Medical egg freezing and cancer patients’ hopes: Fertility preservation at the intersection of life and death

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ABSTRACT

Egg freezing (i.e., oocyte cryopreservation) is a new reproductive technology that allows women's eggs to be frozen and stored for future use. Over the past five years, so-called “medical egg freezing” (MEF) has begun to play a major role as a form of fertility preservation for young women with cancer and other fertility-threatening medical conditions. Indeed, women who are candidates for MEF are often facing the “double jeopardy” of fertility loss and potential death. In this article, we examine the experiences of the first generation of women to use MEF in the United States and Israel, two countries where experimental use of MEF began early, and where MEF is now offered clinically in many in vitro fertilization (IVF) clinics. Through an ethnographic, interview-based study carried out between June 2014 and August 2016 with 45 women (33 American, 12 Israeli) who had completed at least one cycle of MEF, we highlight women's reflections on their egg freezing experiences, and their considerable hopes for future recovery and motherhood. However, MEF is a Janus-faced new “hope technology.” On the one hand, it holds out the promise of life in terms of recovery and future childbearing. As such, women's reflections on MEF reveal hope and gratitude for the technology's existence. However, as with IVF itself, future motherhood can never be guaranteed. This is especially true for women facing death from advanced or aggressive forms of cancers. Three ethnographic case studies of cancer patients, two from the US and one from Israel, highlight how MEF offers hope for life among women confronted with a deadly disease.

1. Introduction

Egg freezing (i.e., oocyte cryopreservation) is a new reproductive technology that allows human eggs to be frozen for the purpose of fertility preservation. Following more than a decade of experimental use, egg freezing began to gain clinical approval in several countries, including in Israel in 2011 and the United States in 2012, both early entrants into the field of fertility preservation (American Society for Reproductive Medicine, 2013a; Garcia-Velasco et al., 2013; Lockwood, 2011; Shked-Rafid and Hashiloni-Doele, 2011). Over the past five years, egg freezing has been offered in increasing numbers of in vitro fertilization (IVF) clinics around the world, with clinical studies confirming that eggs can be successfully cryopreserved by vitrification (i.e., flash freezing), and later thawed and fertilized, leading to live birth outcomes (Cobo et al., 2016; Doyle et al., 2016). A recent review shows that oocyte vitrification has become an established component of assisted reproduction, with pregnancy rates now similar to those achieved with fresh oocytes (Argyle et al., 2016).

Because of this clinical success, oocyte cryopreservation is increasingly being offered to women of reproductive age with cancer or other medical conditions whose treatment with chemotherapeutic drugs places them at high risk of infertility (Baysal et al., 2015; Hersberger et al., 2013). Such “medical egg freezing” (MEF), as it is known in the literature (Lockwood, 2011), is primarily being used by young women with cancer, who are not in a position to freeze embryos with either a partner's or donor sperm. In such cases, MEF can potentially preserve a woman's ability to conceive a future genetically related child, thereby preventing anticipatory fertility-related regret (Baysal et al., 2015; Benedict et al., 2015), or the need to use donor eggs to conceive. MEF may also give female cancer patients the feeling of psychological comfort that sperm cryopreservation has offered to generations of young men with cancer (Peddie et al., 2012; Reinblatt et al., 2011; Ryan, 2011).

Among reproductive-aged women with cancer, the risk of losing one's reproductive ability may come as a major blow—not only to self-esteem and gender identity, but to a future in which motherhood and children are viewed as definitive. A small number of qualitative studies, mostly among breast cancer patients, have shown that fertility loss can...
produce deep and long-lasting sorrow (Benedict et al., 2015; Corney and Swinglehurst, 2013; Hershberger et al., 2013; Kirkman et al., 2014). For example, an Australian study of 10 breast cancer survivors showed that cancer was a “pivotal” life event, making women feel “robbed” of time, choice, and fertility options (Kirkman et al., 2014). Most women in the study had always assumed that they would become mothers; thus, fertility loss was a “preoccupying sorrow,” lasting years after treatment had ended.

Among women with cancer, it is usually the treatment, rather than the disease, that diminishes or destroys a woman's ovarian function. Chemotherapeutic alkylating agents, such as cyclophosphamide and procarbazine, are particularly gonadotoxic, putting women at high risk for ovarian failure (American Society for Reproductive Medicine, 2013b). Furthermore, some breast cancer tumors are endocrine sensitive, requiring that women undergo five-to ten-year courses of adjuvant hormonal therapy with tamoxifen or letrozole, and during this prolonged period of treatment, pregnancy may not be recommended (Pagani et al., 2014). Furthermore, even when a woman's menstrual cycle resumes after treatment, her fertility may be compromised due to treatment damage, and her age-related decline in ovarian reserve may be accelerated, especially if she is in her late thirties when the chemotherapy is administered (Klemp et al., 2012). As a result, about one in six cancer survivors experience premature ovarian failure, and about a 30 to 50 percent reduction in live births (Chung et al., 2013).

