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Martha Dirnfeld, et al.**

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Patient-centered elective egg freezing: a binational qualitative study of best practices for women's quality of care

Marcia C. Inhorn¹ · Daphna Birenbaum-Carmeli² · Lynn M. Westphal³ · Joseph Doyle⁴ · Norbert Gleicher⁵ · Dror Meirow⁶ · Martha Dirnfeld⁷ · Daniel Seidman⁸ · Arik Kahane⁹ · Pasquale Patrizio¹⁰

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Abstract

Purpose How can elective egg freezing (EEF) be made patient centered? This study asked women to reflect on their experiences of EEF, which included their insights and recommendations on the optimal delivery of patient-centered care.

Methods In this binational, qualitative study, 150 women (114 in the USA, 36 in Israel) who had completed at least one cycle of EEF were recruited from four American IVF clinics (two academic, two private) and three in Israel (one academic, two private) over a two-year period (June 2014–August 2016). Women who volunteered for the study were interviewed by two medical anthropologists. Interviews were audio recorded, transcribed, and entered into a qualitative data management program (Dedoose) for analysis.

Results The majority (85%) of women were without partners at the time of EEF, and thus were undertaking EEF alone in mostly couples-oriented IVF clinics. Following the conceptual framework known as “patient-centered infertility care,” we identified two broad categories and eleven specific dimensions of patient-centered EEF care, including (1) system factors: information, competence of clinic and staff, coordination and integration, accessibility, physical comfort, continuity and transition, and cost and (2) human factors: attitude and relationship with staff, communication, patient involvement and privacy, and emotional support. Cost was a unique factor of importance in both countries, despite their different healthcare delivery systems.

✉ Marcia C. Inhorn
marcia.inhorn@yale.edu

Daphna Birenbaum-Carmeli
daphna@research.haifa.ac.il

Lynn M. Westphal
lynnw@stanford.edu

Joseph Doyle
Joseph.Doyle@Integramed.com

Norbert Gleicher
ngleicher@thechr.com

Dror Meirow
meirow@post.tau.ac.il

Martha Dirnfeld
dirnfeld_martha@clalit.org.il

Daniel Seidman
seidman@012.net.il

Arik Kahane
Arik.kahane@gmail.com

Pasquale Patrizio
pasquale.patrizio@yale.edu

- ¹ Department of Anthropology, Yale University, 10 Sachem Street, New Haven, CT 06520, USA
- ² Department of Nursing, University of Haifa, 3498838 Haifa, Israel
- ³ Stanford Fertility and Reproductive Medicine Center, Stanford University, 1195 W. Fremont Ave, Sunnyvale, CA 94087, USA
- ⁴ Shady Grove Fertility, 9600 Blackwell Road, Rockville, MD 20850, USA
- ⁵ Center for Human Reproduction, 21 E. 69th Street, New York, NY 10021, USA
- ⁶ Division Reproductive Endocrinology-IVF, Department of Obstetrics & Gynecology, Carmel Medical Center, Ruth & Bruce Faculty of Medicine, Technion, 3436212 Haifa, Israel
- ⁷ Clinical Center for Fertility Preservation and Fertility Preservation Research Laboratory, Department of Obstetrics and Gynecology, Sheba Medical Center, IVF and Fertility Unit, 1 Emek Ha'ella St, 52621 Ramat Gan, Israel
- ⁸ Department of Obstetrics and Gynecology, Sheba Medical Center, IVF and Fertility Unit, 1 Emek Ha'ella St, 52621 Ramat Gan, Israel
- ⁹ Assuta Medical Center, 13 Eliezer Mazal, 75653 Rishon Lezion, Israel
- ¹⁰ Yale Fertility Center, Yale University, 150 Sargent Drive, New Haven, CT 06511, USA

Conclusions Single women who are pursuing EEF alone in the mostly couples-oriented world of IVF have distinct and multifaceted needs. IVF clinics should strive to make best practices for patient-centered EEF care a high priority.

Keywords Fertility preservation · Elective egg freezing · Patient-centered care · United States · Israel

Introduction

Elective oocyte cryopreservation via vitrification—or “elective egg freezing” (EEF), as women themselves prefer to call it [1, 2]—for healthy women who are hoping to preserve their reproductive potential is gaining increasing international acceptance [3–9]. Although EEF has been considered a key way for reproductive-age women to defer or delay childbearing while pursuing their educations and careers [10–12], the emerging empirical evidence strongly suggests that the primary users of EEF are women reaching the end of their reproductive lifespans (i.e., late 30s to early 40s) who would like to pursue childbearing, but find themselves without a male partner. Five major surveys conducted in urban centers around the globe foreground the single status of most EEF patients, who are pursuing EEF at an average age of 36–38 [13–18]. Similarly, qualitative interview-based studies of EEF patients carried out in the USA [1, 2, 19], the UK [20–23], and Turkey [24, 25] also show that most women are pursuing EEF in their late 30s or early 40s, primarily because they lack a male partner.

