services.

major impediments—which has implications for patient-provider discussion about fertility—this barrier takes on greater urgency when we consider that nearly 45 % of Puerto Ricans live under the federal poverty line, 20 % more than the poorest US state [38]. In addition, income inequality is steep, leading to a highly variable situation regarding access to reproductive care. Financial assistance programs operate on the island through several non-profit organizations, such as the American Cancer Society; however, participants' knowledge of their existence was low.

Other departures from US studies are evident in these findings. First, the role of religious beliefs in referral to FP is ambiguous; a number of providers believed strongly that some oncologists object on religious grounds to ARTs and could even cite specific examples, while others disregarded this view. It was more broadly acknowledged that the religious views of some patients may prevent use of ARTs in general, or if services are sought, those patients may be more likely to keep the experience private for fear of judgment from friends and family. Further research would shed light on the role of religious belief in referral to and use of ARTs. Second, a consistent theme in the US-based literature is the time crunch that oncologists must negotiate during discussions with newly diagnosed cancer patients. Fertility issues are often brushed to the side and accorded a low priority, if they are discussed at all. However, this theme almost never arose among participants in this study; indeed, both physicians and patients expressed a high value on communication, interaction and time spent together, which leaves the door open for an increased focus on fertility-related conversation. While providers' comments did reflect assumptions about traditional gender roles (e.g., women placing a higher value on parenthood), it is unclear whether or not those beliefs ultimately influence patient-provider discussions about FP. Finally, the challenges that fertility clinics face in maintaining FP offerings are in many ways unique to the Puerto Rican context. For example, clinics must lower their prices given the comparatively lower income in PR, even though they use the same materials that oftentimes are costlier because they must be imported from the USA. The low numbers of cancer patients using FP in PR has implications for the maintenance of expensive technology and high-level technological expertise.

The strengths of this study lie in its inclusion of multiple perspectives on cancer-related infertility and FP and the generation of in-depth data in a cultural context that is markedly different from those in which the majority of studies have been conducted. At the same time, the extent of barriers is likely underreported:

participants were probably skewed towards those most interested or invested in the topic. As with all qualitative research, results are not generalizable to other groups or populations. Further survey research would be beneficial in examining the extent of these beliefs and practices among cancer care providers in PR.

Conclusion

Infertility is a continuing source of distress for cancer survivors and some barriers to FP vary cross-culturally. While a multitude of factors inhibit the use of FP services by cancer patients in PR, several important context-specific factors indicate potential areas of intervention and may be amenable to change. Communication and social relationships are highly culturally valued in PR, which has promising implications for patient-provider discussions. Secondly, new alliances are being formed between the Puerto Rican oncology and reproductive medicine fields with cross-specialty training taking place after the completion of data collection for this study. This has potential to lead to increased communication and referral. Greater awareness of context-specific issues and the available options can be fostered through this type of physician training in conjunction with organizational measures targeting cost barriers.

While significant disparities in access to FP certainly exist in high-income settings like the USA and Western Europe, they may likely be exacerbated in more resource-limited societies such as Puerto Rico. At the same time, the vast majority of research has been conducted in the former, and we know very little about the specific barriers confronting patients in other settings. It is therefore critical to continue this line of research as a first step in addressing global inequalities in FP access.

Compliance with ethical standards

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Conflict of interest The authors declare that they have no conflicts of interest.

Research involving human participants All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committees and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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