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## ARTICLE

# Medical egg freezing: How cost and lack of insurance cover impact women and their families

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**Abstract** Medical egg freezing (MEF) is being recommended increasingly for women at risk of losing their reproductive ability due to cancer chemotherapy or other fertility-threatening medical conditions. This first, binational, ethnographic study of women who had undergone MEF sought to explore women's experiences under two different funding systems: (i) the USA, where the cost of MEF is rarely covered by private or state health insurance; and (ii) Israel, where the cost of MEF is covered by national health insurance. Women were recruited from four American and two Israeli in-vitro fertilization clinics where MEF is offered. In-depth, semi-structured interviews were conducted with 45 women (33 Americans, 12 Israelis) who had completed at least one cycle of MEF. All of the Israeli women had cancer diagnoses, but were not faced with the additional burden of funding an MEF cycle. In marked contrast, the American women – 23 with cancer diagnoses and 10 with other fertility-threatening medical conditions – struggled, along with their families, to 'piece together' MEF funding, which added significant financial pressure to an already stressful situation. Given the high priority that both American and Israeli women in this study placed on survival and future motherhood, it is suggested that insurance funding for MEF should be mandated in the USA, as it is in Israel. This article concludes by describing new state legislative efforts in this regard.

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**KEYWORDS:** medical egg freezing, fertility preservation, cancer, insurance coverage, USA, Israel

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## Introduction

Over the past 5 years, fertility preservation via oocyte vitrification has been recommended increasingly for young women who are at risk of losing their reproductive ability and the chance to conceive their own genetic offspring (Argyle et al., 2016; Doyle et al., 2016). This includes cancer patients scheduled to undergo treatment with cytotoxic chemotherapy (Baysal et al., 2015; Cobo et al., 2013; Hershberger et al., 2013), as well as women with other medical conditions (e.g. autoimmune disorders, severe endometriosis, genetic profiles including BRCA1 and 2, Turner syndrome and fragile X syndrome) that threaten their future fertility (Cobo et al., 2013; Garvelink et al., 2013). In such cases, medical egg freezing (MEF) is an option for women who are not in a position to freeze embryos created with sperm from either a partner or a donor. In such cases, MEF can potentially preserve a woman's ability to conceive a genetically related child in the future, thereby preventing infertility-related regret (Baysal et al., 2015; Benedict et al., 2015). 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).

Studies of MEF, especially among cancer patients, report numerous current barriers to access. These include inadequate presentation of fertility-related information to patients (Banerjee and Tsiapali, 2016; Corney and Swinglehurst, 2013; Vindrola-Padros et al., 2017), lack of available MEF specialists to whom referrals can be made easily (Kim and Mersereau, 2015; Louwe et al., 2016; Srikanthan et al., 2016), and patient-provider communication issues (Louwe et al., 2016), which include physicians' own discomfort in discussing future fertility, especially when time is of the essence (Ben-Aharon et al., 2016; Benedict et al., 2015; Mathur et al., 2013; Moore, 2017; Quinn et al., 2008, 2009; Vindrola-Padros et al., 2017). In an overview of 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 showed that oncofertility services and support are often not delivered to eligible patients according to current guidelines (Logan et al., 2017).

Most of these studies have focused primarily on provider issues. Significantly less attention has been paid to the cost of MEF as a potential barrier to access. In two web-based surveys of cancer survivors conducted in the USA, concerns about the cost of MEF, especially among lower-income patients, were a significant factor in women's decisional conflict (i.e. 'to preserve or not to preserve') (Mersereau et al., 2013). This was true despite the fact that the cost of MEF has decreased over time as the technology and support for cancer patients have become more common in in-vitro fertilization (IVF) clinics in the USA (Bann et al., 2015). For example, in a study of 550 young adult cancer survivors (males and females) diagnosed between the ages of 15 and 39 years, only 182 pursued fertility preservation, with 40% of the women choosing MEF. Between the years 2006 and 2009, 41% of MEF users paid \$15,000 or more for a single cycle. However,

between the years 2010 and 2012, the cost of MEF had decreased, with only 14% of women paying that much (Bann et al., 2015). Despite this reduction in cost over time, both American surveys showed that between one-quarter and one-third of respondents considered the cost of MEF to be prohibitive. This was particularly true of those reporting annual incomes of <\$50,000, who were twice as likely to report cost concerns and half as likely to undergo MEF (Mersereau et al., 2013). Similarly, in a recent multi-country, population-based survey of paediatric and adolescent cancer patients in Europe, the cost of MEF and the availability of public funding were found to be prominent factors affecting patients' MEF decision making (Diesch et al., 2017), as well as physicians' recommendations about whether to pursue fertility preservation (Srikanthan et al., 2016).

