

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Women's interpretation of and responses to potential gynaecological cancer symptoms: a qualitative interview study
<b>AUTHORS</b>	Low, Emma; Whitaker, Katriina; Simon, Alice; Sekhon, Mandy; Waller, Jo

### VERSION 1 - REVIEW

<b>REVIEWER</b>	Julie Evans University of Oxford, United Kingdom
<b>REVIEW RETURNED</b>	18-Mar-2015

<b>GENERAL COMMENTS</b>	<p>This paper reports a qualitative interview study that explores women's responses to recent symptoms that might indicate gynaecological cancer, but without imposing a cancer perspective. This study appears to follow on from a larger study conducted by the same team (reference 13) that sought to quantify the prevalence and severity of such symptoms in the population, but in neither the published paper or the current manuscript have the authors discussed the rationale for further research on this topic using a qualitative approach.</p> <p>On first reading I was unclear as to the aims of this study and specifically why the authors felt it was important to explore appraisal of potential cancer symptoms outside the cancer context. I think that the introduction section could explain this more succinctly, as could the objective in the abstract.</p> <p>I was unsure when reading the results section of the abstract whether cancer was dismissed as a possible cause by a medical professional or by the women themselves. It is clear in the paper itself that it is the latter, but this could be worded more clearly in the abstract.</p> <p>I wanted to know much more about participant selection and recruitment than was detailed in the methods section. What were the non-medical settings that women were recruited through? What was the content of the online and paper-based screening questionnaire? What did the information sheet say about the purpose of the study, given that the team sought to avoid a cancer context? How were the 26 eligible women selected for interview?</p> <p>Although the study was approved by an ethics committee, I would have liked to see some mention and discussion in the paper of the ethical issues associated with inviting women to take part in a study about cancer symptoms but without raising the topic of cancer with them, and how the research team should respond when they hear accounts of symptoms that are very likely to indicate a cancer</p>
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	<p>diagnosis from women who have not sought medical advice.</p> <p>To use the Model of Pathways to Treatment as a theoretical framework for this study was appropriate. I read the thematic analysis with interest; it was well presented and quotes were chosen appropriately.</p> <p>At the start of the discussion section the authors state that theirs is the first qualitative study to explore how British women appraise and respond to changes in their bodies that may indicate gynaecological cancer. This is not true, although it may be the first to do it outside the cancer context. I have listed three additional references below; there may well be others.</p> <p>In the 2nd paragraph of the discussion the authors talk about the importance of close family members and social networks in prompting people to seek medical help for symptoms as if it is a new concept, whereas it has been recognised for a very long time e.g. the work of Zola in the 1970s.</p> <p>In paragraphs 2 and 3 of the discussion the authors refer to 'clinical samples'. I was not totally sure what was meant by this. If they mean studies of people with a cancer diagnosis then it might be helpful to state this.</p> <p>Lastly, a very minor point: I was surprised to see in the methods section that interview transcripts were only checked against portions of each digital recording for accuracy rather than against the whole recording. Transcription and typographical errors can occur anywhere in a transcript and can sometimes change the meaning of what was said. It is normal in my research group, and important, I feel, to check the whole transcript against the whole recording.</p> <p>Additional references</p> <p>Julie Evans, Sue Ziebland, Ann McPherson. Minimising delays in ovarian cancer diagnosis: an expansion of Andersen's model of 'total patient delay'. Family Practice. 2007; 24: 48-55.</p> <p>CR Bankhead*, C Collins, H Stokes-Lampard, P Rose, S Wilson, A Clements, D Mant, ST Kehoe, J Austoker. Identifying symptoms of ovarian cancer: a qualitative and quantitative study. BJOG: An International Journal of Obstetrics &amp; Gynaecology Volume 115, Issue 8, pages 1008–1014, July 2008</p> <p>A. MOLASSIOTIS, B. WILSON, L. BRUNTON, C. CHANDLER. Mapping patients' experiences from initial change in health to cancer diagnosis: a qualitative exploration of patient and system factors mediating this process. European Journal of Cancer Care Volume 19, Issue 1, pages 98–109, January 2010</p>
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<b>REVIEWER</b>	Maggie Hendry Bangor University, UK
<b>REVIEW RETURNED</b>	15-May-2015

<b>GENERAL COMMENTS</b>	<p>An excellent paper from an experienced team; I enjoyed reading it.</p> <p>I agree it's really tricky to know how to inform women about</p>
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	<p>symptoms that are likely trivial but potentially very serious, indeed it's hard to gauge what the appropriate help-seeking behaviour would be. What I find quite concerning is the under-reporting of these unpleasant and uncomfortable symptoms because they are accepted as a "normal" part of being female or getting older, because in many cases they are likely to be treatable.</p> <p>If I were to be picky, my personal preference would be to have symptoms in question described/listed right up front in the introductory section.</p> <p>There is a typo on page 14, where I think "you GP" should probably read "your GP".</p>
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<b>REVIEWER</b>	Kate Brain Cardiff University School of Medicine Cardiff UK
<b>REVIEW RETURNED</b>	22-May-2015