To date, no attention has been paid to the specific needs of these EEF patients, or how they, as single women under reproductive time pressure, experience their care and treatment. Single EEF patients may feel a sense of isolation and loneliness in the couples-oriented world of IVF. Furthermore, women undertaking EEF may have specific needs and desires for patient-centered care as they navigate the various challenges of ovarian testing, stimulation, and retrieval on their own.

The need for patient-centered clinical care has been well documented over the past decade and is now considered one of six key dimensions of quality care, the others being safety, effectiveness, timeliness, efficiency, and equity of access [26]. Although definitions of patient-centeredness vary, “patient-centered infertility care” has been defined as care that is “respectful of, and responsive to, individual patient preferences, needs and values,” thus “ensuring that patient values guide all clinical decisions” (27:589).

In a large-scale European evaluation of patient-centered IVF care, Dutch and Belgian investigators surveyed 925 IVF patients, 227 IVF physicians, and conducted 14 focus groups with 103 infertility patients. The study uncovered major discrepancies between physician and patient attitudes toward patient centeredness [27, 28]. Based upon these findings, Dancet et al. developed a sophisticated conceptual framework outlining ten key dimensions of patient-centered infertility

care [29]. These included six system factors (information, competence of clinic and staff, coordination and integration, accessibility, continuity and transition, physical comfort) and four human factors (attitude and relationship with staff, communication, patient involvement and privacy, emotional support). This framework has since been applied in a number of European studies of infertile couples [30–34].

However, the meaning of patient centeredness may differ, either slightly or significantly, for (1) patients outside of Western Europe, (2) single women entering IVF clinics without partner support, and (3) older single women (in their late 30s and early 40s), who are facing age-related fertility decline in the absence of a male partner. To understand the needs of these older single women, it is necessary to study the experiences of those who have undertaken at least one cycle of EEF. Women themselves may be invaluable resources for articulating the optimal delivery of patient-centered EEF care. Dancet et al. have urged researchers to conduct such qualitative research and “to listen to the patient’s voice” [29].

In an earlier paper, we have explored the needs for patient-centered medical egg freezing (MEF) among mostly young, single cancer patients, who are facing the “double jeopardy” of both fertility- and life-threatening conditions [35]. However, because no studies have as yet been conducted on the patient-centered needs and desires of mostly older, single EEF patients, this study was undertaken to assess these women’s experiences, as well as any recommendations from them regarding optimal clinical care and support.

Methods

This binational, qualitative study of EEF took place between June 2014 and August 2016 and was supported by the US National Science Foundation’s Cultural Anthropology and Science, Technology, and Society programs. Women who volunteered for the study were recruited from seven IVF clinics, four in the US (two academic, two private) and three in Israel (one academic, two private). Recruitment in the US occurred primarily by study flyers, which were emailed or given directly to EEF patients during their appointments. In Israel, IVF clinic staff phoned EEF patients directly, inviting them to participate in the study. In both countries, women’s participation in the study was entirely voluntary; thus, no attempt was made to randomly sample EEF patients or to calculate response and

non-response rates. Instead, women who volunteered to participate contacted the first and second authors to set a convenient time and place for their interviews, either in the clinic or at a location of their own choosing.

In total, 150 healthy women who had undertaken at least one EEF cycle participated in this study (114 in the US, 36 in Israel). All participants signed written informed consent forms, agreeing to a confidential, audio-recorded interview. In both countries, an identical semi-structured, but open-ended interview schedule was used to guide the interviews, with the interview schedule being translated into Hebrew in Israel. Interviews were conducted entirely by the first and second authors, who are medical anthropologists with years of experience interviewing assisted reproduction patients in a variety of research settings. The American anthropologist interviewed all the American participants in the study, while the Israeli anthropologist interviewed all the Israeli participants in Hebrew.