Given these potential MEF cost concerns, this study sought to compare women's experiences of MEF under two different state funding systems: (i) the USA, where MEF is rarely covered by private health insurance, even in states with insurance mandates for infertility treatment; and (ii) Israel, where MEF is routinely covered by the state's national health insurance. The authors were interested to learn how women experienced MEF in light of its cost and the divergent funding strategies in the two countries. In the USA, the authors were interested to know how women paid for MEF, and what they thought about the lack of insurance coverage for this form of fertility preservation.

## Materials and 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 was conducted in the USA and Israel, two countries where clinical approval of oocyte vitrification, including for medical purposes, occurred relatively early (in 2012 and 2011, respectively). 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 programmes. Forty-five women who had undertaken MEF were recruited from six IVF clinics offering oocyte cryopreservation: four in the USA (two academic, two private) and two in Israel (both academic).

In the USA, recruitment occurred primarily by e-mail flyers sent out by the participating clinics to women who had completed at least one cycle of MEF. Women who were interested in participating in the study contacted the first author (MCI), either directly or through the clinic. In the two 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 telephone, with IVF clinicians and their assistants inviting women to participate in the study. Women who volunteered to participate were contacted by telephone by the second author (DB-C), 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 and usually lasted for 60 min, but ranged

from 30 to 120 min. All the interviews were undertaken by two senior medical anthropologists, both of whom have years of experience in interviewing patients receiving assisted reproduction treatment. The American anthropologist interviewed all the American participants in the study (in English), while the Israeli anthropologist interviewed all the Israeli participants (in Hebrew). As the American women lived in a variety of cities on both the east and west coasts (e.g. Boston, New Haven, New York, Baltimore, Washington, DC, San Francisco, Los Angeles), as well as in a number of other metropolitan areas, some of the interviews were conducted in person (often in cancer centres, IVF clinics or patients' homes), while others were carried out from afar by Skype or telephone. In Israel, all but one of the interviews with women who had undertaken MEF were conducted in person, generally in the two major cities of Tel Aviv and Haifa.

In both the USA and Israel, the same institutional review board (IRB)-approved, semi-structured interview schedule was used to conduct interviews, although the schedule was translated into Hebrew for the Israeli participants. All women in the study were asked a brief series of sociodemographic 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 a more ethnographic turn, with women asked to tell the anthropologists their egg-freezing 'stories' in an open-ended fashion. Most of these stories began with a cancer diagnosis or the discovery of some other fertility-threatening condition. The anthropologists probed women's motivations to undertake oocyte cryopreservation in the midst of medical treatment, 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 ethnographic 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 translated from Hebrew into English by a professional bilingual translator. All interview transcripts were uploaded into a qualitative data analysis software program (Dedoose), and detailed case synopses were written to summarize each interview. Descriptive statistical information was transferred into Excel (Microsoft Corp, Redmond, WA, USA) files. As is usual for qualitative, interview-based research, the main data analytic strategy was to systematically search for and examine key words, themes and patterns emerging from the interview materials, and to compare the similarities and differences between the data from the USA and Israeli. The research protocol was approved by IRBs at Yale University and the University of Haifa, and by the ethics committees of all the collaborating IVF clinics.

Due to the binational design of the study, it was possible to compare the experiences of American and Israeli women,

analysing both similarities and differences. The cost and insurance coverage of MEF were found to differ dramatically between the two countries, with significant implications for women and their families. This was the single most important point of divergence between the two countries. This article thus focuses on the cost of MEF and insurance coverage, given their significant impact on sick women and their families.

## Results

Over a 2-year period, it was hoped that approximately 50 women who had undertaken MEF, either during the initial "experimental" decade (2000–2010) or in the years following clinical approval in Israel and the USA (2011–2016), would be recruited. In the USA, 33 women who had undertaken MEF for cancer ( $n = 23$ ) or other fertility-threatening medical conditions ( $n = 10$ ) volunteered for the study, as did 12 cancer patients in Israel. Thus, in total, 45 women who had completed at least one cycle of MEF were recruited, which was close to the study goal.

Cancer was by far the most common reason for MEF in this study (Table 1). Of the 45 women interviewed, 35 (78%; 23 Americans and 12 Israelis) had a cancer diagnosis, with breast cancer being the most common type (15 cases, 33%), followed by blood cancers (leukaemia and lymphoma) (11

**Table 1** Characteristics of the study participants.

Characteristic	No. of women (%)
Nationality	
American	33 (73)
Israeli	12 (27)
Medical diagnosis	
Breast cancer	15 (33)
Blood cancer	11 (24)
Other cancer	9 (20)
Other condition	10 (22)
Educational level	
High school	11 (24)
University	16 (36)
Graduate school	18 (40)
Age at MEF (years)	
<20	5 (11)
20–29	16 (36)
30–39	22 (49)
>40	2 (4)
Year of MEF	
2000–2010	11 (24)
2011–2016	34 (76)
No. of eggs frozen	
<5	7 (16)
5–10	15 (33)
11–15	6 (13)
16–20	8 (18)
21–25	2 (5)
>26	6 (13)
Unsure	1 (2)

