Reviewer's report

Title: Using a state cancer registry to recruit young breast cancer survivors and high-risk relatives: a protocol of a randomized trial testing the efficacy of a targeted versus a tailored intervention to increase breast cancer screening

Version: 2 Date: 9 November 2012

Reviewer: edmundo mauad

Reviewer's report:

Paper: Using a state cancer registry to recruit young breast cancer survivors and high-risk relatives: a protocol of a randomized trial testing the efficacy of a targeted intervention versus tailored to the power increase breast cancer screening

The authors present the design of a randomized clinical trial (no blinding) to evaluate the efficacy of two education strategies for breast cancer screening. The database of a Cancer Registry will be used to identify young women (<45 years) breast cancer survivors (YBCS). Educational strategies to be evaluated were named by the authors as "Target intervention" (less complete) and "Enhanced Tailored intervention" (more complete), both based on written information materials. Besides efficiency, the authors also wish to evaluate: 1) The status of trace YBCS and their families, 2) The barriers / the facilitators for the screening of breast cancer, 3) Acceptance of YBCS and their families to participate in a program to increase breast cancer screening; 4) Acceptance of YBCS to be spokesman of the program for their families. Several data collection instruments will be used to collect data before and after the intervention (9 months). Randomization will occur per family unit.

The paper is very interesting, will bring a breakthrough in understanding how women supposedly with high-risk cancer can live with that risk and what they do in terms of prevention, to reduce their risk and their families regarding the development of new cancers.

1 - In our institution's experience with genetic counseling, is noted that a patient with high risk breast cancer comes for consultation with a poor perception about the risks of the disease. In the orientation of these women with high risk cancer the understanding is not always totally absorbed by the patients and their families, due to the emotional aspects (general concerns, anxieties, etc.) social, cultural aspects etc., it takes the health professional (geneticist, nurses) which transmit the information to suit each patient and their family in the transfer of such information.

Therefore the proposed intervention by the paper via letter, booklet and brochure not seem appropriate.

2-In the questionnaire, if it were included in the manuscript as an attachment will certainly simplify the understanding of some aspects of the study, since the lack...
of it ends up generating some questions such as: What types of questions are about family history of cancer, such as "genetic counselors" will choose which family will be included in the study, etc.?

3 - Since there will be no personal contact, but only written informational material, I really doubt whether the proposed intervention will be effective in the study. Depending on the number of individuals with low education, there may be difficulty in reading and understanding the material. According to the authors, it will only include YBCS and families capable of reading and understanding English. But how the understanding degree will be checked among women who are included in the study? The suspicion that this difficulty will occur is reinforced by the fact that the authors describe on page 9 which will conduct the study with larger samples of black women living in cities with high mortality rate due to breast cancer.

4 - It also not clear, the reason why the methodology will be done larger samples in this group of women "underserved". Is there any specific reason? This subgroup has less risk perception?

5 - It is also not possible to infer the amount of questions to be answered in the questionnaires before and after the intervention. As there are many collection tools, there may be low adherence to the test if the number of questions to be answered is high.

6 - Will be invited until two family members at high risk to participate the study? However, if the invitation is not extended to all family members at high risk (not just one or two), there is a serious risk of selection bias. The program’s effectiveness will obviously be higher among those family members who agreed to participate in the program. The lack of interest in the study by a relative may indicate, for example, the dismissal as inappropriate intervention, devoid of significance or judge to not have the ability or time to read all the material. This question cannot be neglected in the analysis of effectiveness of the intervention.

7 - Figure 2 makes you think mistakenly that the family will be randomized at high risk, when in fact, is the family unit (defined YBCS) that will be.

8 - As described on page 9 of the 3000 YBCS around 1200 would accept to participate (40% response rate). This type of recruitment by informational material written may force those who respond tends to be better educated and a group of a better economy class. I suggest doing a most effective strategy to increase the response rate.

In conclusion, the aim of the work is very interesting, with great social responsibility and deserves its development for a project in the medium term.

Mutations in the BRCA 1 and BRCA 2 carries predispose to power increase lifetime risk of up to 70% of breast cancers and 65% of ovarian cancer.

Besides the per-patient lifetime costs of breast cancer in USA raged from U$ 20,000 to U$ 100,000 and multiples studies confirmed that costs increased with increased stage of the disease.

Therefore I suggest the evaluation of the comments made and do not carry out the proposed intervention in the study. This intervention, in my view, should be
further studied after the responses obtained in the questions 1 and 2 and that such intervention must be performed later by health professionals trained for this purpose and that is through a personal consultation or group.

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**Statistical review:** Yes, but I do not feel adequately qualified to assess the statistics.

**Declaration of competing interests:**

I declare that I have no competing interests’ below. If your reply is yes to any, please give details below