Given the high toll of cancer treatment on fertility, increasing numbers of reproductive-aged women are being referred by their oncologists for MEF, at least in countries where IVF clinics can now offer this new technology. MEF is often performed on an emergent basis, prior to chemotherapy, and generally in the initial month following a cancer diagnosis. Because of the urgency of cancer treatment and the need for rapid completion of an MEF cycle, referral and scheduling remain an ongoing challenge (Hammarberg et al., 2017; Peddie et al., 2012).

A range of studies from Western countries have documented obstacles to MEF provision, including inadequate presentation of information (Banerjee and Tsiapali, 2016; Corney and Swinglehurst, 2013; Vindrola-Padros et al., 2017), lack of timely and direct referral (Kim and Mersereau, 2015; Louwe et al., 2016; Srikanthan et al., 2016), and patient-provider communication problems (Louwe et al., 2016), particularly physicians’ uncertainty about the success of MEF and their discomfort in raising future fertility among women who are facing the threat of death (Ben-Aharon et al., 2016; Benedict et al., 2015; Mathur et al., 2013; Quin et al., 2008, 2009; Vindrola-Padros et al., 2017). In a recent overview of these barriers to fertility preservation among cancer patients, both intrinsic factors (i.e., patients’ attitudes and health literacy, clinicians’ approaches and skills, doctor-patient relationships) and extrinsic factors (i.e., fertility preservation resources, institutional characteristics) were found to influence patients’ and healthcare professionals’ decision making at the time of cancer diagnosis (Panagiotopoulou et al., 2015). A recent meta-analysis also shows that oncofertility services and support are often not delivered to eligible patients according to current guidelines (Logan et al., 2017).

For women of reproductive age, cancer brings with it the “double jeopardy” of fertility loss and potential death (Hershberger et al., 2013). In this state of double jeopardy, women who are offered MEF may view it as a source of “double hope”—namely, the life-affirming optimism of recovery and survival, along with the imagined future as a mother of biogenetically related children. MEF is thus a new “hope technology,” according to the definition forwarded by Sarah Franklin (1997) in her seminal ethnography, Embodied Progress: A Cultural Account of Assisted Conception. In her study of the first generation of IVF users in England, Franklin reported the “language of hope, miracles, and progress” as major features of both patient narratives and early media accounts (Franklin, 1997, p. 96). Furthermore, women expressed high levels of praise for this new technology: “Women frequently expressed their gratitude, good fortune and ‘luck’ in being able to undergo IVF, even when they failed” (Franklin, 1997, p. 193, emphasis in the original).

Indeed, failure at the end of the IVF “obstacle course” was a common outcome for women in Franklin’s study. According to Franklin, “hope” is the important flip-side of the fact that assisted conception usually does not work (p. 96). Twenty years on, success rates for IVF have not improved substantially, in England as elsewhere. In three large-scale European studies, the so-called “take-home baby rate”—or the actual delivery rate per started cycle of IVF—was only 18 to 25 percent (DeMouzon et al., 2010; Mantikow et al., 2013; Nelson and Lawlor, 2011). Given that MEF relies on IVF techniques (i.e., oocyte fertilization and embryo transfer) to achieve a pregnancy outcome, MEF is at best only as successful as IVF itself.

In his book, Hope in Health: The Socio-politics of Optimism, Petersen (2015, p. 11) argues that the term “hope” conveys the emotionally charged desire that something will happen, even when no solid prediction can be made to guarantee the efficacy of a novel medical technology. With new medical technologies such as MEF, there is always a potential gap between “wishful thinking” and “reality” (Kitzinger and Williams, 2005, p. 738). Furthermore, as Rose and Novas (2002, p. 5) argue, “The other side of hope is undoubtedly anxiety, fear, even dread at what one's biological future might hold.”

The Janus-faced nature of new medical technologies—which offer hope, when so much is uncertain—is particularly relevant to MEF. This is because the majority of users are reproductive-aged women who are not in the position to freeze embryos (usually because they do not have male partners and do not want to use donor sperm), and who are also facing life-threatening forms of cancer. Thus, it seems important to ask women themselves about their cancer diagnoses, their desires for motherhood, and their journeys to and through the MEF process. What does it mean to have undertaken MEF? How is a life-threatening diagnosis experienced in conjunction with, or in the aftermath of, an MEF cycle? In short, what kind of “frozen hope” (Quin et al., 2010) does MEF offer to women, amidst the looming threat of a cancer diagnosis? Only after asking such questions may we begin to understand “what is at stake”—or “what really matters” (Kleinman, 2006)—for female cancer patients investing their hopes in MEF.