<b>GENERAL COMMENTS</b>	<p>I enjoyed reading this well written and thoughtfully designed qualitative study, which makes an important contribution to our understanding of how women interpret and respond to gynaecological symptoms. A novel aspect of the study was the use of a screening questionnaire in non-clinical settings to gauge whether symptoms had been experienced during the previous three months. The study is clearly underpinned by the Model of Pathways to Treatment (MPT), which provided a framework for interpreting the interview data.</p> <p><b>Abstract:</b> The conclusions are a bit repetitive of results. What were the broader implications of findings for research and practice?</p> <p><b>Introduction:</b> In the opening description of the problem context, it could also be relevant to say that routes to early diagnosis of gynaecological cancers are currently limited, with screening only routinely available for cervical but not other forms of gynaecological cancer.</p> <p><b>Methods:</b> Please confirm that ethical approval for the study was obtained. What did the consent process involve? Were participants offered further information or a helpline number in the event of any concerns or distress raised by the subject matter?</p> <p>Please include some examples of non-medical settings that were used to identify and recruit participants.</p> <p>Why were interviews carried out on UCL premises, rather than in women's own homes? Might this have been off-putting for some people, hence the under-representation of certain demographic groups?</p> <p><b>Results:</b> Please clarify whether two or three main themes were identified – the text reports three, whereas Box 1 only shows two main themes.</p>
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	<p>In your reference to Table 1, please add some narrative regarding demographic characteristics of the sample.</p> <p>Discussion: The findings relating to women’s normalisation and downplaying of gynaecological symptoms put the meat on the bones of the MPT. The authors may wish to comment on the usefulness of the MPT – a fairly broad and descriptive model of patient appraisal and help seeking intervals.</p> <p>It may also be interesting to discuss gender roles/differences in responses to symptoms, with women perhaps more likely than men to minimise symptoms in the face of competing demands and expected caregiving roles. This suggestion is at the authors’ discretion.</p> <p>Strengths and weaknesses The authors acknowledge that the study sample was primarily white and affluent, which may limit generalisability of findings. I don’t think it’s quite accurate to infer on the basis of one qualitative study (reference 24) that socioeconomic group is not associated with differences in help seeking, when a larger body of evidence suggests that it is.</p> <p>It may also be important to acknowledge that study participants in fact correctly attributed somatic changes to benign conditions (although not feasible to verify/validate self-reported symptoms).</p> <p>Conclusion The final statement could be strengthened by including a sentence about broader research/practice implications.</p>
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### VERSION 1 – AUTHOR RESPONSE

Thank you to all 3 reviewers for their careful reading of the paper and their insightful comments. We have responded to them all below, and hope that the manuscript is now stronger as a result.

Reviewer 1 Name Julie Evans

Institution and Country University of Oxford, United Kingdom

Please state any competing interests or state ‘None declared’: None declared

Please leave your comments for the authors below

This paper reports a qualitative interview study that explores women’s responses to recent symptoms that might indicate gynaecological cancer, but without imposing a cancer perspective. This study appears to follow on from a larger study conducted by the same team (reference 13) that sought to quantify the prevalence and severity of such symptoms in the population, but in neither the published paper nor the current manuscript have the authors discussed the rationale for further research on this topic using a qualitative approach.

1. On first reading I was unclear as to the aims of this study and specifically why the authors felt it was important to explore appraisal of potential cancer symptoms outside the cancer context. I think that the introduction section could explain this more succinctly, as could the objective in the abstract.

Response 1. We have edited the objective in the abstract (p2) and added some further justification/references into the introduction to clarify the importance of this study.

2. I was unsure when reading the results section of the abstract whether cancer was dismissed as a possible cause by a medical professional or by the women themselves. It is clear in the paper itself

that it is the latter, but this could be worded more clearly in the abstract.

Response 2. It was the women themselves and we have edited the abstract to clarify this (p2).

3. I wanted to know much more about participant selection and recruitment than was detailed in the methods section. What were the non-medical settings that women were recruited through? What was the content of the online and paper-based screening questionnaire? What did the information sheet say about the purpose of the study, given that the team sought to avoid a cancer context? How were the 26 eligible women selected for interview?