MEF, medical egg freezing.



cases, 24%) and a variety of other cancers (nine cases, 20%). Whereas all the Israeli participants were cancer survivors, 10 of the 33 American participants had undergone MEF for other reasons, including severe endometriosis or dermoid tumours requiring full or partial oophorectomies (four women), BRCA-positive genetic profiles requiring future oophorectomies (two women), a benign pituitary tumour (one woman) and other diseases (type 1 diabetes and autoimmune disorder; three women). However, given the high proportion of cancer diagnoses, the majority of women (40/45, 89%) were able to complete only one cycle of MEF before beginning chemotherapy.

Several relevant findings emerging from this population of MEF patients are presented in Table 2. The first concerns the increasing prevalence of MEF over time in both the USA and Israel (Column 1). The earliest cases of MEF were conducted experimentally in the USA in the late 1990s/early 2000s. The next cases in this study did not occur until the mid-2000s (2005–2006), when oocyte vitrification was starting to be tested in clinical trials in academic IVF units in both countries. Until 2011, oocyte vitrification was being performed in Israel under the 'experimental' label, and thus had to be approved for each patient by a local IRB. In January 2011, MEF via oocyte vitrification was approved by the Israeli Ministry of Health, and began to be used routinely. In this regard, the USA lagged behind somewhat, as the experimental label was not lifted until October 2012 (American Society for Reproductive Medicine, 2013). After that point, however, increasing numbers of cancer patients began to be referred for MEF in the USA, as is clearly reflected in Table 2 for the years 2013–2016.

A second finding reflects the sociodemographic makeup of the MEF patient population in both countries, as shown in Columns 2 (ethnicity/nationality) and 3 (education/highest degree and profession). Women who had undertaken MEF were heterogeneous in terms of their ethnicity, education, profession and class backgrounds. Although approximately half of the American women had obtained postgraduate degrees (i.e. master's level or higher), the other half had completed less education, sometimes due to their youth (e.g. still in high school or college), but also due to their socio-economic status. More than one-third of the American women (12 of 33) came from working-class/working-poor or lower-middle-class backgrounds, including most of the Latinas and African-American women in the study. The same was true in Israel, where the majority of women undertaking MEF were of Mizrahi (i.e. Sephardic, Oriental) descent, and hailed from lower- or middle-class families. The class backgrounds of the study participants are summarized in Table 3.

However, as shown in Table 2, the major difference between the USA and Israel was that, without exception, MEF was free of charge for all the Israeli women in the study. Although one Israeli breast cancer patient and her mother paid \$2500 before being reimbursed by her health maintenance organization, and two Hodgkin lymphoma patients paid several hundred dollars to secure appointments with a particular specialist, the MEF cycle itself, as well as all medications and subsequent specialist appointments, were free of charge. As a result, none of the Israeli women in the study ever raised the issue of the cost of MEF. When financial difficulties were mentioned by Israeli women, they spoke

about the ways in which their illness had put a strain on their earning capacity and financial resources overall.

Among the American women, on the other hand, the cost of MEF was a major factor on many levels, including whether or not MEF was feasible and with what financial resources. In this study, out-of-pocket MEF expenses ranged from as little as \$1000 per cycle to more than \$18,000 per cycle. The average cost per cycle was \$6966, representing a significant expense for most young women in this study. All of them had access to health insurance of some form, including those who lived in states with mandated insurance coverage for fertility treatments (e.g. Connecticut, Maryland). However, even in these so-called 'mandate states', MEF was not considered an insurable expense. Thus, in only four cases did a woman's insurance (or her father's insurance, if she was a dependent) cover the entire cost of MEF. Instead, women – and usually their supportive family members – 'pieced together' resources to cover the cost of MEF.

Indeed, without family financial support, many young American women in this study would not have been able to pay for MEF. Nearly half of the Americans (16 of 33) relied on family members in part or in full to fund their MEF cycles, or to loan them money to do so, or to generate money through fundraisers undertaken in communities, workplaces and online. The great lengths to which many families went to ensure access to MEF for their sick daughters and sisters were notable. For example, two working-class fathers living in small towns in Connecticut organized community fundraisers and raffles at local restaurants to generate money for the MEF cycle. In another case, a divorced mother in Maryland organized an online funding campaign for her daughter with breast cancer. The patient's sister convinced her then-boyfriend to donate a month's proceeds from his tattoo parlour to help cover the remaining cost. Once the MEF was completed, the patient's father paid for the transfer of the frozen eggs to a storage facility in another state, to reduce the annual storage fees.