In the initial semi-structured portion, all women were asked a brief series of socio-demographic questions, as well as relevant details of reproductive history. Following these semi-structured questions, women were then asked a series of open-ended questions focusing on their life circumstances at the time of EEF, their primary motivations for undertaking the procedure, their experiences of the EEF process and its outcomes, and any final thoughts or recommendations. Women were not asked direct questions about quality of EEF care, but many women volunteered their thoughts and recommendations, especially in the US portion of the study, with its larger number of participants. Because of the open-ended nature of the qualitative research process, women often “led” the interviews, describing their EEF “stories” in detail. These interviews usually lasted about 1 h, but could range in length from one-half to more than 2 h. The theoretical framework of this study was thus person centered and experiential, with women encouraged to share their thoughts and personal reflections [36].

Completed interviews were transcribed verbatim by trained research assistants at the authors’ universities. In Israel, interview transcripts were then translated from Hebrew into English by a professional bilingual translator. Following transcription and translation, all interview transcripts were uploaded into a qualitative data analysis software program (Dedoose) for thematic content analysis, using a coding scheme co-developed by the two medical anthropologist investigators. As is usual for qualitative, interview-based research, the main data analytic strategy was to systematically search for and examine themes and patterns emerging from the interview materials and to compare the similarities and differences between the US and Israeli data. The research protocol was approved by Institutional Review Boards at both universities and by the ethics committees of all the collaborating IVF clinic sites.

Results

Women’s socio-demographic characteristics are shown in Table 1. Women in this study were 36.3 years of age on average, and 85% of women were single. Almost all women in the study identified as heterosexual, and most were freezing their eggs while still hoping to find a committed male partner with whom to pursue childbearing. Table 1 also demonstrates the high level of educational achievement among these women, with nearly three-quarters (72%) completing postgraduate degrees. In both countries, study participants were also ethnically and racially diverse. While two-thirds (69%) of American women were Caucasian, the rest came from a variety of ethnic and racial backgrounds. While nearly three-quarters (72%) of Israeli women were Ashkenazi (European) Jews, the rest were from Mizrahi or mixed Ashkenazi-Mizrahi backgrounds.

More than half of the women (57%) had completed one EEF cycle at the time of the study. But the rest had completed two (31%) or more (11%) cycles. Altogether, these women had experienced more than 230 EEF cycles among them. On average, 18 eggs per woman were retrieved and frozen among the US group versus 13 in Israel.

Given that most of these women were single, with no relationship in sight, they were pursuing EEF in the hope of retaining their reproductive abilities. As many women explained, undertaking EEF was thus an attempt to take back some measure of control over their reproductive futures, especially in the absence of a partner. Thus, their attitudes toward and experiences with EEF were generally positive and hopeful. Women were grateful for EEF, praising it as a new fertility preservation option. Furthermore, women in both countries were generally quite satisfied with the EEF care they had received. Thus, during interviews, they shared their insights about the aspects of EEF care that were important to them, while also highlighting recommendations for the future. In some but not all cases, women volunteered their thoughts about what they perceived to be optimal in terms of clinical care and support.

As shown in Table 2, women’s responses generally fell into the two broad categories—system and human factors—as outlined by Dancet et al. [29]. In addition to Dancet et al.’s ten specific dimensions of patient-centered care, our study added an eleventh dimension—cost—because it was a significant aspect of patient-centered care for women in both countries. These factors and dimensions of patient-centered EEF care are described here. Brief interview excerpts are also included to “listen to the patient’s voice,” per Dancet et al.’s [29] recommendation.

System factors

Information One of women’s greatest desires is for detailed EEF information. Women would like to see the development

Table 1 Elective egg freezing in the USA and Israel: sociodemographic Characteristics of study participants

Characteristics	United States, <i>n</i> (%)		Israel, <i>n</i> (%)		Total, <i>n</i> (%)	
Age at EEF						
25–29	1	<1	0	0	1	1
30–34	19	17	7	19	26	17
35–39	83	73	27	75	110	73
> 40	11	10	2	6	13	9
Total	114	100	36	100	150	100
Number of EEF cycles						
1	65	57	21	58	86	57
2	35	31	11	30	46	31
3	10	9	1	3	11	8
> 3	4	3	1	3	5	3
Unrevealed	0	0	2	6	2	1
Total	114	100	36	100	150	100
Relationship status at EEF						
Single	94	82	33	91	127	85
Partnered	20	18	3	9	23	15
Highest degree						
High school	0	.0	1	3	1	1
Associates degree (2-Year)	1	1	0	0	1	1
Professional arts performance	2	2	0	0	2	1
Bachelors	23	20	14	39	37	25
Masters	52	45	13	36	65	43
MD	16	14	7	19	23	15
PhD	11	10	1	3	12	8
JD	8	7	0	0	8	5
MD-PhD	1	1	0	0	1	1
Total	114	100	36	100	150	100
Ethnicity						
American Women						
Caucasian American	79	69	–	–	79	53
Asian American	20	18	–	–	20	13
African American	5	4	–	–	5	3.5
Latinx American	4	3.5	–	–	4	2.5
Mixed race	4	3.5	–	–	4	2.5
Middle eastern heritage	2	2	–	–	2	1.5
Israeli Women						
Ashkenazi	–	–	26	72	26	17
Mizrahi	–	–	3	8	3	2
Mixed	–	–	7	20	7	5
Total	114	100	36	100	150	100

