Reviewer's report

Title: Using the Heath Belief Model to explore why women decide for or against the removal of their ovaries to reduce their risk of developing cancer

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Reviewer: Natalie Evans

Reviewer's report:

I enjoyed reading this article, the subject of which deserves more attention in the literature. The article is valuable in revealing women's experiences of decision-making in the context of high risk for ovarian cancer, particularly the lack of decision-making support and preferences for information delivery and. The use of the Health Belief Model (HBM) is appropriate.

I have quite a few comments, but they are mostly minor in nature.

General comments

1. The HBM is used quite narrowly - looking only at the decision for prophylactic surgery, rather than exploring all practices perceived by women to be preventative, including screening and lifestyle factors. This might be appropriate given the scope of the article, but it also means that attitudes and beliefs related to broader preventative strategies that might influence a surgery decision are neglected.

2. There is a lack of transparency about the composition of the sample of 18 women. For example, how many pre-menopausal women are interviewed?

3. There is a lack of recognition throughout of the varying risks related the gene mutation. The age related risks and the clinical recommendations for age of surgery for BRCA1, BRCA 2, and Lynch are different. The risks and recommendations for those with no known mutation but a first degree relative are also very different.

Comments and suggestions for each section
Abstract

The authors state that participants appreciated if their doctor explained their treatment choice. This is of course, a very nice recommendation - it is also a basic requirement for informed consent.

Introduction

Pg 4 - line 30 - The authors state that most research is from outside of Australia - please see the work of Nina Hallowell and Bettina Meiser.


Bettina Meiser - https://research.unsw.edu.au/people/professor-bettina-meiser

Methods

Pg 5 line 60 - typo BRCA gene is called 'BCRA' gene throughout.

The method of recruitment - with participants being invited by clinicians with access to patient records - is great. Nice to see an attempt to sample all women with a prophylactic oophorectomy indication.

Small point about anonymity - were only voice recordings made, or also recording of the video conferences? Were voice/video recordings - which are identifiable - destroyed after transcription?

Pg 10 Line 53 - reference needed.
Results

Participant characteristics table

What is the age range? How many premenopausal women were interviewed? The consequences of oophorectomy are very different for this group. Number of people per age category e.g. 30-39, 40-49 etc, would be informative.

The majority, 67% had no identified mutation. Had these women been tested? These women may not have a high risk. Their health beliefs and decision-making might be very different to those of women with an identified high risk mutation.

What about other surgeries? Did any participants have previous cancer diagnoses themselves? Prophylactic mastectomies? This is all useful to know.

HBM domains

For the quotes - I'd like to see a participant number and perhaps risk indication.
E.g. Participant 1, 34, BRCA2 carrier, oophorectomy

This would let me know when quotes are from the same participant and give me more context.

Perceived severity
None of the quotes about the perceived severity of ovarian cancer seem to come from those who didn't opt for oophorectomy.

Some quotes need more explanation. E.g. end page 12 - Quote from 34 year old - "it's not really realistic"? Was this followed up? What isn't realistic? The perception of the risk?
Perceived susceptibility

The authors state that not all BRCA women opted for surgery - but not all BRCA women are recommended to have oophorectomies. What are the guidelines for BRCA2 women in Australia? In the Netherlands, for example, oophorectomy is recommended for BRCA2 women 40-45. There are no BRCA1 women in the sample so recommendations for them are not relevant here. When the risks are different and the clinical recommendations are different you cannot lump these groups together.

Did you ask people what they thought their risk was? Was it in line with the current evidence? Where did they get their risk information from? Did the older women who had oophorectomies go to the doctors themselves or was it suggested by a HCP?

There appear to only be quotes from older women with low risk in the perceived susceptibility section.

Perceived benefits

The first quote is not reflective of the text:

But if I was living in fear and I was worried every day of my life that I may get cancer again then I probably would have had surgery. (patient, 60 years)

There appear to be a lot of quotes from a 34 year old patient. Is this the same participant? Participant numbers would be useful.

Perceived barriers

Small point, the use of the word 'cost' in the following sentence is poorly chosen as it can be confused with economic cost. "Women identified a number of barriers which they felt increased the cost of having the surgery".