Because no research to date has studied women who have been through at least one MEF cycle, the major aims of this medical anthropological investigation were three-fold: 1) to understand women’s motivations for undertaking MEF; 2) to learn about their experiences of the MEF process, from the point at which it was introduced as a fertility preservation option to the storage of frozen eggs after one or more MEF cycles; and 3) to assess women’s reflections on their use of MEF, once one or more cycles were completed.

2. Methods

This medical anthropological study was designed as a binational, ethnographic investigation of oocyte cryopreservation among women who had completed at least one cycle of MEF. The study took place from June 2014 to August 2016, and was supported by the US National Science Foundation’s Cultural Anthropology and Science, Technology, and Society programs. The study was conducted in the US and Israel, two countries where clinical approval of oocyte vitrification, including for medical purposes, occurred relatively early, in 2012 and 2011, respectively. Women who had undertaken MEF were recruited from 6 IVF clinics offering oocyte cryopreservation, 4 in the US (2 academic, 2 private) and 2 in Israel (both academic). In the US, recruitment occurred primarily by email flyers sent out by the 4 participating clinics. Women who were interested in volunteering for the study then contacted the first author, either directly or through the clinic. In the two US academic IVF clinics, some women were given the study flyer directly by their clinicians during appointments, and were invited to contact the first author if they were interested in participating in the study. In Israel, recruitment occurred by phone, with IVF clinicians and their assistants inviting women to participate in the study. Women who
volunteered to participate were then contacted by phone by the second author, who set a time and place for the interview at the women’s convenience.

Women who volunteered for the study signed written informed consent forms, agreeing to a confidential, audio-recorded interview in a private setting. The interviews were semi-structured, usually lasting about 1 h, but ranging in length from one-half to several hours. The American anthropologist interviewed all the American participants in the study (in English), while the Israeli anthropologist interviewed all the Israeli participants (in Hebrew). Because the American women lived in a variety of US cities on both the East and West Coasts (e.g., New Haven, New York, Baltimore, Washington, DC, San Francisco, San Jose), as well as in a number of other metropolitan areas, some of the interviews were conducted in person (often in cancer centers, IVF clinics, or patients’ homes), while others were carried out from afar by skype or phone. In Israel, on the other hand, all but one interview was carried out in person, generally in the two major cities of Tel Aviv and Haifa. Furthermore, in one case, the woman had passed away, but her parents were willing to participate in the ethnographic study, sharing their recollections with the anthropologist.

In both the US and Israel, the same IRB-approved, semi-structured interview schedule was used to conduct interviews, although the schedule was translated into Hebrew for the Israeli participants. All the women in the study were asked a brief series of socio-demographic questions (i.e., age, place of birth, current residence, education completed, current employment, marital status, ethnicity, religion), as well as relevant details of reproductive history (i.e., age at menarche, contraceptive use, any known reproductive problems). Following these standardized questions, the interviews took an ethnographic turn, with women asked to tell the anthropologists their egg freezing “stories” in an open-ended fashion.

The anthropologists probed women’s motivations to undertake MEF, women’s physical responses to the MEF hormonal stimulation and retrieval process (including self-injection), numbers of eggs frozen, and plans for egg storage and/or eventual disposition. Women were also asked about their support systems during the MEF process and how much the total process cost, with or without insurance coverage. At the end of these open-ended interviews, women were asked to reflect, retrospectively, on how they felt about having undertaken MEF and how they viewed their frozen eggs in storage.

Completed interviews were transcribed verbatim by research assistants at Yale University and the University of Haifa. At the University of Haifa, interview transcripts were then translated from Hebrew into English by a professional bilingual translator. All interview transcripts were uploaded into an ethnographic data analysis software program (Dedoose), and detailed ethnographic case studies summarizing each interview were written by the two anthropologists. Descriptive statistical information was transferred into Excel files. As is usual for ethnographic research in medical anthropology, the main data analytic strategy was a systematic reading of each interview to search for and examine common themes (e.g., fear of fertility loss, hope, gratitude) and common patterns emerging from the ethnographic interview materials. Furthermore, ethnographic data analysis involved comparing the similarities and differences between the US and Israeli data, based on careful review of all interview transcripts by the medical anthropologists, who shared their research materials, including interview transcripts and ethnographic case summaries. The research protocol was approved by Institutional Review Boards and by the ethics committees of all the collaborating IVF clinic sites.

3. Results

3.1. The women

As the first study of women who completed MEF, we hoped to reach approximately 50 participants, including women who had undertaken MEF during the initial “experimental” decade of oocyte vitrification (2000–2010), as well as in the years following its clinical approval in Israel (2011) and the US (2012). We came close to reaching this goal. Over the two-year study period, 45 women volunteered to participate, including 33 women in the US and 12 in Israel.