of national clinic registries and databanks (e.g., of the kind provided by SART) to help them select an EEF clinic. At the individual clinic level, women appreciate information and instructional materials delivered through a variety of media (e.g., websites, brochures, webinars, data sheets, and consent forms). Since so many EEF patients are single professional women, they desire instructional materials that can be used at home or the office (e.g., webinars and videos on self-injection) and appreciate clinic-based information sessions that are delivered after working hours. They also want instructional materials to be made EEF specific, focusing on women only rather than couples.

In personal appointments, EEF patients, especially those in their late 30s and early 40s, hope for honest, anticipatory guidance on what to expect from an EEF procedure (e.g., numbers of cycles and number of eggs), based on the realities of women's age and fertility profiles. In general, women EEF patients are highly educated professionals, and they crave

information that is up-to-date and tailored to their needs. They note that a comprehensive and informative book on EEF still needs to be published, to allay the fears and uncertainties sometimes generated through popular media attention to this subject.

Competence of clinic and staff Women in this study were generally pleased with the guidance they received from their primary EEF clinicians. However, because IVF clinics often include a large number of ancillary staff (e.g., nurses, ultrasound technicians, and psychologists), there is a need for all staff to be well informed about EEF and to be consistent in the delivery of patient information. Furthermore, clinic staff need to be comfortable and sensitive to the needs of all EEF patients, not only women who are single, but women who may be gay or ethnic and religious minorities. Indeed, staff diversity was mentioned by some women as an enhancement to patient-centered care overall.

Table 2 Best practice guidelines for patient-centered elective egg freezing: listening to women's voices and recommendations

Dimensions	Recommendations of EEF patients
System factors	
Information	<ul style="list-style-type: none"> • National registries (i.e., of clinics providing EEF services, numbers of cycles performed, and pregnancy outcomes) • Specific information on EEF on clinic websites and advertising materials • Instructional media for home or office use (e.g., webinars and videos on self-injection), which are EEF specific (i.e., focusing on women only) • Written materials on EEF (e.g., brochures and data sheets), including up-to-date clinical outcome data, provided during office visits • Clear consent forms, free of excessive legalese, for EEF patients only • Clinic-based EEF informational sessions in evenings for single professional women • Detailed information on EEF procedures, risks, and outcomes, provided face-to-face and in a timely fashion • Anticipatory EEF guidance on ideal numbers of eggs and cycles • Provision of realistic expectations for EEF outcomes based on women's age and fertility profiles
Competence of clinic and staff	<ul style="list-style-type: none"> • Education of community-based gynecologists on women's fertility decline and EEF options to raise women's awareness • Education of all EEF clinical staff (i.e., physicians, nurses, ultrasound technicians, and clinical psychologists) on EEF procedures and outcomes for delivery of accurate and consistent information • Hiring of diverse clinical staff with expertise on EEF care for single, lesbian, ethnic, and religious minority women
Coordination and integration	<ul style="list-style-type: none"> • Timely recommendations and referrals to EEF services from community-based gynecologists during well-woman exams • Ease of transfer from local physicians' offices to EEF clinics • Coordination with on-site and community-based pharmacies for ease of access to EEF hormonal medications
Accessibility	<ul style="list-style-type: none"> • Convenient EEF clinic hours for single working women (e.g., before and after work) • Reasonable wait times and waiting lines for EEF appointments and procedures • Woman-only EEF injection classes during evening hours • Private areas within clinics devoted exclusively to EEF patients, apart from couples-oriented infertility patient waiting areas • EEF stand-alone specialty clinics
Physical comfort	<ul style="list-style-type: none"> • Injection instruction, support, and assistance to address fear of needles and self-injection among single EEF patients • Information on EEF physical discomforts, including expectations about potential side effects and days lost from work • Timely management of post-EEF complications (e.g., OHSS)
Continuity and transition	<ul style="list-style-type: none"> • Reliable transportation services and home health-care options for single EEF patients on day of egg retrieval • Consistent follow-up for EEF patients post-retrieval • Provision of EEF information and next steps, based on number of eggs retrieved and stored • Clear information and guidelines on egg disposition and storage limits, including on consent forms and annual renewal forms
Cost	<ul style="list-style-type: none"> • EEF "packages" (e.g., discounted prices for multiple cycles) • EEF financing options (e.g., loans and monthly payment plans) • Acceptance of credit card payments for EEF services • Refunds for EEF cancellations • Stable annual storage fees and billing practices for EEF patients • Income-based EEF discounts for low-income patients • Acceptance of EEF insurance (and increased insurance coverage on part of employers and states) • Clinic price consciousness and reduction of EEF fees to increase patient access, especially for low- and middle-income and minority patients
Human Factors	
Attitude and relationship with staff	<ul style="list-style-type: none"> • Consistent one-on-one relationships with providers (especially physicians) throughout the EEF process • Extra clinical support for single women, who are navigating and absorbing EEF information on their own
Communication	<ul style="list-style-type: none"> • Adequate pre-EEF fertility screening and counseling • Appropriate bedside manner during EEF appointments and post-retrieval to avoid information delivery perceived as cavalier, overly optimistic, or "doomsday" • Delivery of post-EEF "bad news" (e.g., low numbers of eggs retrieved) appropriately and compassionately • Realistic information on potential outcomes of egg thawing (e.g., potential loss of frozen eggs)
Patient involvement and privacy	<ul style="list-style-type: none"> • Sensitivity to EEF patients without male partners (i.e., the majority) by not assuming accompaniment of husbands • EEF-specific informed consent forms that do not require partners' consent • Assessment of EEF patients' post-retrieval assistance and transportation needs
Emotional support	<ul style="list-style-type: none"> • Psychologists and social workers within clinic settings who specialize in EEF and needs of single women • Provision of EEF support groups, especially in clinics serving large EEF patient populations • Extra emotional support for the significant numbers of EEF patients whose partners have left or divorced them • Acknowledgement of the potential "loneliness" of EEF patients in IVF clinic settings and provision of maximal social support