In a particularly moving case, a single Peruvian-American nanny, who worked for an upper-middle-class family outside of New York City, discovered that she had breast cancer. Desperate to have her own children someday, she sought MEF at a private IVF clinic in the area, where she was turned away for lack of sufficient funds. She persevered, however, undergoing MEF at an academic IVF clinic. Although the IVF clinic offered a generous 'compassionate care' discount and Medicaid covered the cost of her medications, the woman depleted her personal savings and took loans from her brother and several friends to cover the remaining cost of MEF.

In this case and many others, the cost of MEF weighed heavily on the American women in the study. They were appreciative of the ways in which IVF clinics attempted to ease the financial burden of MEF through monthly payment plans, compassionate care discounts, coordination with cancer charities, and pharmacies that donated free or discounted medications. However, as is clearly shown in Table 1, paying for MEF in America was usually a 'patchwork' proposition – a 'piecing' or 'cobbling' together of varied funding sources, discounts and payment plans to enable MEF.

Table 4 summarizes the percentage of women who relied on any given funding option. Israeli women received MEF for

**Table 2** Comparison of medical egg freezing (MEF) details and funding sources among the American and Israeli women in the study.

Year of MEF	Nationality/ethnicity	Education/highest degree and profession	Diagnosis	Age at MEF (years)	No. of eggs frozen	MEF funding sources
2000	USA Caucasian American	MBA, social finance entrepreneur	Tongue cancer (recurrent)	24	29	1. Fought for insurance coverage 2. Founded oncofertility non-profit
2006	Latina American	High school graduate, nanny (currently unemployed)	Breast cancer (metastatic)	41	10	1. IVF clinic discount 2. Medicaid paid for medications 3. Personal savings (depleted) 4. Loans from family and friends (unable to repay)
2008	Caucasian American	MFA, college writing instructor	Endometriosis with endometriomas; oophorectomy	29	22	1. Parents paid for two cycles
2009	Caucasian American	MA, social work case manager	Chronic myeloid leukaemia; cervical cancer <i>in situ</i>	25	16	1. Covered by state employees' insurance
2011	Caucasian American	MA, school counsellor	Endometriosis with frozen pelvis	32	18	1. Covered by state teachers' insurance
2011	Caucasian American	MA, sustainability consultant	Autoimmune disorder	35	16	1. Mother paid
2011	Caucasian American	Community college student, working three jobs (clerk, maid, secretary)	Endometriosis with endometriomas	28	7	1. Clinical trial participation 2. Monthly payment plan to cover medications
2012	Caucasian American	High school senior	Leukaemia	16	7	1. Cancer charity paid
2012	Caucasian American	BS, clinical trial data manager	Breast cancer (metastatic, deceased)	35	3	1. IVF clinic discount 2. Pharmacy donation of medications 3. Self-paying monthly payment plan
2013	Asian American	High school senior	Lymphoma	17	4	1. Father's insurance
2013	Caucasian American	MA, public defender	BRCA1 positive	33	11	1. IVF clinic discount 2. Online pharmacy discounts for medications
2013	Caucasian American	MPH, health insurance analyst	Breast cancer	29	23	1. IVF clinic discount, including storage 2. Patient-donated medications 3. Personal savings
2013	Caucasian American	BS, ultrasonographer (part-time)	Breast cancer	23	4	1. Cancer charity paid 2. Family online fundraiser (GoFundMe) 3. Sister's boyfriend donated month's profits from tattoo parlour 4. Father funded transfer of oocytes to lower-cost storage facility out of state
2014	Caucasian American	College senior	Sarcoma (metastatic, deceased)	21	19	1. Father's workplace fundraiser and raffle 2. Father paying monthly to cover storage
2014	Caucasian American	JD, public interest lawyer	Thyroid cancer (chronic); endometriosis	36	4	1. Insurance coverage of medications 2. Personal savings
2014	Latina American	MD-PhD student	Cervical cancer <i>in situ</i>	34	43	1. Took out five bank loans 2. Military coverage for service-related impairment 3. IVF clinic discount for low-income patients 4. Online pharmacy discounts 5. Professional courtesy to medical student patient

Table 2 (continued)

