Fertility decision-making under certainty and uncertainty in cancer patients

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ABSTRACT

Objective: The objective of this study was to understand how reproductive-age women with breast cancer make fertility-related decisions.
Methods: Using grounded theory methodology, we collected data from 11 reproductive-age women with breast cancer between March and August 2016. Verbatim transcriptions were analyzed using constant comparative analysis and open, axial, and selective coding.
Results: "Fertility Decision-Making under Certainty and Uncertainty" emerged as a core category. Fertility decision-making started with the participants' "values and preferences" about having a child. In making a decision, there were certainty ("Information" and "Emotional support") and uncertainty ("Time constraints," "Recurrent risk," "Labeling," and "Unmet needs") factors. Participants had more uncertainty factors than certainty factors, and healthcare professionals' services accounted for one of the uncertainty factors.
Conclusions: After fertility preservation counseling, women with cancer made difficult decisions in stressful situations without sufficient healthcare information and support. Tailored information should be provided to individual women in collaboration between oncology and reproductive health professionals.

Introduction

Advances in cancer diagnosis and treatment have led to a dramatic improvement in survival rates. Unfortunately, these life-saving treatments can also negatively affect reproductive health [1]. To preserve the full range of options for fertility preservation, possible approaches should be considered as early as possible during treatment planning [2]. The available fertility preservation treatments for young patients with breast cancer include embryo cryopreservation, oocyte cryopreservation, temporary ovarian suppression, and ovarian tissue cryopreservation and transplantation [3]. In addition to the development of guidelines [4,5], fertility preservation or oncofertility programs are available for cancer patients who face fertility and parenting issues to support their decision-making [6,7]. Furthermore, in 2005, the Oncofertility Consortium was formed to meet the needs of cancer patients facing any fertility-threatening conditions in the United States [1]. Since then, many similar programs have been developing worldwide [8,9].

Despite these efforts, many women with breast cancer are not given adequate information about fertility issues [10] because of low levels of knowledge about fertility issues among both patients [11] and healthcare professionals [12], as well as unmet needs [13,14]. Specifically, pre-menopausal women with breast cancer are dissatisfied with the quality of discussion with physicians [15]. Many women with breast cancer still do not receive fertility preservation counseling at diagnosis, particularly those aged 35 and older, and those who are multiparous [16].

Despite increased awareness, the quality of fertility preservation counseling needs to be improved. Accordingly, how women with cancer make decisions about fertility issues should be clarified from their perspectives.

Methods

Aim

This study aimed at understanding how women with breast cancer receiving fertility preservation counseling make fertility-related decisions.

Design

We used grounded theory according to Strauss and Corbin [17] to conceptualize a decision-making process in women with breast cancer who received fertility preservation counseling. We conducted face-to-face interviews using a semi-structured interview guide.

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Study setting

The study was conducted at a general hospital in Tokyo, Japan; the hospital has a reproductive health clinic providing fertility preservation counseling and cryopreservation of embryos and oocytes. Interviews with women with breast cancer were conducted at a meeting room in the general hospital or Keio University or a rental meeting room in Tokyo or Kanagawa.

Participants

Purposive sampling was used from a list of women who were diagnosed with breast cancer and received fertility preservation counseling at a reproductive health clinic of the general hospital between January 2010 and December 2014. Inclusion criteria were as follows: newly diagnosed with breast cancer, being able to communicate in Japanese, and receiving fertility preservation counseling. We did not exclude participants based on recurrence or metastasis and cryopreservation of embryos and oocytes. Patients with strong physical discomfort or depression were excluded.

Data were collected between March and August 2016. First, the attending physician explained the study to women who met the inclusion criteria using a leaflet describing the study at a clinic visit. Those who were interested in the study were referred to the clinic clerk or nurse. Then, the second author (KY) explained the purpose, interview method (including recording and transcribing the interview), and the voluntary nature of the study in a separate room. In particular, a full explanation about protection of personal information was given. After the detailed explanation, women who agreed to participate signed a consent form and chose an interview date and venue. Of the 27 women we approached, 11 agreed to participate. Those who declined participation indicated that they were hesitant to talk about fertility issues while being recorded (3 women), busy (2), and unknown (11).

