

“My choice”: breast cancer patients recollect doctors fertility preservation recommendations

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Abstract

Purpose The increasing rates of early-onset breast cancer (BC) and of woman survival render fertility preservation (FP) a pressing issue. We probe women’s experiences of FP counseling and decision making, aiming to identify emergent counseling patterns.

Methods Semi-structured interviews were conducted with 16 women, who had been diagnosed with BC at the ages of 24–38, 1 to 5 years prior to the interview. BC survivors were recruited through posts in online fora, consented to participate, and were invited to tell their FP stories. The transcribed interviews were analyzed thematically, using the phenomenological paradigm.

Findings Doctors’ FP recommendations belong into three categories: (a) direct clinical rationale—grounding recommendations in the woman’s clinical condition by direct reference to tumor characteristics and prognosis, (b) indirect clinical rationale—reference to the woman’s clinical condition by outlining a pressing time-frame, and (c) sociodemographic rationale—focus on the woman’s family status. Women’s responses revealed primarily detachment and compliance alongside initiative and proactivism. **Conclusion and implications for cancer survivors** Beyond its contribution to women’s future ability to conceive, FP may constitute an arena of personal autonomy and a coping

resource for young BC patients. Raising awareness to this significance may sensitize healthcare providers to the role that FP may play in the moment of cancer diagnosis in adding, alongside sickness and prognosis, a focus on family future planning. As such, FP may affect women’s quality of life and even survival.

Keywords Early onset breast cancer · Fertility · Fertility preservation · Cryopreservation

Introduction

Women who survive breast cancer (BC) in their reproductive years sustain a substantial risk of premature ovarian failure following chemotherapy [1, 2]. The rising rates of early-onset BC and of woman survival, which coincide with the rise in child-bearing age [3], render FP a pressing issue [4]. However, BC diagnosis allows but little time to make this demanding FP decision. Infertility is a major source of distress, sense of loss of control, and poor long-term quality of life for women in general [5–7]. Cancer patients describe chemotherapy-induced infertility as a major agony that jeopardizes their sense of self-fulfillment and female identity [8–10].

At present, clinics vary greatly in their rates of FP counseling and patient FP uptake. Roughly half of young BC patients recall having had fertility counseling shortly after diagnosis; still, numerous clinics provide hardly any fertility-related information to patients [11–17]. Several studies indicated that the existence of a designated program for cancer FP referral was associated with increased rates of actual patient referral [16, 17]. Others did not find such association [15]. The availability of an FP specialist as well as physicians’ knowledge of FP options also increased the likelihood of referral. Lack of time during appointments and physicians’ own discomfort

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with the subject were associated with lower rates of referrals [12–18]. Other reasons were advanced patients' age (>35), patient having children, and severity of the disease at diagnosis [19]. Given the recent recommendations of the American Society of Clinical Oncology, the European Society of BC Specialists regarding FP for young cancer patients, and the Society of Breast Cancer in Young Women (BCY2) to actively refer young cancer patients to FP [11–14, 20–24], it may be expected that the rates of referral will be rising. However, in a multicountry European survey, the availability of public funding and the cost of FP were found to be prominent factors affecting patients' FP decisions [15], as well as physicians' recommendation [17]. On the women's side, though not all women eventually performed FP, most would have liked to be informed about existing options [25, 26]. In practice, women often described fertility-related discussions as inadequate [14, 27], sometimes acutely [28]. Alternatively, women who reported having been properly informed about FP options expressed higher sense of choice and control and experienced less conflict regarding their FP decision-making [8, 25, 29, 30].

Good decisions require issue-related knowledge, support systems, and self-awareness about one's own beliefs and values [31]. The significance of discrepancies between doctors' and patients' values in such situations is widely acknowledged. Equally established is the awareness of doctors' tendency to recommend those modes of action that cohere with their clinical experiences and valuations, as well as their subjective perceptions of the patient's life circumstances [32, 33]. Ruptured communication between professionals and patients is not infrequent. In line with the growing awareness of these dynamics, practitioners are being encouraged to "promote an exchange of relevant preferences and values with their patients to have a sound basis for their recommendations" [33]. This is especially applicable to young BC patients, who are often keen to take active part in the shaping of their treatments [32].