Cancer was by far the most common reason for MEF in our study. Of the 45 women interviewed, 35 women (78%), including 23 Americans and 12 Israelis, had cancer diagnoses. The remaining 10 women (all American) had undergone MEF for non-cancer-related, but fertility-threatening medical conditions. As shown in Table 1, “Cancer and Medical Egg Freezing: Characteristics of the Study Participants,” breast cancer was the most common type (15 cases, or 43%), followed by blood cancers (leukemia and lymphoma) (11 cases, or 31%), and a variety of other cancers (9 cases, or 26%). More than half of these cancer patients had advanced or aggressive forms. Five women had cancer that had metastasized to the lymph nodes, bones, lungs, and/or brain. Four had recurrent blood, tongue, thyroid, and breast cancers. And four had been newly diagnosed with “highly aggressive” breast cancer. In other words, a significant number of women in this study were seriously ill. Given their diagnoses and the consequent urgency of their cancer treatment, the majority of women in our study (40 of 45, or 89%) were able to complete only one MEF cycle, generally before starting chemotherapy.

![Image](image-url)
many were currently grappling with a potentially deadly diagnosis, and some women in this study ultimately received bad news about their cancer prognosis. At such moments of recognition, women who had undertaken MEF, as well as their families, had to rework their understandings of life and death, and the frozen eggs in storage. These three themes are explored in the following sections.

3.2.1. Cancer and fertility loss

In describing their MEF experiences, women usually began at the moment of cancer diagnosis. For almost every woman, a cancer diagnosis was utterly unexpected, catching women off guard, and causing feelings of shock, disbelief, and confusion. The lack of family histories of cancer and the relatively young age of the women in the study—29 on average (range: 16–41)—were factors that made most women unprepared for this bad news. Women used terms like “devastated” or “overwhelmed” to describe the way they felt.

Furthermore, cancer treatment plans generally began rapidly, given the seriousness of the women’s diagnoses. Depending upon the type of cancer, women were often scheduled for some combination of surgery, chemotherapy, and/or radiation. But a few women had to undergo other procedures, including stem cell or bone marrow transplants. Fertility conversations thus began early, usually initiated by a woman’s oncologist. Most women were told that chemotherapy could damage their ovaries and render them infertile in the future. Again, as with the cancer diagnosis itself, this news of potential fertility loss was experienced as “devastating,” causing a kind of anticipatory grief.

Table 2, “Cancer and Medical Egg Freezing: Women’s Reflections on Motherhood and Hope” attempts to capture in an ethnographically synoptic form the anguish of potential fertility loss and women’s profound hopes for MEF. Ten sets of quotes from both American and Israeli women with different forms of cancer, who undertook MEF during both the experimental and clinical phases, show the consistency of responses over time and between countries. As seen in the column on “Importance of Fertility and Motherhood,” women used terms such as “grave,” “dark,” “hard,” “crushing,” “devastating” and much more to describe the ominous potential of fertility loss. Women explained that losing their fertility would be radically life changing, irreversible and permanent, causing a barrier to their future happiness, and the destruction of their vision of themselves both as women and as mothers.

As shown in these women’s comments, fertility loss was almost always cast within larger discourses of motherhood. Desires for motherhood and the love of children were strong sentiments expressed by women in the study, with very little variation between the American and Israeli women. The importance of motherhood, either now or in the future, was an abiding theme of women’s narratives. Many women described their love of children, their life-long desires to become a mother, as well as the number of children they hoped to bear. A few of the women were less sure about motherhood and its importance in their lives. But even so, they decided to pursue MEF to preserve a future motherhood option.

For the youngest women in this study, some of whom were still in their late teens, thinking about motherhood seemed premature. As one 17-year-old with lymphoma described it, “I don’t know, it’s so far off. I mean I want to have kids when I’m older, but I don’t know still what my circumstances would be in 10 years. But I thought I at least want to mean I want to have kids when I’m older, but I don’t know still what my experienced the threat of fertility loss as significant and frightening (see also Diesch et al., 2017).

3.2.2. Gratitude and hope

For most of the women in this study, prompt and direct referrals to IVF clinics allowed them to undertake a cycle of MEF prior to chemotherapy. Despite the rushed timeframe and the “blur” of the MEF process, most women were quite happy with the outcome of their MEF procedures. As shown in Table 1, the most common number of eggs to be frozen in a single cycle was 5–10. But the number ranged from 3 to 55, with 14 eggs frozen on average. A few women expressed disappointment in their results (< 5 eggs). However, the overarching response was one of gratitude for MEF. As seen in Table 2, MEF was often described by women as a “gift,” “blessing,” “miracle,” and form of “empowerment.” Women also expressed their “luck” in having been diagnosed now, rather than in the pre-MEF era, when fertility preservation was not yet an option for women.

Beyond the gratitude, MEF brought with it hope—hope for a brighter future, one without cancer, and with children. As seen in women’s reflections in Table 2, MEF was clearly a new hope technology, increasing women’s feelings of relief, security, peace of mind, and a sense of control over an uncertain future. As one 32-year-old American woman who had been able to freeze 18 eggs put it, “It definitely gives me peace of mind. I’m so glad that I did it, and that it was successful ... So I’m at peace in knowing that I’ve done everything in my control to try to be a biological mother someday.”

