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1 Medical egg freezing: How cost and lack of insurance 2 cover impact women and their families


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15 **Abstract** Medical egg freezing (MEF) is being recommended increasingly for women at risk of losing their reproductive ability due to
16 cancer chemotherapy or other fertility-threatening medical conditions. This first, binational, ethnographic study of women who had
17 undergone MEF sought to explore women's experiences under two different funding systems: (i) the USA, where the cost of MEF is rarely
18 covered by private or state health insurance; and (ii) Israel, where the cost of MEF is covered by national health insurance. Women
19 were recruited from four American and two Israeli in-vitro fertilization clinics where MEF is offered. In-depth, semi-structured
20 interviews were conducted with 45 women (33 Americans, 12 Israelis) who had completed at least one cycle of MEF. All of the Israeli
21 women had cancer diagnoses, but were not faced with the additional burden of funding an MEF cycle. In marked contrast, the American
22 women – 23 with cancer diagnoses and 10 with other fertility-threatening medical conditions – struggled, along with their families, to
23 'piece together' MEF funding, which added significant financial pressure to an already stressful situation. Given the high priority that
24 both American and Israeli women in this study placed on survival and future motherhood, it is suggested that insurance funding for MEF
25 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

<https://doi.org/10.1016/j.rbms.2017.12.001>

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Please cite this article as: Marcia C. Inhorn, et al., Medical egg freezing: How cost and lack of insurance cover impact women and their families, *Reprod. BioMed. Soc. Online* (2018), <https://doi.org/10.1016/j.rbms.2017.12.001>

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

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