In the present study, we aim to probe the perspectives of Israeli BC patients on FP counseling and decision making and elucidate the significance that women attribute to the counseling sessions, as they emerge from their retrospective accounts. We also explore the women's reactions to the doctors' FP recommendations and their experiences throughout the various FP procedures. Israel's public health system covers FP to any woman of reproductive age whose fertility is at risk due to a medical reason. This entitlement is part of Israel's broader reproductive policy, which provides state-funded fertility treatments to any woman, irrespective of her family status, financial standing, or sexual orientation, until she has two children with her current partner [34].

Methods

This study is based on interviews with 16 Israeli Jewish women who were diagnosed with BC when they were 24 to 38 years of age. With one exception of 7 years, all were diagnosed 1 to 5 years prior to the interview. Table 1 describes the participants' sociodemographic profiles, in ascending number of children.

Women were recruited through posts in online fora and consented to participate. The study was approved by the ethics committee of the University of Haifa. We invited the women to tell their stories of BC and fertility. Specifically, we asked about their experiences of doctors' FP recommendations. The women's narratives enabled us to gain an insight into the meanings they attributed to fertility at the time of BC diagnosis. We used a qualitative phenomenological perspective to elucidate the women's lived experiences through descriptive means [35].

We interviewed each woman once in the years 2011 and 2012. Questions addressed the woman's medical history, her reproductive profile and perception of fertility after the cancer diagnosis and treatments, the participant's need for information about future conception, and whether or not she had been offered consultation with an FP expert. The interviews averaged an hour in length and were audio-recorded with permission, at a location of the participants' choice.

After transcribing all the interviews, we conducted a thematic analysis of the content using the phenomenological paradigm as customary [36, 37]. We analyzed the interview materials in the Israeli context, as it might have underpinned both the women's attitudes as well as the doctors'.

Findings

Being based on interviews with the women only, the interviews present the women's experiences as they are captured retrospectively. The findings are presented in two sections. The first section outlines the women's depictions of the doctors' FP recommendations. The second describes the women's reactions to the doctors' recommendations. All names in this manuscript are pseudonyms.

Doctors' FP recommendations

Direct reference to the woman's clinical condition

Somewhat surprisingly, only two women recalled clinical considerations as the primary factor that doctors presented as underlying their FP recommendations. In both cases, the doctor recommended to refrain from FP.

Yarden was diagnosed at age 31, after the birth of her second son. She reported that the doctor suggested that "if the

Table 1 Sociodemographic and clinical characteristics of 16 breast cancer patients

No.	Participant	Year of birth	Age at interview	Marital status at BC diagnosis	Number of children at BC diagnosis	Level of education	Level of income	Religiosity	Age at BC diagnosis	FP
1	Moran	1973	39	Partner	–	Academic	Below average	Secular	26 and 34 ^a	Yes
2	Hannah	1977	35	Married	–	Academic	Below average	Secular	30	Yes
3	Ornit	1978	34	Divorced	–	Academic	Below average	Secular	33	Yes
4	Ronit	1978	34	Single	–	Diploma	Below average	Secular	33	Yes
5	Carmel	1979	33	Single	–	Academic	Below average	Secular	32	Yes
6	Bat-El	1980	32	Single	–	Academic	Below average	Secular	30	Yes
7	Revital	1985	27	Single	–	High school	Below average	Secular	25	Yes
8	Hofit	1985	25	Single	–	Academic	Below average	Secular	25	Yes
9	Stav	1987	25	Partner	–	High school	Below average	Secular	24	Yes
10	Liat	1974	38	Married	1	Academic	Below average	Secular	33	Yes
11	Yaffa	1971	41	Married	2	Academic	Above average	Secular	38	No
12	Karin	1971	41	Divorced	2	High school	Below average	Secular	34	No
13	Sarah	1972	40	Married	2	Academic	Below average	Secular	37	Yes
14	Yarden	1979	33	Married	2	Academic	Average	Traditional	31	Yes
15	Moria	1969	43	Married	3	Academic	Average	Secular	38	No
16	Eden	1980	32	Married	3	Diploma	Average	Religious	32	No

BC breast cancer, FP fertility preservation

^aMoran had metachronous breast cancer

disease had not metastasized, I could have FP.” Yarden described the conversations with her doctor as substantive, open, and sharing.

