



Original article

Childbearing across borders: Fertility and parenthood attitudes and decisions among breast cancer survivors in USA and Portugal



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ABSTRACT

Objective: To compare fertility and childbearing attitudes and decisions of Portuguese and American female reproductive aged breast cancer survivors.

Methods: This was a cross-sectional study of 102 young breast cancer survivors (59 from Portugal and 43 from USA). Demographic, clinical and reproductive information were collected. Fertility and parenthood attitudes and decisions were assessed through a self-report questionnaire devised specifically for the study.

Results: Fertility issues became very important after the diagnosis for most of the women (51%). Few differences existed between USA and Portuguese participants. USA participants were more likely to undergo FP (23% USA vs Portugal 5%, $p = 0.01$). Portuguese women were more dissatisfied with their physician's explanations about fertility (Portugal: 23% vs USA: 3%; $p = 0.01$). Overall, women relied on their oncologist for fertility information (70%); only Portuguese women discussed fertility with their family medicine physician (11%). Overall, women showed positive attitudes towards motherhood. Portuguese women were more likely to report their partners placed more value on the family after their illness (Portuguese agree: 55% vs USA agree: 14%; $p < 0.001$).

Conclusions: Fertility and childbearing after breast cancer are important issues regardless of culture, background or country's health care system. Overall, few differences across the USA and Portuguese samples were found on fertility and childbearing attitudes and decisions.

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1. Introduction

Breast cancer is the most common malignancy in reproductive aged women [1]. Aggressive treatment regimens [2,3] are often recommended, which have the potential to impair fertility

permanently or temporarily [4]. At diagnosis, many women have not yet started or completed their families [5] and still hope to have children in the future. Therefore, issues regarding fertility and pregnancy are paramount for women's quality of life (QOL) [6,7]. Advances in assisted reproductive technologies (ART) brought new hope for women who want to preserve their fertility. The decision to pursue fertility preservation (FP) is often complex for both patients and clinicians. Considering women's fertility needs and promoting a shared decision-making process may result in improvements in women's psychological outcomes [5].

Although fertility issues in breast cancer have attracted recent attention, there is still a paucity of data on women's attitudes and decisions about childbearing after treatment [8]. Further

Abbreviations: ART, Assisted reproductive technologies; FP, Fertility Preservation; QOL, Quality of Life.

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understanding of those attitudes and decisions is imperative to health communication. There is need to acknowledge the impact reproductive concerns may have on women's life and decision-making. Although, some suggest these issues are secondary in light of a life-threatening illness, research suggests fertility discussions are important for adjustment [9,10]. Current advances in ART offer survivors new options for FP. Understanding women's attitudes is essential to devise better decision making/educational tools, improve patient-provider communication, and provide support [8]. There is also need to overcome methodological limitations of previous research. Further, there is a paucity of data on culturally and linguistically diverse samples [5] and a need to examine attitudes across differing cultural values related to childbearing and varying degrees of access to fertility counseling in the context of cancer and FP techniques.

This study compared fertility and childbearing attitudes and decisions of young survivors in Portugal and USA. We examined the influence of demographic, reproductive and clinical variables on their fertility attitudes. The relationship between fertility and parenthood attitudes after diagnosis was also examined. Finally, we examined differences between these two groups on the extent health care professionals provided fertility information.

2. Methods

2.1. Study design and participants

This study employed a cross-sectional design. Portuguese women were recruited through the Gynecology Department of Santa Maria Hospital in Lisbon and Health Centers belonging to ACES Médio Tejo and ACES Baixo Mondego. Women were also recruited online through a web link containing information about the study. USA women were recruited from the Moffitt Cancer Center breast clinic. Ethical approval was obtained from the Institutional Review Boards at Moffitt and the Ethics Committees and Direction Boards in Portugal. Recruitment occurred between December 2012 and June 2015.

Eligible participants were breast cancer survivors who: underwent adjuvant therapy (chemotherapy, radiotherapy, hormonal therapy); were diagnosed at least 2 years before the study; were 18–40 years at recruitment; were not undergoing cancer treatment (except endocrine therapy); did not have other cancer diagnosis (except non-melanoma skin cancer); were able to write and read Portuguese language (Portuguese sample), English or Spanish language (USA sample). Written consent was obtained from all participants recruited through Health Institutions. Women recruited online consented to participate in the study by agreeing to respond to the questionnaires.

2.2. Procedure

2.2.1. Portuguese sample

2.2.1.1. Health institutions recruitment. Potential participants were screened via medical databases or when attending medical consultations and then approached by a medical team member to gauge interest. Interested women were then contacted by a research team member, who invited them to participate. Those who agreed were mailed a study description, a consent form, self-report questionnaires and a pre-stamped envelope with which to return the signed consent and questionnaires. Participants who did not return the questionnaires within two weeks were contacted again to prompt the return of the questionnaires.

2.2.1.2. Online recruitment. The study web link was disseminated by several Portuguese national breast cancer associations through

their webpage, social media web sites (e.g. Facebook) and mailing lists. The web link was directed at Portuguese women, and contained information about the study, study eligibility criteria, anonymity and confidentiality and the questionnaires. It was clearly stated on the website, before women had access to questionnaires, that by completing the subsequent questionnaires they were consenting to participate.

2.2.2. USA sample

Potential participants were identified via Moffitt Cancer Center cancer registry. Eligible participants were mailed a letter inviting study participation and a telephone number and email address to decline further contact. After two weeks, patients who did not opt out were mailed the questionnaires with a consent form (which included HIPAA Authorization information) and a pre-paid envelope to return the signed consent and questionnaires. Participants who did not return the packet within 2 weeks received a second mailing. If no response was received within 4 weeks, a third mailing was sent. Participants were also approached at an upcoming clinic appointment. These women were given the option of signing the consent and completing the questionnaires in clinic or by mail.

2.3. Measures

2.3.1. Demographic and clinical information

Age, marital status, education and employment status were collected via a standardized form. Race and ethnicity data were not collected in Portugal; therefore, data for the US sample were not reported. Participants self-reported their histological diagnosis, stage of disease and treatment type received. This information was verified in the USA sample through patient's medical records. A subjective rating of physical health was obtained by asking respondents to rate their physical health on a 10-point scale (0 = extremely ill to 10 = healthy, very well) [adapted [11]]. Current and past mental health problems, current and past psychological treatment were also assessed (as present or absent).

2.3.2. Reproductive information

Data on parity (i.e., the number of children/pregnancies) at the time of the study and before the diagnosis were collected. Women were asked if, at diagnosis, they already had their desired number of children.

2.3.3. Fertility and parenthood attitudes and decisions

A self-report questionnaire was specifically designed for this study. It comprised items on fertility attitudes and decisions and health care professionals' fertility-related information provision, with responses in a "yes" or "no" format. In addition, it contained 18 attitudinal statements about parenthood after cancer, answered using a 5-point scale, ranging from "disagree" to "agree". The selection of questions and statements was guided by the existing literature [12,13] and investigators' clinical experience. A small pilot study was conducted with young Portuguese breast cancer survivors to confirm the suitability of this questionnaire for this population. Afterwards, through an extensive process of translation and back-translation, as well as expert panel review, which included bilingual and bi-cultural members, English and Spanish versions were developed. These versions were then tested for content, clarity and acceptability.

2.4. Analysis

Descriptive summary statistics (percentages or means and standard deviations as appropriate) are presented for demographic, clinical and reproductive characteristics, and fertility and

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