We developed a semi-structured interview guide based on the literature. The first author (HK) and second author (KY) conducted all individual interviews using the interview guide between March and August 2016. At the interview, we sought an understanding of each participant's whole process from diagnosis of breast cancer by asking the first question, "Please tell me how you dealt with cancer treatment and fertility issues after being diagnosed with breast cancer?" Then, we continued the interview using the semi-structured interview guide: (1) "What did you value when you made a decision among multiple options regarding cancer treatment and fertility issues?" (2) "Did you share your feelings or value with someone? Please tell me your experience." (3) "What is your true need or wish which you want to be supported? Did you share your value with someone?" (4) "When you were supported, did anything change?" (5) "When did you feel that you were protected? Please recall your experience." (6) "What care or support would you like to have from healthcare professionals?"

All the participants were pre-menopausal women between 2 and 6 years after breast cancer diagnosis. After collection of the second interview data, we conducted theoretical sampling in which analysis of data and further data collection occurred simultaneously [17]. After the seventh interview and analysis, HK and KY discussed about the data again, and continued theoretical sampling. After the eleventh interview, no new themes emerged from the data, and we agreed that the data had reached saturation.

Data analysis

We analyzed the data according to Grounded Theory [17] with the following process. For open coding, line-by-line coding was conducted focusing on the participants' decision-making process about fertility, and each meaning was extracted to identify properties and dimensions. After the meanings were labeled, codes were grouped to form subcategories and categories. By relating categories and subcategories, a core category was identified. For data management, we used qualitative data software QSR NVivo10®.

Regarding the trustworthiness of the study [18], credibility of the interview data was confirmed by researchers' triangulation. In the analysis process, we conducted peer debriefing, reviewed quotations, and identification of categories and a core category. The categories and quotations were translated into English after identification of themes and supporting quotations.

Ethical considerations

This study was approved by the Internal Review Board of the Faculty of Nursing and Medical Care, Keio University (No. 240), and the Internal Review Board of St. Luke's International Hospital (15-R063). We obtained written and oral informed consent from all participants.

Results

The participants were 11 Asian women with mean age of 41.2 years (SD 4.24, range, 33–46 years). There were 8 women with partners and 3 women without partners. There were 8 full-time and 2 part-time workers. All participants underwent surgery, combined with chemotherapy, radiation, and/or hormonal therapy. Four women had oocyte cryopreservation, while three had embryo cryopreservation. One woman had a biological child before cancer diagnosis. Of the 7 women with oocyte or embryo cryopreservation after cancer diagnosis, none were pregnant. The mean interview time was 63.8 min (range 40–95).

Fertility decision-making under certainty and uncertainty

The present study revealed that "Fertility Decision-Making under Certainty and Uncertainty" as a core category. Fertility decision-making started with the participants' "values and preferences" about having a child. To make a decision, there were certainty ("Information" and "Emotional support") and uncertainty ("Time constraints," "Recurrent risk," "Labeling," and "Unmet needs") factors. The participants had more uncertainty factors than certainty factors, and health professional services accounted for the uncertainty factor (Fig. 1).

Personal values/preferences

Fertility decisions began with whether cancer patients wanted to have a child or not. Participants who wanted to have a child made a decision to undergo fertility treatment.

"Yes, probably having a child has been the first priority in my life (Participant B)."

The desire to become a mother was not lost even after development of cancer.

"There is a road to become a mother. Having been a cancer patient is not the same path to become a mother. The road to become a mother is lateral to it (cancer path) (Participant D)."

"If I am able to have a family, I want to raise a loving family (Participant J)."

"I have a strong desire to be a mother. It has been a supportive driving force. To be a mother has been my supportive driving force for treatment (Participant D)."

Certainty

There are two categories in certainty, "Information" and "Emotional support."