Sarah, a mother of two girls, discovered a lump in her breast at age 37. When she has initiated a discussion on FP, her oncologist recommended against any such procedure. According to Sarah, the doctor based his recommendation on clinical considerations: the assumption that hormonal activity would resume and the type of cancer, which would allow ovulation induction, if needed.

In both cases, the woman’s medical condition was discussed as formative of the doctor’s FP recommendation. Yarden’s doctor presented his clinical concerns out of his own initiative whereas Sarah’s doctor addressed the subject only in response to her query.

Indirect reference to clinical considerations—the language of time

Five other women described dialogs with doctors in which clinical reasoning was tacitly inscribed into time terminology. Though the doctors did not elaborate concretely on disease characteristics, e.g., type of tumor or disease staging, the

women interpreted a pressing timetable as an indication of severe illness.

Hannah was 30, married without children. She had had one abortion and two miscarriages and had started fertility treatments. The disease was diagnosed immediately following the second miscarriage. Hannah described that FP treatment was mentioned haphazardly:

Everything happened terribly quickly because we were in a hurry to start chemotherapy. The doctor... gave us two weeks to get all the documents and to meet a fertility expert. I went to see him and he extracted oocytes.

Hofit, aged 25, single without children at diagnosis, described a similar sequence. Within 2 weeks of diagnosis, she underwent surgery and started chemotherapy. In between, she went through FP by freezing both ovarian tissue and embryos. Hofit recollected that “the fertility expert asked for more time in order to use hormones and to increase the number of eggs, but the oncologist wouldn’t wait longer.”

Neither Hannah nor Hofit recalled any concrete clinical characteristics being mentioned as the basis for the FP advices. Rather, both described the hurried timeline that the

doctors had drawn as encapsulating underlying clinical considerations.

Sociodemographic considerations as basis for FP recommendations

Contrary to the sidestepping of clinical considerations, the women's sociodemographic circumstances were placed center stage by several doctors. This approach was especially evident when the woman had no children. Single patients recalled being referred to FP almost automatically, with little discussion, if any, of clinical, physical, or emotional aspects of the procedure.

Bat-El, aged 30 and single at the time of diagnosis, presented the fact that she did not have any children as the obvious reason for her immediate referral to a fertility expert prior to chemotherapy: "Right away, [the doctor] called a fertility expert and told him that she was sending him a young woman". *Bat-El* made a direct connection between her family status and the FP, fully identifying with the doctors' stance: "I started FP treatment because I'm single."

In *Carmel's* description, the oncologist did not mention the disease at all but rather dwelled on her sociodemographic situation: a single woman aged 32 with no children.

When the woman had two or more children, this fact was equally formative of the doctors' recommendations, which were almost invariably against FP. *Karin* was 34 and the mother of two at diagnosis. According to her recollection, FP was not discussed at all: "No one brought up the issue of future children. They apparently saw that I have two children and decided that I don't need it."

Yaffa, diagnosed at the beginning of her third pregnancy, did recall a discussion about FP, in which her doctor dismissed this option:

We talked about the need to terminate the pregnancy right away. I mentioned future pregnancies, but [the doctor] said that there was no point in FP, because I have two daughters and I'm 37, and anyway, by the time I recover, I'll be 40.

The doctor did not include any clinical rationale in his attempts to dissuade *Yaffa* from FP. Rather, he focused on her age and her two existing children.