Another quote in need of further explanation:

The risk factors of osteoporosis and that sort of thing that was relevant to me. I thought, oh, well maybe it's better if there's something else that we can do, as opposed to then needing to take
hormone replacement and all that sort of stuff, which puts you at higher risk of breast cancer once again anyway. (patient, 34 years) I don't understand this - what does the participant mean by 'if there's something else that we can do'.

The authors state that "Many" younger women were advised by their treating doctor to have their children first and then undergo the surgery. But I still don't know how many women in childbearing years are in the sample - if there is only one 34 year old - then there might just be one!

The authors state that "A number of women reported that they had not been offered a choice of whether to have the surgery. They felt a lack of control over the decision-making process and wished that their doctor had explained the reason for this lack of choice more in detail." However, doctors may not have discussed options not recommended for younger women. Indeed I think women should be made aware of recommended actions for the future, but that doesn't necessarily mean 30 year olds BRCA2 women should be offered oophorectomies - because an offer of a treatment in a health care setting sometimes implies a recommendation. Again, it should be linked to existing guidance for BRCA2/Lynch Syndrome women in Australia.

Perceived self-efficacy

Pg 18 - line 26 - first mention of screening (presumably vaginal ultrasound, as it is described as invasive). Some women however may also get CA125 marker screening - some high risk women access this privately even if it is not recommended by their health care professional. Without knowing other preventative practices, it is difficult to fully understand women's 'health beliefs' and weakens the argumentation for the use of the HBM.

Modifying factors and cues for action

The authors state that women in their 30s based their decision for surgery based on ovarian cancer anxiety. But what about their perceptions of a subsequent decrease in breast cancer risk - did this influence any of the younger women's decision-making?
The decision-making process

The time women took to make the decisions was said to differ considerably, and that this was to do with personal factors. But did it also have to do with risk factors? High risk women with a high age related risk might feel a greater urgency to take preventative measures.

Discussion

The comparison most frequently made with the published literature throughout is with a 2009 syst review of decision making in hereditary cancer. There is a lack of comparison with more recent literature. See Dean, Hesse-Biber, Hallowell etc.

The authors state that previous qualitative literature lacks a guiding theoretical framework, however Dean (2017) used the Theory of Motivated Information Management whereas Hallowell (2006) drew on sociological theories of risk. Given the rationale for the study - to explore decision-making in a theoretically guided manner - what does using the HBM add? Do the results differ greatly to those of other studies using other theoretical frameworks?

The introduction also gives a rational for the qualitative approach to "enhance our understanding of existing quantitative data on patients' views and experiences" - but the authors do not do this in the discussion. Comparison with related survey studies is appropriate - see Hesse-Biber and An (2016) and Claes et al (2005), which uses the HBM.

The authors highlight the influence of familial and online experiences. The importance of these in decision-making needs further exploration.

Implications for clinical practice

The authors state that "Women appreciated being provided with a choice of whether to have an oophorectomy. Although some clinicians may perceive that having their ovaries surgically removed is not an option for younger patients who still wish to have children, women in our study indicated that they would still like to receive comprehensive information on the potential risks and benefits of the surgery, as well as details on why their doctor thinks they were not eligible for this procedure." Women need information about interventions indicated by age
related risk, and they need an overview of this as soon as they are identified as being at high risk of ovarian cancer, whatever their age.

The authors also state that "Many women reported a lack of information on the risks and benefits of having an oophorectomy. A documentation of what had been discussed during the consultation could help women recall and use the information provided to them." This very generously assumes that all risks and benefits have indeed been communicated during the consultation, and it is only women's recall or physicians "communication style" that is problematic. I fear this is not the case.

The lack of use of existing decision-support is a very interesting finding and deserves more emphasis.

References

Dean, M., et al. (2017). "'When information is not enough': A model for understanding BRCA-positive previvors' information needs regarding hereditary breast and ovarian cancer risk." Patient education and counseling 100(9): 1738-1743.


Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

Yes

Does the work include the necessary controls?
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