Women often described their frozen eggs as a type of “insurance policy,” even while acknowledging that frozen eggs were no “guarantee” for a future pregnancy. Some women had listened carefully to the health information presented to them at IVF clinics—namely, that there is no one-to-one correspondence between a frozen egg and a live birth, and that approximately 10 eggs (i.e., 8 to 11, depending upon the woman’s age) should be stored to produce a live birth outcome (Cobo et al., 2016). Thus, they realized that most of their frozen eggs, even if successfully thawed, would not result in a future pregnancy. Having said this, frozen eggs often took on a heightened meaning in the lives of these sick and vulnerable women. As shown in Table 2, several cancer patients in this study called their frozen eggs “my babies,” “my kids,” and “my future family” (c.f., De Lacey, 2013 for similar views of frozen IVF embryos). A few described driving past IVF clinic storage facilities, feeling hopeful that their future children were waiting for them inside.

3.2.3. Life and death

Although MEF is experienced as bringing hope, the reality is that at least some women undertaking MEF have uncertain futures, because they are very sick. As noted earlier, a significant number of women in this study were faced with dire prognoses, particularly those with metastatic cancer that had spread to vital organs, including the lungs, liver, or brain. In these cases, questions about egg disposition—namely, what to do with unused frozen eggs—were both imminent and difficult to answer. In general, egg disposition, either through prolonged storage, eventual disposal, donation to other women, or donation to research, involves difficult decision-making for women (Mertes et al., 2012), as has also been shown in studies of embryo disposition after IVF (De Lacey et al., 2012, 2016). But for women with cancer, and especially metastatic cancer, these disposition decisions may be particularly painful reminders of future mortality and dreams unrealized. Furthermore, issues of “posthumous disposition” may also arise, involving familial intervention and legal questions (Knapp et al., 2011; Mertes et al., 2012; Spielman, 2011).

In our study, all of these issues came to the fore. None of the women in the study were asked directly about death, but a few raised it, at least obliquely. Some of the women who had undergone multiple courses of taxing chemotherapy admitted that they had wanted to “give up.” At least two women in the study, one with a sarcoma that confounded several sets of oncologists, and another whose case would be described below, had informed their IVF clinics in writing via consent forms and
Cancer and medical egg freezing: Women’s reflections on motherhood and hope.

<table>
<thead>
<tr>
<th>Year MEF</th>
<th>Nationality</th>
<th>Age at MEF, Diagnosis</th>
<th>Importance of Fertility and Motherhood</th>
<th>Gratitude and Hopes for MEF</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>American</td>
<td>25, Leukemia</td>
<td>“They give you an option, and it’s like a gift, a chance, even the smallest chance. It gives you much more hope. . . . Even that small chance is worth it. It makes you appreciate things more.”</td>
<td>“Just think this is another kind of miracle thing, to tell you the truth. Someone who really wants kids, you know, I think they can make something like this happen.”</td>
</tr>
<tr>
<td>2011</td>
<td>Israeli</td>
<td>21, Hodgkin lymphoma</td>
<td>“Since I was a kid I wanted to have kids. That’s one of the things I want, to have a kid. . . . I just wanted to make sure that one day I would be able to have babies.”</td>
<td>“I think it’s important for all women, for whatever reason, for whatever reason they can’t have kids, they be able to.”</td>
</tr>
<tr>
<td>2014</td>
<td>American</td>
<td>21, Rhabdomyosarcoma</td>
<td>“Since I was a kid I wanted to have kids. That’s one of the things I want, to have a kid. . . .”</td>
<td>“I wish I can have six children. I have this number stuck in my head.”</td>
</tr>
<tr>
<td>2014</td>
<td>Israeli</td>
<td>32, Hodgkin lymphoma</td>
<td>“I want children very much. If I had to choose between getting married and having kids, I’d choose to have children. In both cases I want to have at least two kids.”</td>
<td>“I want children very much. If I had to choose between getting married and having kids, I’d choose to have children. In both cases I want to have at least two kids.”</td>
</tr>
<tr>
<td>2014</td>
<td>American</td>
<td>37, Breast Cancer</td>
<td>“I don’t think of being a mother as being a career. It’s a career, I’d say, if you can call it career. But being a mother is much more important to me.”</td>
<td>“I think it’s pretty important for both of us [she and partner] that we have children.”</td>
</tr>
<tr>
<td>2015</td>
<td>American</td>
<td>23, Ovarian Tumor</td>
<td>“Then the question [is] whether the science will be in 5 years. When will it be? When will it be? When will it be? . . .”</td>
<td>“I have to write to my doctor. I’m happy that I was able to do it. And I’m really, really happy that I did it.”</td>
</tr>
<tr>
<td>2016</td>
<td>Israeli</td>
<td>21, Leukemia</td>
<td>“I don’t think of being a mother as being a career. It’s a career, I’d say, if you can call it career. But being a mother is much more important to me.”</td>
<td>“I think it’s pretty important for both of us [she and partner] that we have children.”</td>
</tr>
</tbody>
</table>
legal documents that they planned to donate or “will” their eggs to their sisters. Another woman, who had just learned that her breast cancer had metastasized to her brain, was making hasty plans for a weekend wedding, so that her boyfriend of seven years could become her husband-caretaker (through the Family Medical Leave Act). This woman had produced an unusually high number of eggs in a single cycle (55), and had joked that she was a “superstar,” deserving of a “gold medal.” But her dark humor could not hide the fact that she had experienced borderline ovarian hyperstimulation syndrome as a result of the MEF cycle. She also wondered out loud whether the hormonal medications used in MEF, or the slight delay required to undertake the MEF prior to chemotherapy, were somehow related to her cancer’s spread. Facing her own mortality, she was clearly questioning her MEF decision.