Year of MEF	Nationality/ethnicity	Education/highest degree and profession	Diagnosis	Age at MEF (years)	No. of eggs frozen	MEF funding sources
2014	African American	PhD, pharmacy regulator	Breast cancer (recurrent)	33	5	1. Covered by state insurance mandate 2. Pharmacy donation of medications 3. Self-paying storage
2014	Asian American	MPH, public health non-profits (currently unemployed)	Type 1 diabetes; polycystic ovary syndrome	34	36	1. Personal savings
2014	Caucasian American	MA, applied mathematician	BRCA2-positive breast cancer	38	11	1. IVF clinic discount 2. Pharmacy donation of medications 3. Friend donation of medications 4. Personal savings
2014	African American	MA, kindergarten teacher	Breast cancer	36	12	1. IVF clinic discount 2. Insurance coverage of medications 3. Monthly payment plan 4. IVF clinic discount of storage
2015	Asian American	BA, philanthropy consultant (part-time)	Autoimmune disorder	32	12	1. Mother paid half 2. Self-paid half 3. Online pharmacy discounts
2015	Caucasian American	High school graduate, retail manager	Breast cancer	32	6	1. Covered by state insurance mandate 2. Community fundraiser
2015	Caucasian American	MA, student	Breast cancer	24	20	1. Parents paid 2. Pharmacy donation of medications
2015	Latina American	BA, military linguist and language tester	Breast cancer	34	8	1. IVF clinic discount 2. Pharmacy donation of medications 3. Family online fundraiser 4. Personal savings
2015	Caucasian American	BS, vice president, corporate communications	Sarcoma	30	5	1. Insurance covered; Fortune 500 company
2015	Caucasian American	MD, gastroenterologist	Dermoid tumours; oophorectomy	36	32	1. Personal savings
2015	Latina American	BA, elementary school teacher	Breast cancer (metastatic)	30	55	1. IVF clinic discount 2. Pharmacy donation of medications 3. Father paid
2015	African American	High school graduate, retail clerk	Leukaemia	22	9	1. IVF clinic discount 2. Pharmacy donation of medications 3. Monthly payment plan, mother contributing
2016	Caucasian American	MPP, survey analyst	BRCA1 positive	32	9	1. Switched jobs for insurance coverage of pre-existing condition 2. Borrowed from parents, repaying with interest 3. Credit card 4. Personal savings
2016	Caucasian American	College senior	Leukaemia	21	5	1. Covered by state insurance mandate 2. Community fundraiser at local restaurant
2016	Caucasian American	BS, accountant	Breast cancer	29	18	1. Covered by state insurance mandate 2. Cancer charity paid for medications 3. Pharmacy donation of medications 4. IVF clinic discount for low-income patients

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Table 2 (continued)

Year of MEF	Nationality/ethnicity	Education/highest degree and profession	Diagnosis	Age at MEF (years)	No. of eggs frozen	MEF funding sources
2016	Caucasian American	BA, high school teacher	Pituitary tumour (benign)	36	12	1. Covered by state insurance mandate 2. Took out loan 3. Parents paid insurance deductible
2016	Caucasian American	PhD, student	Breast cancer	30	29	1. IVF clinic discount 2. Pharmacy donation of medications 3. Cancer charity donation of medications 4. Patient donation of medications 5. Parents paid
2005	ISRAELI Ashkenazi Jewish	High school graduate; video editor	Hodgkin lymphoma	18	6 <sup>a</sup>	Free
2008	Mixed Jewish Israeli	BA, employee in family business	Hodgkin lymphoma	21	Unsure <sup>a</sup>	Paid for office visits with a particular specialist, but OC free of charge
2008	Ashkenazi Jewish Israeli	BA, sport therapist	Breast cancer	28	16 <sup>a</sup>	Patient and her mother paid \$2500, but were reimbursed by health maintenance organization
2009	Mizrachi Jewish Israeli	High school graduate with post-secondary coursework; artist (part-time)	Breast cancer	32	9	Free
2010	Mizrachi Jewish Israeli	MA, student, informatics	Hodgkin lymphoma	20	10 <sup>a</sup>	Free
2010	Ashkenazi Jewish Israeli	BA, teacher	Sarcoma	24	3 <sup>a</sup>	Free
2010	Mixed Jewish Israeli	High school graduate with post-secondary coursework; alternative medicine therapist	Thyroid cancer	40	16	Free
2011	Mizrachi Jewish Israeli	BA, bank teller	Sarcoma	20	8	Free
2012	Mizrachi Jewish Israeli	High school graduate with post-secondary coursework; secretary	Hodgkin lymphoma	32	4	Paid for office visits with a particular specialist, but OC free of charge
2012	Mixed Jewish Israeli	BA, organizational consultant (currently unemployed)	Lymphoma	27	5 <sup>a</sup>	Free
2014	Arab Israeli	BS, computer engineer	Ovarian tumour (borderline)	23	15	Free
2014	Ashkenazi Jewish Israeli	High school graduate with post-secondary coursework; customer service representative	Hodgkin lymphoma	37	3	Free

IVF, in-vitro fertilization.