Eden, a religious woman, was 32 at diagnosis and a mother of three. She described her doctors' astonishment when she requested FP:

[My oncologist] explained to me that I already have three children and it would be better not to postpone the treatment... [The] fertility expert... couldn't believe his ears. He didn't understand why I would want FP

when I already had three children. He said: Your children need a healthy mother.

The women thus portrayed the doctors' perceptions of their family status as formative of their FP recommendations. Their medical condition was not nearly as prominent in the doctors' FP reasoning. Nine out of the 16 women attributed the doctors' decision to refer them to FP to their having children or not.

The aftermath of chemotherapy embodies the unpredictability that probably underlies some of the doctors' ambiguity: *Moran*, the single 26-year-old who had been referred to FP, had two spontaneous pregnancies after chemotherapy and did not make use of her frozen oocytes, whereas *Karin*, who had two children at diagnosis, whose doctors had not even mentioned FP, tried to become pregnant following recovery, but was unsuccessful.

The receiving end: women's reactions to the doctors' recommendations

Detachment and compliance

For quite a few women, whether because they had had children or due to the turmoil of the diagnosis, the subject of future childbirth was beyond their immediate concerns. Four women described themselves as both fear stricken and numb, passive "onlookers" in the medical procedure, including FP. *Moriah* described her mindset during the discussion with the oncologist:

I was thinking just five months ahead, when I will have finished the chemo [therapy]. I didn't think or ask about fertility, though I was planning to have at least another two [children] ... I didn't know that such an option [FP] existed.

Given the importance of childbearing for *Moriah*, her account suggests how, under the physical and psychological burden of cancer diagnosis, fertility may be pushed aside, rendering the doctor's recommendation crucial. Possibly, however, both *Moriah* and the doctor pushed fertility aside because all have been preoccupied with the severe disease and were relatively assured by *Moriah's* existing three children. Nonetheless, looking back at these consultations, *Moriah* expressed great frustration, that "they had practically made the decision for me."

Detachment and overlooking of FP were not limited to the mothers among the patients. Several women without children described that childbearing and FP were altogether irrelevant to them at the time of diagnosis. As mentioned, when the diagnosed woman had no children, most doctors incorporated FP almost automatically into the cancer workup. *Revital*, aged

27, single without children, described her detachment: “You get there and you don’t want children just now. You don’t want anything to do with that. You’re there only because you have no choice.” *Hofit*, aged 25, was even more graphic in articulating her mindlessness:

The first two weeks, you are brain dead. You operate on “automatic,” do whatever you’re being told... so I didn’t make a stop on fertility. ... I worried about the disease, the treatments. I was preoccupied with survival, with losing my hair. What about my studies? Fertility didn’t interest me one bit... I was like a machine.

Bat-El was aware of her detachment and therefore relied on her brother to liaise between her and the external environment: “I walked around like a robot. I let them have my body and everything they wanted to do to me, but I wasn’t really there.”

Obviously, the women’s depictions related only to the early phase of diagnosis, when the FP decisions had to be made. At that point in time, future fertility was apparently well beyond their scope and lives and the FP procedure comprised but an additional item in the chain of decisions and procedures that they had to undertake following diagnosis. Notably, among our interviewees, we heard women without children who described FP as irrelevant and women with children who were highly interested in FP, and vice versa.

Proactive response

In stark contrast to the detached passivity described above, other women assumed entrepreneurial roles and actively demanded FP. As expected, five of the women, who were single and had no children, were diligent in this sphere.

Stav was 24 and had no children at diagnosis. Her doctors decided to include chemotherapy protocol just days before it was due to start. *Stav* recalled that the doctor mentioned fertility in passing and made no FP suggestions. However, she insisted on FP and the doctor made way for the consultation and procedure. *Stav* stressed the importance of fertility for her and was still horrified during the interview that FP might have been overlooked. *Stav*’s frustration echoed the importance of FP for some childless women and the potential harm that its omission might entail. Notably, such omission was exceptional in the case of women who had no children.