Coordination and integration Many women in this study also argued that education about EEF must extend beyond IVF clinics to the general gynecological community. In this study, only 13% of women had received counseling or referral by their gynecologists for EEF. Those who did were generally

grateful to their gynecologists for "planting a seed." As one woman put it: "I really credit my doctor, my OB/GYN, with opening the discussion. She said, 'You know, today you're 34 and you're healthy and, you know, you're in a position to do something about it. So I think you should give some thought

to this.' I didn't even really know much about it at that time. I mean, I'd heard of it but I hadn't really known anyone who had talked about it with me, so it was really doctor driven."

Such discussions were rare, according to women in this study. The few who attempted to raise EEF with their gynecologists were met with ignorance (e.g., "They were asking *me* questions"!) or incredulity (e.g., "Why don't you just get knocked up?"). As one woman complained: "One of the great injustices for women's health is that no one ever talks to you about this. It's always just how *not* to get pregnant, and I think that's really not serving women well. And I will tell you that I asked about egg freezing with my gynecologist the same year that I did it. I asked her, 'Do you think I should do this?' First of all, she told me it was experimental, but it hasn't been experimental for three years. So that was wrong...and then she told me, 'You're just not there yet. If you're at the point where we need to be thinking about this for you, I'll let you know.' And I was 33."

Given this overarching lack of EEF education and referral, women often had to seek EEF information on their own. Thus, in their view, timely and coordinated referrals from community gynecologists to EEF providers are a major need. Furthermore, within EEF clinics, women want referrals to pharmacies where they can obtain hormonal medications without difficulty. Some clinics have made an effort to coordinate medication sharing among EEF patients, which women in this study considered an asset.

Accessibility Some IVF clinics have attempted to increase their accessibility for single working women. EEF patients are generally self-supporting professionals, who are holding down busy jobs. Thus, any efforts to increase clinic accessibility during non-working hours (e.g., early mornings and early evenings) are seen as desirable, as are efforts to reduce long waiting times for appointments and ultrasounds. Several American women in this study also mentioned the need for more stand-alone clinics offering specialized EEF services.

Another key dimension of patient centeredness mentioned by women in this study is psychological accessibility. Women wanted EEF-only information sessions and ideally private spaces within clinics for EEF patients, apart from IVF patients and their male partners. Explaining the need for "separate tracks," one woman said: "You know, you go to these clinics and everybody is there with their husbands. So it's like adding insult to injury. They did a little training course for the needles, the injections, and it was like me and two couples. And then at the end when they show you how to do the big injection, they're like, 'Oh well, your husband can do it. You don't have to do it.' And I just started crying. Afterwards, [the nurse] stayed and she talked to me. She was very understanding and nice and said, 'Do you think we should have a separate course for people who are doing egg freezing?' And I said yes!"

