Reviewer’s report

Title: Decisions about prophylactic gynecologic surgery: A qualitative study of the experience of female Lynch Syndrome mutation carriers

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Reviewer: Eli Marie Grindedal

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The study addresses an important question; what factors underlie the choices of prophylactic surgery for women with LS. They find that there are several factors influencing their decisions such as age and parity, cancer worry and personal and social knowledge of gynecologic cancer. They conclude that the findings raise questions as to whether the women are fully informed about life after surgery. The described aim of the study is interesting and that the women may not be adequately informed about life after surgery is relevant and important knowledge for health care providers (geneticists, genetic counselors, gynecologists and general practitioners) who are in contact with women with LS.

Major Compulsory Revisions

1: Aim and conclusion of the study

To my understanding, the aim of the study is both to study the factors that underly the women’s surgical decisions, and their information needs. However, I think if these two aims were written more specifically both in the text and in the abstract it would be easier for the reader to follow.

I would also like to make this point about the conclusion. In the abstract, the conclusion is that the study findings raise questions about the extent to which women are fully informed about life after prophylactic surgery. In the manuscript the authors write that the study reveals motivations behind the prophylactic surgical decisions and the women’s information needs. It would be easier for the reader if these two conclusions were more similar. It could also be more clearly pointed out in the conclusion what they need information about so that they can make an informed decision about surgery.

If the aim and the conclusion is written more similarly and precise it will be easier to follow how the conclusion is linked to the aim.

Based on their findings, the author’s suggest that the women may not be fully informed about life after surgery. Maybe they could discuss more closely the consequences of not being fully informed? Would they have chosen differently if information had been better?
2: Results

The authors have previously written that 14 women were contacted by telephone but only 10 were included in the study. If the consents allow for it, it would be relevant for the reader to have more information about those who were not interviewed. Had they gone through surgery? Were they younger than the ones included? It could be discussed how the exclusion of these four may have influenced the results?

3: Discussion.

In the first paragraph, the authors discuss the uptake of prophylactic surgery in their sample and compare their findings with other studies. This comparison cannot be made in this study. Uptake is not the aim of this study and they have not presented an estimate of uptake in their series. If they were to study uptake of gynecologic prophylactic surgery among LS women they need a larger sample and a different method of selecting their material, i.e. selecting all women who tested positive for a MMR mutation at a genetics clinic. Selecting among women who attend a gynecologic oncologic clinic may bias the findings.

Minor Essential Revisions

1: Background, first paragraph This paragraph may be rewritten to be more coherent. The author’s first write that there is a high risk of colorectal cancer and an increased risk of endometrial cancer. I understand this as referring to the endometrial cancer risk as lower than the colorectal cancer risk. However, they then write that the risk of gynecological cancer is dramatically elevated. If the risk of endometrial/gynecological cancer is described twice in the paragraph the grading of the risk should be similar.

2: The first sentence in the second paragraph could also be rephrased. It is unclear to me whether they mean that the effect of gynecological screening is not studied or that the surveillance recommendations have not been well studied. If they mean the former, there are several relevant studies on the effect of screening for endometrial cancer in LS women. If they mean the latter I do not think that this can be compared with the fact that adherence to colonoscopy screening reduces survival.

3: In the sentence "removal of non-cancerous ovaries" "non-cancerous" may be removed.

4: Tumor maker should be tumor marker

5: When discussing effectiveness of screening for ovarian cancer it is relevant to clarify whether the authors refer to sporadic or LS related cancers and also whether they refer to endometrial or ovarian cancer. The study the authors refer to with reference number 8 only addresses sporadic ovarian cancer and may not be relevant when discussing LS ovarian cancers, as we know that they have a different distribution of both histology and staging and have a more favourable
prognosis compared to sporadic ovarian cancer. Also, some adjustments should be made in terms of references. The paper with reference number 8 does not address effectiveness of screening for endometrial cancer. Some studies have been performed addressing the effectiveness of screening for endometrial cancer in LS patients. It would be more relevant to refer to these. The study that the authors refer to with reference number 9 is not a study but an editorial to Schmeler and colleagues study (reference number 10), and as I read it it does not address the question of effectiveness of gynecological screening.

6: The authors refer to both the original and the revised Mallorca guidelines (reference number 7 and 13) in paragraph number 3 when writing that prophylactic hysterectomy with RRSO is recommended in LS women. However in the preceding paragraph they have used the original guidelines as a reference when writing that routine screening has been recommended. This seems a bit confusing. It should be clear in the text when and why refer to the original and the revised criteria. Also, the study with reference number 12 does not address recommendations for screening and it may not be correct to use this study as a reference here.

7: The two sentences in this paragraph are to a large extent overlapping and should be rewritten.

8: In the next three paragraphs when discussing HRT use in women with BRCA-mutation and women with LS it could be relevant to mention that the risks associated with such use (for example increased risk of breast cancer and endometrial cancer) are lower for LS women than for BRCA-women.

9: Paragraphs number five and six seem to be somewhat contradictory. In paragraph number five the authors state that LS women have a low awareness and understanding of their cancer risk. However in paragraph number six they refer to studies demonstrating that they are compliant with guidelines. Also, the study that demonstrate that LS women have a low awareness of extra-colonic cancers and decreased use of endometrial screening before genetic counseling (reference number 18) may not be adequate to suggest that they do not understand the complexity of the diagnosis post-genetic counseling. Also, the study involving women at risk for familial ovarian cancer does not clarify whether any of these women have LS (reference number 17), and it is difficult to consider whether this is a relevant reference for LS women. This should be specified in the manuscript if the reference is used.

10: In paragraph number six the authors use the term "providers". It should be specified whether this refers to the patient’s GP, gynecologist, geneticist, genetic counselor etc.

11: In methods, the authors use the term "purposeful sampling" and then "purposively sampled". Do they mean the same?

12: Methods, third paragraph: "breath" should be "breadth".
13: Results. One of the women had only a laparoscopic right oophorectomy performed. It should be presented whether the uterus and left ovary had been removed earlier. If it had not been performed earlier this should also be clarified and explained why she is included in the study when she has only removed the right ovary.

14: In the last paragraph of the results section the authors describe that some of the women were unaware of the possibility of HRT, and this is an important finding. However, two of the women that they refer to (Madonna and Laura) as having had no information about this were 56 and 61 years of age at time of surgery. It is therefore relevant to discuss whether their age (and others included in the study?) could explain this absence of information.

15: Discussion, first paragraph: The study with reference number 12 does not address the question of effectiveness of gynecologic screening

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I have no competing interests.