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A longitudinal prospective study to develop and validate a reproductive health-related educational and decision aid for young women with breast cancer.

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This presentation intends to describe a study protocol for the development and validation of a fertility-related decision aid for young women with breast cancer.

Introduction

Fertility is a vital issue for young breast cancer patients, regardless of culture, background or country's health system, as demonstrated by our pioneer work with Portuguese and USA patients. However, some survivors reported lack of fertility-related information provision or dissatisfaction with the information provided by health care professionals. Lack of information can negatively influence decision-making and increase decisional conflict, which can be associated with emotional distress and future decisions' regret. Educational materials, decision aids (DA), assist with decision-making. Based on the DA validated by Peate et al (2011), we aim to transcreate and validate a fertility DA for young Portuguese breast cancer patients.

Methods

At stage I, a process of forward translation, followed by an appraisal of the most recent literature and clinical guidelines on fertility for cancer patients, combined with a panel of Portuguese experts will revise the scientific and cultural aspects of the DA content for a Portuguese context. After employing a process of back-translation, the adequacy of DA's content for a Portuguese audience, is assessed using Learning Verification (LV) in a qualitative cross sectional study, using focus groups. Results from the DA acceptability assessment will inform the final version of the DA. Data will be analyzed using content analysis and constant comparison method to identify key themes/textual units related to LV.

At stage II, a randomized control trial (RCT) will compare DA with standard materials. Patients will be assessed at baseline, one month after and 12 months follow-up by self-reported questionnaires. We will compare measures of cancer fertility knowledge, decisional regret and conflict, psychological distress and QOL.

Results and conclusions:

To our knowledge, this is the first study in Portugal to develop and validate a DA designed for young breast cancer patients. We anticipate that it will reduce decisional conflict and increase fertility knowledge. Our project will contribute greatly to improve clinical practice, patient provider communication and knowledge in Oncofertility.

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