Possibly, the clinical condition deterred the doctors from postponing chemotherapy or approving the hormone stimulation required in FP. Nonetheless, once a woman made a request, the doctors accommodated FP and postponed the chemotherapy onset. However, it was not necessarily the childlessness that prompted women’s entrepreneurial reactions. Several mothers among our interviewees were as preoccupied with FP. *Liat*, 33 when diagnosed, had had one daughter following IVF. *Liat*’s doctors did not mention FP. However, she

insisted on understanding the clinical considerations that underlay this omission. At the interview, 5 years after diagnosis, *Liat* was still enraged that the surgeon had not discussed FP with her and concluded: “The bottom line is that if you don’t talk about your fertility, no one else will!”

Sarah’s account was similar. *Sarah* had two daughters at diagnosis at age 37. Like *Liat*, she was not offered FP advice but initiated her own enquiry: “I don’t think that anyone would have initiated anything.” *Eden* had three children at diagnosis. Her doctors strongly opposed FP when she brought up the subject and grounded their objection in her having three children. Nonetheless, *Eden* demanded to consult a fertility expert, and though he, too, was against FP, she carried out one FP cycle. Evidently, *Eden*’s priorities differed from those of her doctors. For her and her partner, not only conception but also the very effort to preserve fertility were supremely important. Her retrospective explanation offers an insight into another kind of significance for FP:

They must give me the option to preserve my fertility and make my own decision... If, one of these days, I choose not to have any more children, that will be my choice, but all the options will be open to me, and my fate won’t be sealed irreversibly . . . I understand the rationale behind their decisions but it was terribly important to know that I did everything and used every possible means to fight to preserve my fertility. And this knowledge is a comfort.

Eden’s account powerfully illustrates the intense passion that some women with children may have for FP. Furthermore, *Eden* underscores the importance of autonomous choice and control at the time of cancer diagnosis. She did not dwell on her clinical condition or on the size of her family. She rather focused on the ability to make her own life choices at her own time. FP thus emerges not only as a means to increase the likelihood of future conception but also as a sphere of action, a symbolic token of control and containment of the disease with the least possible secondary damage.

Discussion

The importance of discussing chemotherapy-induced risk to fertility with young cancer patients has been acknowledged widely over the last decade, by individual professionals as well as associations [20, 21, 38, 39]. Shared decision-making and FP counseling shortly following cancer diagnosis have been shown to benefit patients by reducing decisional conflict and regret [40–44]. Still, the women’s retrospective accounts revealed uncertainty regarding the possible damage to their future fertility, the FP options, and the referral criteria.

Dissatisfaction was especially evident among women who had children and who were hardly presented with FP options. Apparently, despite the challenges that FP entails and despite the turmoil of BC diagnosis, our interviewees had desired to undergo FP and most of them ($n = 11$) eventually completed such procedures.

On the doctors' part, as it emerged from the women's accounts [12, 13], the FP counseling and recommendations hardly included the patients or their families. The recurrent sequence of marginalizing FP followed by the woman's request for FP and subsequent "relaxation" of the protocol so as to allow FP procedures captures the limited inclusion of the women in the decision-making process. It also discloses the flexibility that doctors can introduce into the treatment protocols for a reason that they consider "worthy." We should bear in mind that since in Israel FP for cancer patients is publically funded [34], financial aspects are not part of the physicians' consideration. These patient-doctor exchanges are of great importance as the role of the attending doctors emerged as crucial in the early days following diagnosis.

When the doctors did discuss FP with the women, most did not place clinical considerations up front. The prevalent substitute that we had identified was a language of time that implied urgency, thereby conveying to the woman the seriousness of the disease and the resulting difficulty of delaying treatment for FP. This proxy terminology might suggest that doctors themselves were struggling while facing young women, whose lives and futures were disrupted by cancer [13, 40, 45, 46]. Possibly, the language of time was the doctors' strategy to somewhat soften the "bad news."