<sup>a</sup> Of the 12 Israeli women, one was totally unsure of eggs frozen and could not recall any figure at all. Five others were also unsure, but provided the number of eggs they believe to have frozen.

free, although two chose to pay out of pocket for visits to particular oncofertility specialists. In contrast, collectively, the American women used almost 20 different ways to cover the cost of MEF, with most women relying on multiple funding strategies (as a result, the percentages in Table 4

exceed 100%). Most important were compassionate care discounts offered by IVF clinics and local pharmacies, which played a major role in easing women's financial burdens through discounted or donated services and medications. Nearly half of all American women relied on IVF clinic or



**Table 3** Medical egg freezing: social class backgrounds of study participants.

Country	Social class	n (%)
USA	Working class/working poor	4 (12)
	Lower-middle class	4 (12)
	Middle class	18 (55)
	Upper-middle class	7 (21)
	Total	33 (100)
Israel	Working class	4 (33)
	Middle class	8 (67)
	Total	12 (100)

pharmacy discounts, or both. As is made clear in Table 4, only one-third (33%) of the American women had sufficient personal savings or monthly salaries to finance their MEF cycles. The fact that two-thirds were unable to afford MEF was a reflection not only of women's class backgrounds, but also their young age (average 29 years; range 16–41 years). Many of the women in this study were students, part-time workers or unemployed as a result of their cancer diagnoses.

Although most of the American women diagnosed with cancer had some form of health insurance, as noted earlier, they were often shocked to discover that MEF was the only

part of their cancer treatment that was not covered by insurance. Some of them compared MEF with wigs, breast reconstructions and nipple tattoos (all fully funded), arguing that the ability to become a mother was clearly much more important to them. In this study at least, most women with cancer and other fertility-threatening diagnoses were eager to freeze their eggs, expressing considerable gratitude for the existence of MEF. Many of them described the anguish of potentially losing their fertility, the possibility of which they described as 'devastating'. Their future reproduction and motherhood, they explained, was 'crucial' to them, a true 'necessity'. Thus, for the women in this study, all of whom managed to obtain MEF, preserving their fertility was viewed as a critical component of their identities as women and their hopes for a full recovery.

Given women's desires for MEF, they were often indignant about the lack of MEF coverage and were ardent supporters of MEF insurance reform. They also demonstrated empathy towards their sick compatriots who were prevented from undertaking MEF altogether. Indeed, due to the high cost of MEF in the USA, American women knew of other women who had been unable to pursue MEF. Yet, because this study focused solely on women who had undertaken MEF, the voices of women without adequate resources to access MEF are entirely missing from this discussion.

**Table 4** Medical egg freezing (MEF): women's funding strategies.

Country	Funding strategy	No. of women utilizing (%) <sup>a</sup>
USA	IVF clinic compassionate care discount	15 (45)
	Pharmacy medication discount/donation	14 (42)
	Personal salary or savings	11 (33)
	Parents paid	8 (24)
	Partial insurance coverage	8 (24)
	Family/community fundraiser	5 (15)
	Full insurance coverage	4 (12)
	Cancer charity contribution	4 (12)
	Monthly payment plan	4 (12)
	Medications donated by other patients	3 (9)
	Bank loan	2 (6)
	Family loan	2 (6)
	Friend loan	1 (3)
	Family donation	1 (3)
	Medicaid coverage	1 (3)
	Military coverage for impaired veteran	1 (3)
	Professional courtesy for medical student	1 (3)
	Credit card payment	1 (3)
	Clinical trial participation	1 (3)
Israel	Free	10 (83)
	Paid for specialist visit, but MEF free	2 (17)

IVF, in-vitro fertilization.

<sup>a</sup> Many American women used multiple strategies, so percentage total > 100.

## Discussion

Prior qualitative studies of fertility preservation have focused on small numbers of women, primarily those with breast cancer, some of whom have experienced regret for not having had the option to pursue MEF (Banerjee and Tsiapali, 2016; Baysal et al., 2015; Garvelink et al., 2013; Kirkman et al., 2014). This is the first study to examine the experiences of women who have completed MEF for a variety of fertility-threatening conditions, primarily cancer. It is also the only binational study to date, and comparison of the cost of MEF and insurance funding between the USA and Israel led to important findings.

As shown in this study, women's ability to access MEF diverged considerably between the two countries. While MEF is fully subsidized by national health insurance in Israel, young patients in the USA must pay thousands of dollars for a single cycle of MEF. Given the lack of insurance funding, the relatively high cost of MEF was a source of emotional stress and financial pressure for most American women, who hailed primarily from working-class or middle-class families. Families were often quite valiant, finding creative ways to finance MEF for their sick daughters and sisters. They held fundraisers in their communities, negotiated special payment plans, or applied to cancer charities to fund the procedure. Furthermore, clinics and pharmacies often provided significant discounts for cancer patients. Nevertheless, covering the cost of MEF was experienced as a significant hardship in most cases, and many young American women in this study expressed outright anger and resentment.