At least two of the American women who participated in this study died the year following their interviews. In one of these cases, the mother hoped to keep her daughter’s 19 eggs. In Israel, one woman died, but her parents spoke to the anthropologist five years on about whether to donate or dispose of their daughter’s frozen eggs.

4. Ethnographic stories

Here, we share three ethnographic stories, including two of those just mentioned. We have chosen these stories from among those shared by participants with advanced or terminal forms of cancer. These stories highlight two major issues: first, that MEF occurs at the “intersection” of life and death, and second, that MEF is a Janus-faced technology. On the one hand, women facing cancer may be grateful for MEF as a hope technology, one that implies the possibility of recovery and future motherhood. However, MEF can provide no guarantees, particularly for women with advanced or aggressive cancers. Some women who undertake MEF may receive uncertain prognoses, and some of them will die. These three ethnographic stories (utilizing pseudonyms, including verbatim quotations, but necessarily condensing the details of lengthy interviews) show that new medical technologies such as MEF, which are experienced by women as conferring hope, cannot eliminate the possibility of failure, including the haunting specter of death.

4.1. Emma: living with chronic cancer

Emma was a lawyer, who met up with the anthropologist in a coffee shop in a small New England town. There, over several hours, Emma explained how her thyroid cancer diagnosis had led to her egg freezing. Now 37, Emma was diagnosed six years earlier, but only after many months of delay. Her internist had initially treated her for a chronic ear infection. When the ear infection did not resolve, Emma was sent to an endocrinologist, who was unable to interpret an ultrasound scan “full of cancer.” Over these months of misdiagnosis, Emma’s cancer “spread everywhere.” As Emma explained, “I had eight tumors in my thyroid, and then it spread to all the lymph nodes on the right, which is why I was having ear pain, ‘cause this [pointing to her mastoid beneath her jaw] had swollen, with all the lymph nodes.” Emma underwent thyroidec¬tomy and treatment with radioactive iodine, which required a week of hospital isolation. During the course of treatment, her family rallied, and Emma’s older sister was by her side, “like Florence Nightingale.” However, Emma’s boyfriend, with whom she had already been discussing pregnancy, couldn’t “handle” the cancer diagnosis. The relationship ended in the midst of treatment.

Now single, Emma was told by her oncologist that the subsequent cancer treatment could lead to early menopause. “I was like, ‘What am I going to do? I’m 35.’ And I was really freaking out. I was feeling so super anxious about it, like to a point where I couldn’t tolerate it I was so anxious.” At this point, Emma was referred to an IVF clinic where MEF was being offered. Yet, Emma’s MEF cycle produced only four viable eggs, a result that both Emma and her IVF specialist found disappointing. Yet, even with four eggs, MEF gave Emma some peace of mind. “You know, it wasn’t that bad. So I think it’s worth it. You know, I do. Considering what we’re talking about.” Emma explained that fertility preservation through MEF was the one thing that she could “control” in an uncertain cancer trajectory. As she put it,

There are so many things I can’t control about what’s happening this minute. But this is one thing I can do, so if I look back and regret it, I can say, ‘Hey, I tried.’ This is the thing I could do, and I did that thing I could do at that time with the money I had, with the motivation I had. So at least I tried. Yeah, at least I did something. I think it also made me feel better at that time, with how I was feeling, to just do something. Also, this is kind of a dorky aspect of it, but I think I just liked the idea of—this is going to sound so horrible—I liked the idea of participating in something that’s so cutting edge, like that’s so modern and fascinating, what they can do now.

Having undertaken MEF, Emma also moved from feeling “devastated” about her potential fertility loss to feeling much more sanguine about future motherhood. As she said,

I’m just not sure how I feel about it anymore. It’s interesting. So this is something I’ve thought a lot about. Like, my feelings about kids have changed a lot over the last couple of years. Always before that, during that [cancer treatment], I felt like if it couldn’t happen, if it couldn’t be mine, this would be the most devastating thing. Like there would be no comfort to me. I would just be so devastated. And also just like, the idea of having your own [children] … I was really intent on it. But I went back again. I went to not caring if they’re my own, yeah, I don’t care. I think it’s through all this medical stuff is maybe why. Like, my genetics aren’t that great.