The language of sociodemography might be another channel of distancing the counseling encounter—and the subject at stake—from the world of pathology to the realm of family and life plans. The extensive use of sociodemography and the emphasis on the woman's existing or future children as basis for FP recommendations point in this direction. Indeed, a simple logic could be identified: for women who have no children, an effort should be made to preserve fertility, even at the cost of treatment postponement, whereas for women who have two or more children, FP does not justify deviation from the lifesaving treatment protocol and, possibly, not even a discussion. Although this family concept was supported by women's accounts elsewhere [45], our study revealed a more diverse picture. Not all women who had no children and no partner at the time of diagnosis were keen to undergo FP [47], and not all women with two or more children were willing to forego this option. Several interviewees adopted a dissociated manner, detached from the physical and the emotional distress that accompanied FP and its incongruence to their current life situation. In contrast, other women, who were mothers at diagnosis, attributed supreme importance to FP and defied the doctors' reluctance to delay treatment on grounds of FP.

To this value-based explanation, we wish to add another layer of potential doctor-woman divergence regarding FP. Possibly, the proactivism and resolve that some women exhibited regarding FP were in themselves of significance for the women at this critical moment. Initiating consultations and obtaining referrals, acquiring knowledge about available options, selecting the FP method, coordinating the implementation, and eventually undergoing the procedure were all instances of self-determination, wherein entrepreneurial patients took active part in shaping their own treatment. Thus, the burdening FP tasks, potentially overwhelming at the difficult moment of cancer diagnosis, might paradoxically comprise an arena of self-expression, an embodiment of the woman's free will and life beyond the clinic. It is important to recall, in this context, that since FP for young cancer patients is fully funded in Israel, women's FP initiatives did not entail financial consequences. As such, it can also cut through all social classes [15, 34].

As such, FP may comprise a momentary escape from the disease situation, eventually contributing to lower decisional conflict and regret [41, 42, 48]. From this perspective, FP may be construed as a symbol of control over one's life in a situation that robs the young women of nearly all their autonomy. At this moment, when their normal routines and future plans have been ruptured, some of these young women might experience FP as a space of discretion in the bitterly imposed disease reality. In this capacity, FP may have a crucial significance for mothers and childless women alike. Eden's emphasis on retaining her choice and making her own decision in the future, which was cited above, captures this aspect.

Women who have undertaken FP have described their experiences as physically and emotionally taxing [5–7, 48]. These difficulties do not negate our argument but rather reinforce it, as they embody women's persistence despite the difficulty. Being viewed within this perspective, the FP tasks, especially when they emanate from the woman's own initiative, burdensome as they are, may nonetheless be charged with uplifting emotional, adaptive significance, as an enclave of autonomous reasoning and relative control that has actual impact on the cancer treatment and the woman's future.

Strength and limitations

Due to its preliminary nature, the present study has a few substantial limitations. The study sample is small and the analysis is based solely on women's' descriptions. The doctors' accounts may well be different. The sample is also homogeneous in consisting only of Israeli Jewish BC patients. The ability to generalize our observation to broader subpopulations of young BC patients is therefore limited. Furthermore, the observed disregard of some doctors of FP might have been heavily influenced by the study timing, when FP technologies were just being routinized [20, 38, 39]. It is therefore possible

that the picture outlined above captures a period of transition, when great differences existed among different doctors and clinics. Moreover, various nuances that have been depicted in the present article (e.g., public funding of FP or high levels of fertility) are context specific and as such may carry somewhat different meanings elsewhere.

Nonetheless, our material does voice the utmost importance of future fertility and of FP for some young BC patients, thereby suggesting that the subject needs to be presented to any woman as part of the cancer workup and treatment planning [42–44].

Implications for cancer survivors and conclusion

We suggest that beyond its potential contribution to future fertility, FP may harbor extra-clinical significances, primarily embodying a somewhat alternative focus of patient attention. As such, FP may constitute an arena of personal autonomy and an important coping resource for young BC patients who face the highly imposed disease situation and concomitant medical treatment.

Raising doctors' awareness to this potential significance may help promote FP discussions and shared decision making, which would benefit young women struggling with BC, both clinically and emotionally.

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Compliance with ethical standards All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the ethics committee of the University of Haifa.

Conflict of interest The authors declare they have no conflict of interest.

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