Physical comfort Physical comfort was also an important dimension of patient-centered care for women in this study. Not surprisingly, many women admitted a "fear of needles," which was a primary challenge when learning to self-inject. Particular concerns also revolved around self-injection of the trigger shot into the gluteus muscle. To that end, some women recommended that clinics provide injection assistance—not only woman-friendly injection classes and instructional materials, but also actual on-call assistance. Those who were able to master injections on their own often took pride in this self-injection experience.

Women also desired explicit preparatory information on what to expect during and after an EEF cycle. Some women in this study experienced significant abdominal bloating and pain after egg retrievals, requiring extra, unplanned days off from work. Women also wanted to know the warning signs of ovarian hyperstimulation syndrome (OHSS), given their need to assess any symptoms on their own. Overall, "expectation management" regarding the physical experience of EEF was considered by women to be a priority for patient-centered care.

Continuity and transition One aspect of the EEF cycle that does prove difficult for many women is finding accompaniment on the day of egg retrieval. In the USA, many women live far from their natal family members. Thus, women were often perplexed about whom to ask, especially since friends or co-workers would have to take time off from work—and on a day that could not be predicted ahead of time. Although family members often rose to the occasion, women pursuing EEF said that they could use better options for accompaniment and transition on the day of retrieval, including clinic-based referrals to transportation services and home-based healthcare. Since most women recovered at home alone, they also wanted clinics to follow up and make sure that they were well.

Women in this study also noted that post-retrieval information should be delivered in a timely fashion. Not surprisingly, women pursuing EEF are extremely concerned about the number of eggs retrieved and the number frozen. They also need to know whether additional cycles are recommended. In terms of storage, women appreciated clear and detailed information on egg storage and disposition, not only on EEF consent forms, but also on storage renewal forms sent on an annual basis. In this regard, women also appreciated consent forms that were easy to understand and free of excessive "legalese."

Cost Although cost was not foregrounded as a dimension of patient-centered care in the Dancet et al. framework [29], it was very important to both American and Israeli women in this study. In the USA, the cost of egg freezing, including hormonal medications, is minimally US\$10,000 per cycle. In Israel, the cost is lower, but it is still

substantial (i.e., US\$3200–US\$6500 per cycle), in a country where women's average monthly salary is only US\$1971.

In the USA, most of the women in this study were highly paid professionals and could afford to pay the costs of EEF directly. Nonetheless, they were troubled by how high EEF costs could limit access for other women, including their own sisters and middle-class friends. Furthermore, some American women experienced the cost of EEF as a financial strain, especially when repeated cycles were recommended. These women often appreciated the various ways in which US clinics attempt to make EEF more affordable. Such strategies include provision of EEF “packages” (i.e., discounted prices for multiple cycles); access to EEF financing options, including low-cost loans and monthly payment plans; acceptance of credit card payments for EEF services; and refunds on EEF cycle cancellations. Women also appreciated consistent billing practices and stable annual storage fees. In general, women felt that clinics needed to be “price conscious,” and they advocated for income-based discounts, including, for example, for graduate students and medical residents, whose pay is low and student debt may be high.

Women in both countries complained about the lack of EEF insurance coverage, which they considered to be a form of discrimination against single women. In the USA, women noted that many Fortune 500 companies and some US states (e.g., Connecticut) include “fertility benefits” for married couples. However, few companies and no US states cover EEF in their health insurance plans. Thus, many of the American women in this study were distressed by the lack of EEF insurance coverage, because they viewed EEF as a primary way to prevent potential age-related infertility.

The lack of insurance coverage was especially distressing to women in Israel, where IVF is subsidized through the Israeli national health insurance plan (up to two live births from the current relationship, if applicable). Thus, in a situation where the state provides almost unlimited funding for IVF, single Israeli women were frustrated that they had to pay thousands of dollars for EEF out of their pockets, while married women (including those sitting next to them in waiting areas) were undergoing the same process with full public funding. Furthermore, single Israeli women who have decided to build a family alone (and also share the same waiting rooms) are usually doing IVF with donor sperm; in Israel, this is fully covered, while EEF is never covered. Beyond the obvious personal frustration, most Israeli women criticized this policy as irrational. They highlighted the absurdity that the state would not pay for their fertility preservation, but would end up paying for their future infertility treatments. State funding of EEF, they ventured, could spare future IVF cycles and at a much lower cost.