In Israel, on the other hand, MEF posed no financial challenges, given that every Israeli citizen with cancer is entitled to public funding for MEF. As free access is guaranteed, MEF for cancer patients is never postponed for financial reasons, nor does it delay the onset of cancer

treatment. At the present time in Israel, survivors of cancer who did not undertake MEF prior to treatment are not entitled to free MEF after their recovery, nor are young women with other non-cancer-related medical conditions, who must pay approximately \$3000 per cycle. However, some of those patients do receive MEF coverage on a case-by-case basis, and MEF coverage for cancer survivors (at least those with ongoing ovarian function) is currently being considered.

The ever-expanding, state-dictated funding of MEF in Israel as part of the country's national health insurance conveys a range of supportive messages to young women who are grappling with fertility-impairing, sometimes life-threatening conditions. The public funding of MEF embodies a general belief in women's positive prognoses and prospect for recovery (Birenbaum-Carmeli et al., 2017; Dagan et al., 2017). Additionally, the investment of public resources into MEF encapsulates the state's faith in the clinical efficacy of MEF as a method of fertility preservation, consistent with the swift endorsement of most novel reproductive technologies as soon as they appear on the clinical scene.

On the whole, the state-dictated insurance funding of MEF envelopes Israeli women in a culture of support, allowing them to better cope with the other challenges surrounding their illnesses. This free access to MEF is a reflection of Israeli pronatalist policies. Indeed, reproduction has been constituted as a national pursuit in Israel since the foundation of the country in 1948. Not only is Israel's total fertility rate higher than that of any other industrialized country (3.11 vs 1.7 in the Organization of Economic Cooperation and Development countries, or 1.58 in the European Union), Israeli women have also been the world's heaviest consumers of IVF and other assisted reproductive technologies due to their practically unlimited universal public funding (Birenbaum-Carmeli, 2016).

In the USA, on the other hand, women who need MEF are rarely entitled to full insurance coverage. This is because fertility treatments are rarely subsidized by insurance providers in the USA. Insurance benefits for fertility treatments generally come in two forms: (i) through Fortune 500 companies that are self-insured and offer fertility coverage as part of their employee benefits packages; or (ii) through state mandates, which are offered in only 15 out of 50 USA states, and vary considerably in their entitlements. In this study, only four women had access to such insurance funding: one woman worked for a Fortune 500 company, which covered her MEF cycle completely; another young woman's father worked for a Fortune 500 company, which also covered her MEF cycle in full; and two other women were part of state labour unions (i.e. teachers, correctional officers), where fertility benefits, including full MEF funding, were part of generous union-negotiated insurance policies.

However, most of the American women were not so lucky. Although 15 USA mandate states have passed laws requiring insurers to cover fertility treatments for infertile couples, MEF – which is generally needed among single women to prevent infertility – is not included in the definition of 'infertility'. Even in Massachusetts, which provides an unlimited number of IVF cycles for infertile state residents, MEF is not included under the insurance mandate, although some major health insurance companies in Massachusetts have expanded their fertility benefits to include partial MEF coverage.

State legislation to enforce MEF coverage has proven difficult in the USA. For example, in California, generally considered a staunchly progressive 'blue' state, a bill mandating fertility preservation coverage passed both houses in 2013, but was then vetoed by the state's Democratic Governor, Jerry Brown. In January 2017, the bill was reintroduced as 'SB-172 Health Care Coverage: Fertility Preservation', but no decision had been made at the time of writing.

However, in Connecticut, the home state of 11 MEF patients in this study, 5 years of MEF advocacy on the part of both physicians and patients finally paid off (Phaneuf, 2017). In 2015, a bill to provide fertility coverage for cancer patients failed in the state legislature (i.e. H.B. No. 5500, An Act Requiring Health Insurance Coverage for Fertility Preservation for Insureds Diagnosed With Cancer). However, on 25 May 2017, the Connecticut State Senate gave unanimous approval to a bill that would ensure fertility coverage for those facing chemotherapy or any other medically necessary treatment that threatens the ability to have children (i.e. H.B. 5968, An Act Requiring Health Insurance Coverage for Fertility Preservation for Insureds Diagnosed with Cancer). The legislation to fund MEF was largely inspired by a 33-year-old breast cancer survivor from Stamford, CT who struggled to personally pay \$12,000 for her MEF cycle after her insurance provider initially authorized, then reversed, its position because of her cancer diagnosis. 'Do we need to sacrifice our future families to be a cancer survivor? I don't think we should have to,' she argued (Phaneuf, 2017). On 20 June 2017, Connecticut Governor Dannel P. Malloy signed off on the legislation, giving young women in the small east coast state of Connecticut the right to full MEF insurance coverage, just like women in Israel. Along with Connecticut, another small east coast state, Rhode Island, has passed a law specifically mandating MEF insurance coverage (Cardozo et al., 2017). However, to the authors' knowledge, these are the only two states to do so out of 50.