Furthermore, by this point, Emma’s thyroid cancer had become a chronic condition with an unknown trajectory. As she explained, “I think I’ve kind of decided to stop making a plan. Like I’ve kind of just started to feel more like: None of us know what will happen. Maybe it’s not good to get so attached to one idea about what this will look like.” Thus, Emma decided to focus on living her current life and its daily pleasures. She also took up rock climbing and martial arts to start “enjoying” her body again.

Meanwhile, Emma had made some important plans. “Florence Nightingale,” Emma’s older sister, was about to get married at the age of 40, but had already lost one ovary to endometriosis. Thus, Emma had made her egg disposition decision official on her MEF consent form: “If I die, give them to my sister.”

4.2. Julia: the young adult cancer activist

Julia was 37 years old when she agreed to meet the anthropologist in the breast cancer center of the local hospital. As Julia explained, the breast cancer center had become her “home” and its clinicians her “family.” Julia was the only woman in the study whose family members were unable to care for her during her treatment. Furthermore, as she was waking up from her double mastectomy, the man she was dating texted her to say that he was calling off their relationship. In short, Julia lacked crucial support, and this, she explained, is why she became a cancer support activist.

Over the next two years, Julia managed her own treatment, her busy job as a data manager, and her new mission as a supporter and mentor for other young people with cancer. She began by founding the first young adult cancer support group at the hospital. She then became the state leader for the Young Survivors’ Coalition, dedicated to the needs of young women with breast cancer. Eventually, she joined Imerman’s Angels, a one-on-one cancer mentorship and support program. Julia explained her activism in this way:

You know, it’s funny. I would never say cancer’s a good thing, but I think sometimes it provides a direction that maybe you were looking for. ‘Cause I love my job, but like, this just gives me something else.
It gives me a vehicle to give back ... Because it can be, for some people, it is frightening, and they just don't know how to navigate it. Because you're on a path, and you're like, 'Nothing's going to touch me,' and then cancer comes and drops this huge detour that you now have to go around. And the detour it sends you down is this dark, scary path ... So I kind of think of it as that. I'll help you get around that detour. Get you back to your path and stuff.

One of Julia’s “detours” was to an IVF clinic for MEF. Like Emma, Julia “loved” her IVF physician, and was very grateful for MEF itself:

I think it’s worth it for women who are trying to preserve their fertility. I think it’s totally worth it ... I know women who’ve done it, who’ve been able to have babies afterward. I just think [that] if you think that’s something in your future [motherhood], and you want to maybe have [a child], just in case, I think it’s absolutely worth it.

Julia was not particularly disappointed when her MEF cycle yielded only three eggs, for over time, she had learned to handle a variety of bad news. Early on, her cancer had spread to her lungs. But eventually, metastases were also detected in her bones, liver, and brain. As she began aggressive treatment for the brain metastases, she also received her annual consent form from the IVF clinic. By law, the clinic was required to ask Julia what she planned to do with her eggs. As a metastatic breast cancer patient, she explained her decision this way:

You know, you get that letter, the annual letter. It’s kind of like, I looked at that letter. I glared at it for like a month ... This form, it was like: ‘Would you like to destroy your eggs? Would you like to keep your eggs? Or would you like to donate them?” And I was like, ‘This is the worst check-box I have to fill out.’ And it was a struggle for me, because part of me wanted to keep them, but I would never use them ... And there is nothing that I wanted more—a family and children.

Unable to part completely with her eggs, Julia decided to donate them, hoping that they would go to some other woman who needed them. Indeed, the thought of helping an infertile woman to have a baby— but one that would resemble Julia and her personality—“secretly delighted” her. This act of egg donation—the thought that her eggs were “out there”—put Julia’s mind at peace. As she said:

I think you just have to accept certain parts of your diagnosis. And for me, I was like, reaching in, turning that light off, shutting it, and locking it, and knowing that that was kind of closed, that chapter. You know, I love children. I have nephews. I have a niece. All of my friends are married with children. And that just lets me kind of pour more love out to them.

Indeed, those nephews and nieces figured prominently in Julia’s obituary. She died about a year and a half after the interview for this study. She was only 38 years old. All donations were to be made to the young adult cancer support group she had founded.

4.3. Rona: losing the struggle to hold onto life

At age 25, Rona was pursuing an advanced graduate degree in economics in Israel, when she was diagnosed with a rare form of abdominal cancer. When she was told that she would need to undergo chemotherapy, she requested fertility preservation “before anything else.” In the anthropologist's interview with Rona's parents, her mother recalled Rona's words before the egg freezing: “She said: ‘I want children. I don't care about anything else. If I start chemo, I won’t ever have children.'” Since the time pressure was great, Rona received no hormonal stimulation. The doctors therefore retrieved just five eggs, of which only two could be frozen. Rona and her parents thought that if she was unable to carry a pregnancy in the future, her sister might do it for her.