Human factors

Attitude and relationship with staff Beyond the system factors, human factors were also an important dimension of patient-centered EEF. Women in this study were happiest when they had been able to develop a consistent, one-on-one relationship with a particular IVF provider over the course of an entire EEF cycle, as is usually the case in Israel. Thus, to the extent that they can, IVF clinics should attempt to assign specific clinicians to EEF patients. Such consistency of care is especially important to single women, who hope to build a trusting, supportive clinical relationship in the absence of a male partner.

Communication Along with staff consistency, clear and open communication is a key for single women who are absorbing EEF information on their own. In this study, women wanted clear communication at four key points in the EEF process. First, they wanted adequate pre-EEF counseling to gain a clear understanding of their current fertility profiles and what to expect. Second, they wanted appropriate and supportive communication strategies (i.e., “good bedside manner”) during subsequent EEF appointments; they especially wanted their physicians to avoid responses that could be conceived of as cavalier, flippant, overly optimistic, or “doomsday.” Third, women wanted to receive information post-retrieval in an appropriate and compassionate manner, especially women who were receiving “bad news” (e.g., few mature eggs). Finally, when women wanted to use their frozen eggs, they wanted accurate information on the thawing process and what to expect, especially loss during thawing, chances of fertilization, and realistic chances of success.

Patient involvement and privacy Because most women pursuing EEF are single, they are highly involved in their own care and must serve as their own patient advocates. Yet, many women feel sensitive about their single status and want this to be treated with a measure of privacy. To provide patient-centered care for this growing EEF population, clinics must engage EEF patients in their own care. This means avoiding questions about “husbands” or “partners” and providing informational materials, including consent forms, that do not assume a male presence.

Common mentions of “husbands” and “partners” on the part of IVF clinic staff are a source of irritation to EEF patients. As one woman explained, “All the paperwork is actually pre-printed... and they gave me the paper and it was like, ‘Will your partner be picking you up?’ And they’re like, ‘Oh, not you!’ And they crossed it out with a big X. And they wrote ‘No partner.’ And I’m just like, ‘Why don’t you have a separate form for people who are egg freezing, who don’t have partners?’”

Patient-centered EEF also means exhibiting emotional support and sensitivity to women who have undergone traumatic divorces and relationship breakups. In our study, 17% of women were pursuing EEF following a divorce, while another 12% were pursuing EEF after breakups. In other words, nearly one-third of women in our study were grieving losses of long-term relationships in the midst of EEF. Clinicians serving EEF patients must recognize this possibility and show extra sensitivity to single women struggling through the aftermath of separation and divorce.

Emotional support Needless to say, delivering patient-centered EEF care entails emotional support for single women, whose feelings of isolation and loneliness may be profound. One American woman commented, “You know, one thing that I wanted to say about the egg freezing ... that was one of the harder parts for me. Just feeling like that aloneness and feeling by myself. I just wouldn’t wish this on anyone going through it alone. You know, when you’re doing it out of, ‘What choice do I have?’ You know? It was just this very lonely experience in that sense. And like the day that I had the surgery, I was crying on the table before they put me out. I was just crying. Yeah, I just want to share that for what it’s worth. You know, it’s very, very scary. And when you’re coming in for egg freezing, you just feel single ... and ashamed.”

Such poignant comments beg the question: How can EEF patients’ loneliness be assuaged in IVF clinics? Women in this study had two major suggestions. First, IVF clinics should employ psychologists and social workers who specialize in EEF and who are focused on meeting the needs of single women. This would help not only EEF patients, but also single women coming for other purposes, including donor insemination. Second, IVF clinics should develop and maintain EEF support groups, especially clinics serving large numbers of single women. In general, single women need special attention and maximal emotional support. For the delivery of patient-centered EEF care, this must be made a priority.

Discussion

Around the globe, the demand for EEF is growing. For example, in the USA between 2013 and 2018, the total number of egg freezing cycles for all forms of fertility preservation jumped from 5000 to 12,000, according to the most recent SART statistics. Yet, to date, relatively few qualitative studies have examined women’s EEF experiences, and no studies have assessed what patient-centered approaches mean to them.

To that end, this study represents: (1) the first large-scale, qualitative, interview-based study with women who have completed at least one EEF cycle; (2) the first study to focus on dimensions of patient-centered care that are important to

women; and (3) the first binational analysis to explore women’s experiences of EEF patient care outside of Euro-American healthcare settings. Following the call by Dancet et al. [29] to “listen to the patient’s voice,” this study asked women to reflect upon their EEF experiences and to provide their insights on EEF care. With this background in mind, we highlight five important issues.