Thus, despite these two recent legislative successes, it is likely that most young American women will continue to struggle with the high cost of MEF and the lack of insurance coverage. Unlike Israel, the USA has never considered the prevention of infertility or its treatment to be a reproductive right, worthy of subsidized healthcare coverage. As a result, only a minority of American citizens – mostly white, upper-middle-class professionals – are able to access assisted reproductive technologies due to ongoing financial barriers to treatment (Boivin et al., 2007; Inhorn, 2018; Spar, 2006). This study suggests significant ethnic-, age- and class-based disparities in access to MEF in the USA, making MEF yet another example of unequal treatment and 'stratified' reproduction in America (Ginsburg and Rapp, 1995).

Overall, this lack of state support for MEF in the USA perpetuates a view of fertility as something 'elective', even a 'luxury'. Future childbearing is clearly not considered to be an American woman's entitlement, and especially not at state expense. The same is true for young American men, for whom the cost of sperm banking prior to cancer treatment must also be covered by them and their families. In Israel, on the other hand, MEF funding reflects the state's swift endorsement of novel reproductive technologies, faith in the effectiveness of fertility preservation, belief in women's positive prognoses and recovery, and the overall importance of fertility among the local population.

Ultimately, when comparing the experiences of Israeli and American women, this study is limited in a number of ways. As the first medical anthropological, ethnographic study of women who have completed MEF, the overall number of participants was relatively small ( $n = 45$ ), reflecting the difficulty of recruiting a relatively young, vulnerable and hard-to-reach population of sick women who were facing significant financial and time pressures. Furthermore, nearly three times as many women were interviewed in the USA ( $n = 33$ ) as in Israel ( $n = 12$ ), reflecting the different size and scope of MEF services in the two countries. Having said this, nearly one-quarter of the patients who underwent MEF in Israel's most specialized IVF clinic did, in fact, volunteer for the study.

Nonetheless, women in both countries were recruited from a relatively small number of clinics, cities and states, limiting the generalizability of the findings. In addition, because this was a binational study, coordinated between researchers and clinics in the USA 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, and must be acknowledged in assessment of the comparison.

Furthermore, although this study suggests that the uninsured cost of MEF is a significant barrier for women in the USA, and that these barriers may prevent many women from pursuing this fertility preservation option altogether, this study only addressed the experiences of those who had succeeded in obtaining MEF. It is not known how women who pursued MEF, but who did not choose to participate in this study, assessed their MEF experiences and decisions. Their views might well differ from those of the study participants. Finally, based on the study design, it was not possible to assess how women who wished to pursue MEF but were unable to do so experienced the loss of this new fertility preservation option. In this regard, a recently published special issue of *Narrative Inquiry in Bioethics* includes a 'narrative symposium' on cancer and fertility (Vol. 7, No. 2, Summer 2017). It suggests that the inability to pursue fertility preservation is a cruel twist of fate, especially when women (and men) have gone on to 'beat' their life-threatening cancers.

As in that special issue on cancer and fertility, the stories shared by women in this study were richly detailed and often poignant. Women revealed how they grappled with the uncertainty of a serious medical condition, as well as the news that their future fertility was under threat. However, American women in this study also felt righteous anger that all of their medical expenses were being covered by their insurance, with the exception of MEF which was one of the facets of treatment and recovery that was most important to them.

In conclusion, this study shows that MEF cost barriers and lack of insurance coverage have a major impact on American women and their families. Unlike Israeli women, who can undertake MEF without worrying about the cost, women in the USA are often under significant financial duress, requiring the ingenuity of their families to help them. Based on these findings, the authors would urge a serious reconsideration of MEF funding in the USA. Connecticut's and Rhode Island's recent decisions to mandate MEF insurance coverage by law – in response to significant advocacy on the part of young cancer

patients, oncologists and IVF clinicians – is a step in the right direction. In addition, the overall cost structure of MEF – including the price of medications, egg retrieval and egg storage – must be rethought in IVF clinics in the USA. Although some pharmacies and clinics 'do what they can' to help alleviate the financial burdens, the cost of MEF itself must be reconsidered, and future research must be directed to comparing the cost of MEF in the USA with other countries.

Indeed, more and more women around the world are being referred for MEF over time, as has been suggested in a number of recent global assessments (Rashedi et al., 2018a, 2018b; Salama and Woodruff, 2017). Thus, the time will come when MEF is viewed as both a rational and ethical measure for women needing fertility preservation, especially as cancer survival rates improve around the globe (Pereira and Schattman, 2017). As this study suggests, removing barriers to access MEF by reducing the cost and providing universal insurance coverage will have a major positive impact on women and their families. MEF is a new reproductive technology that matters, ultimately signalling a nation's commitment to its young women and their future reproductive health.

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