Rona’s cancer metastasized and her treatment became grueling. She nonetheless insisted on continuing her schooling. She completed her studies with distinction, but did not survive for the graduation ceremony, which took place a year later. Her parents described Rona’s repeated references to the frozen eggs throughout this period as part of her struggle to hold onto life:

She didn’t give up on having kids. I’d often tell her, “Rona, you can always adopt.” But she said: “I want to give birth.” It gave her a lot of hope, that those eggs were there; no matter what else was damaged, she had those eggs and she'd have children ... Yes, even though she had just two eggs.

Only when her condition deteriorated substantially did Rona change her attitude. Her mother described that day:

She said to me: “You know what? I don’t mind being a mother anymore. I don't even care if I give birth or not.” And I knew that something was profoundly wrong. For it was the first time ... she had always insisted [on motherhood].

Several days later, which turned out to be two days before she died, Rona asked her mother to call a lawyer in order to make a formal will. The frozen eggs were the primary motivation for this initiative. Rona told her mother that she had read in the newspaper that the court heaped various obstacles on the use of banked eggs, and so she wanted to ensure that her mother had full discretion regarding any option of egg disposition in the future.

At the time of the interview, Rona’s parents were, in fact, considering what to do with the two frozen eggs of their deceased daughter.

5. Discussion

To our knowledge, this is the first ethnographic study to explore the experiences of MEF among women with different forms of cancer, including both advanced and aggressive types. Unlike other qualitative studies of fertility preservation among cancer patients, all of the women in this study had completed at least one MEF cycle, because they hoped, dreamed, and imagined themselves as future mothers. Under such circumstances, MEF offered a brighter perspective, one that implied recovery, procreativity, futurity, and postraductive growth (Tedeschi and Calhoun, 2004). In this respect, MEF could be seen as offering a temporal bridge across the cancer crisis, through which women hoped to repair the biographical disruption that their cancer diagnoses had caused (Kirkman et al., 2014).

However, as shown in the ethnographic stories above, cancer diagnoses bring with them the double jeopardy of fertility loss and loss of life. Although many—maybe most—women who undertake MEF will eventually survive their cancers, others will not. For cancer patients, MEF brings with it many unresolved questions and uncertainties (Mersereau et al., 2013; Yee et al., 2012). These include, for example, whether cancer patients’ frozen eggs will be viable after long-term storage; whether the number of eggs frozen in a single MEF cycle will be sufficient to produce a future live birth; what should be done with frozen eggs when a woman is facing a cancer death; and whether posthumous reproduction, even if desired by remaining family members or deceased women’s partners, will become accepted in the legal and medical communities (Knapp et al., 2011; Quinn et al., 2012; Spielman, 2011).

In addition, we must acknowledge that, as the first ethnographic investigation of women’s experiences of MEF, there are some limitations. The overall number of participants recruited was relatively small (45), and among the cancer patients (35), nearly twice as many volunteered for the study in the US (23) as in Israel (12). Furthermore, women in both countries were recruited from a relatively small number of cities and states, limiting the generalizability of the findings. In addition, because this was a binational study, coordinated between researchers and clinics in the US and Israel, the women who participated.
were recruited somewhat differently between the two countries, and interviewed by different medical anthropologists in two different languages. These sources of potential bias could not be eliminated because of logistical and funding constraints, but they must be acknowledged in our assessment of the comparison. Finally, our study only addressed the experiences of those who had succeeded in obtaining MEF and were willing to be interviewed. This, in turn, may reflect differential access to the technology between the two countries. In Israel, MEF is free to all cancer patients via national health insurance funding. But in the US, MEF is expensive (nearly $7000 on average in our study) and rarely covered by insurance. Thus, the stories of those cancer patients in the US who were unable to afford MEF could not be included, and possibly of Israeli women with other non-malignant medical conditions, for which MEF is not publicly funded in Israel.

Having said this, our study offers a valuable lens into the experiences and hopes of the first generation of MEF users. We predict that more and more women around the world will be referred for MEF over time, as has been suggested in recent global assessments (Rashedi et al., 2017a,b; Salama and Woodruff, 2017). As seen in this study, women who completed MEF were extremely grateful for the technology’s existence. They considered themselves to be the “lucky ones” who were able to complete at least one MEF cycle. In short, MEF is a new hope technology, but one located precariously at the intersection of life and death. As such, we need to hear the stories of women who have used this technology, and to follow these women over time. Only then will we come to understand the meaning of MEF and motherhood in the lives of cancer survivors (Bann et al., 2015), as well as among the women whose lives are tragically cut short.

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