First, EEF patients are fundamentally different from IVF patients, in that the former are generally single while the latter are generally married (or partnered). Women seeking EEF are affected by their singleness. Indeed, it is the very reason that most women are motivated to seek EEF in the first place [1, 2]. Freezing one’s eggs because of the lack of a male partner is a difficult proposition for many women, one that takes some careful thought and foresight. But being forced to enter into the very couples-oriented world of IVF adds “insult to injury,” as one woman noted above. To the extent that they can, IVF clinics serving EEF patients must be acutely sensitive to the positionalities of single—and usually older—EEF patients and make every effort to provide spaces, materials, and support designed for this specific clinic population.

Second, as shown in this study, women would like timely information and direct referral to EEF providers from their community-based gynecologists. But few women in this study were able to receive such coordinated care, and thus were very critical of the lack of attention to age-related fertility decline or discussion of EEF options among the general gynecological community. Without such clinical guidance, women had to do their own research and make EEF decisions on their own.

Third, both Israeli and American women were deeply concerned about cost as an essential aspect of patient-centered care. This was a dimension not covered in Dancet et al.’s framework [29], but it emerged as highly significant in our study. Even women who could pay for their own EEF cycles believed that increasing EEF’s affordability would significantly increase EEF’s accessibility for women of lesser financial means. In both countries, women also argued for the importance of EEF insurance coverage. Such coverage would (1) prevent future age-related infertility and the need for subsequent IVF cycles and (2) decrease discrimination against single women, who generally do not receive insurance benefits even though married couples do (through the national health insurance system in Israel or through employers and state insurance benefits in the USA).

Fourth, it is important to emphasize that many aspects of patient-centered EEF care described by the single women in this study may also pertain to other IVF clinic populations, including single women pursuing donor conceptions [37, 38], single women serving as egg donors [39], and married professional women adjusting their work schedules to clinic routines, sometimes in the absence of their husbands [40]. In other words, the factors outlined in this article and summarized in Table 2 constitute “good practice guidelines” for

patient-centered care beyond the remit of EEF, in line with the earlier findings of Dancet et al. in Europe [29].

Finally, it is important to emphasize the need for additional qualitative research of the kind carried out in this study. In Israel, EEF has now been clinically available for more than 8 years (since January 2011), and in the USA, for nearly 7 years (since October 2012). Yet, relatively few qualitative studies of women who have completed EEF have been undertaken in either country. To date, this is the single, largest qualitative study of EEF to be conducted, and it is the only one that is binational, designed to include women outside of Euro-America. Through in-depth ethnographic interviews with women in both the USA and Israel who had completed at least one EEF cycle, this study yielded rich findings, and these findings were offered directly by women themselves, whose voices were clearly heard in this study.

As the first major, binational qualitative study, there were some inherent limitations. First, due to the study's qualitative design and the voluntary nature of participation, this study cannot be said to be representative of all women undergoing EEF in any of the participating clinics or in either country, thereby limiting the generalizability of the findings. In addition, because this was a binational study, coordinated between multiple researchers and clinics in the USA and Israel, the women who participated were recruited somewhat differently between the two countries, and interviewed by two medical anthropologists in two different languages. The overall number of participants recruited in the two countries was also unequal, reflecting the difference in population size and hence the smaller number of EEF patients recruited in Israel. Furthermore, our study only addressed the experiences of women who succeeded in accessing EEF and were willing to be interviewed. The experiences of other women who decided against EEF (e.g., by virtue of its cost) or women who declined to participate in this study (e.g., because of untoward EEF experiences) could not be represented. Finally, because this study is qualitative, utilizing open-ended ethnographic interviews, it did not aim at providing statistical analyses of any kind, beyond the basic socio-demographic percentages provided in Table 1. Women were not asked a specific series of questions about patient-centered EEF, which could then be quantified as in a survey research design. Rather, information on patient-centered EEF gathered in this qualitative study was volunteered by the participating women, often in response to a general closing question on "Do you have any final thoughts or recommendations?"

Having said that, our study provides an invaluable lens into the need for patient-centered EEF care. It also offers a variety of specific recommendations for clinics, as outlined in Table 2. Indeed, with more and more women around the world seeking EEF [3, 4], it is very important for IVF clinics to start developing patient-centered EEF protocols. As shown clearly in this study, single women who are pursuing EEF alone in the

couples-oriented world of IVF have distinct and multifaceted needs for patient-centered EEF care. Thus, IVF clinics should adjust their care practices accordingly, making patient-centered care for single EEF patients a high priority.

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Compliance with ethical standards

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

Informed consent Informed consent was obtained from all individual participants included in the study.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committees and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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