Response 3. We have included additional detail about participant recruitment, including examples of non-medical settings. We have also clarified that in fact it was only an online questionnaire but some people were recruited through posters rather than online. The study was presented as a study about women's health in general and we have added this information to the methods section. Although a total of 70 women completed questionnaires and were eligible, we only interviewed 26, as the vast majority were of a higher socioeconomic status and were educated to a mid- or high-level. We have clarified this in the results section, and have also clarified that an additional 53 women responded to the questionnaire, but either did not complete it or were ineligible.

4. Although the study was approved by an ethics committee, I would have liked to see some mention and discussion in the paper of the ethical issues associated with inviting women to take part in a study about cancer symptoms but without raising the topic of cancer with them, and how the research team should respond when they hear accounts of symptoms that are very likely to indicate a cancer diagnosis from women who have not sought medical advice.

Response 4. We have added a sentence to demonstrate that women were encouraged to seek help for persistent symptoms. For the vast majority of women, symptoms would not have indicated cancer and we have added a sentence to the discussion to highlight this point.

5. To use the Model of Pathways to Treatment as a theoretical framework for this study was appropriate. I read the thematic analysis with interest; it was well presented and quotes were chosen appropriately.

Response 5. We are pleased the reviewer considered the framework helpful.

6. At the start of the discussion section the authors state that theirs is the first qualitative study to explore how British women appraise and respond to changes in their bodies that may indicate gynaecological cancer. This is not true, although it may be the first to do it outside the cancer context. I have listed three additional references below; there may well be others.

Response 6. We have edited this sentence to clarify that we meant the first study outside the cancer context. We have also included the additional references where symptom appraisal was explored in women with gynaecological cancers (Evans et al, 2007; Bankhead et al 2008).

7. In the 2nd paragraph of the discussion the authors talk about the importance of close family members and social networks in prompting people to seek medical help for symptoms as if it is a new concept, whereas it has been recognised for a very long time e.g. the work of Zola in the 1970s.

Response 7. We agree with the reviewer and have referred to Zola's work in our discussion of the importance of social networks to reflect this point.

8. In paragraphs 2 and 3 of the discussion the authors refer to 'clinical samples'. I was not totally sure what was meant by this. If they mean studies of people with a cancer diagnosis then it might be helpful to state this.

Response 8. We have edited reference to 'clinical samples' and made it explicit that we mean studies of people with a cancer diagnosis.

9. Lastly, a very minor point: I was surprised to see in the methods section that interview transcripts

were only checked against portions of each digital recording for accuracy rather than against the whole recording. Transcription and typographical errors can occur anywhere in a transcript and can sometimes change the meaning of what was said. It is normal in my research group, and important, I feel, to check the whole transcript against the whole recording.

Response 9. We were interested to read this comment as we have often seen similar approaches taken to checking the accuracy of transcription. However, the first author (who carried out all the interviews) did in fact read and re-read all the transcripts to check the interpretation was accurate and reflected the meaning of the women's verbatim discussions and we have added a sentence to reflect this on p6.

#### Additional references

Julie Evans, Sue Ziebland, Ann McPherson. Minimising delays in ovarian cancer diagnosis: an expansion of Andersen's model of 'total patient delay'. *Family Practice*. 2007; 24: 48-55.

CR Bankhead\*, C Collins, H Stokes-Lampard, P Rose, S Wilson, A Clements, D Mant, ST Kehoe, J Austoker. Identifying symptoms of ovarian cancer: a qualitative and quantitative study. *BJOG: An International Journal of Obstetrics & Gynaecology* Volume 115, Issue 8, pages 1008–1014, July 2008

A. MOLASSIOTIS, B. WILSON, L. BRUNTON, C. CHANDLER. Mapping patients' experiences from initial change in health to cancer diagnosis: a qualitative exploration of patient and system factors mediating this process. *European Journal of Cancer Care* Volume 19, Issue 1, pages 98–109, January 2010

Reviewer 2 Name Maggie Hendry  
Institution and Country Bangor University, UK  
Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below  
An excellent paper from an experienced team; I enjoyed reading it. I agree it's really tricky to know how to inform women about symptoms that are likely trivial but potentially very serious, indeed it's hard to gauge what the appropriate help-seeking behaviour would be. What I find quite concerning is the under-reporting of these unpleasant and uncomfortable symptoms because they are accepted as a "normal" part of being female or getting older, because in many cases they are likely to be treatable.

1. If I were to be picky, my personal preference would be to have symptoms in question described/listed right up front in the introductory section.

Response 1. Perhaps BMJ Open could organise the manuscript so that this table is prominent early on?

2. There is a typo on page 14, where I think "you GP" should probably read "your GP".

Response 2. Thanks- we have corrected this typo.

Reviewer 3 Name Kate Brain  
Institution and Country Cardiff University School of Medicine Cardiff UK  
Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below

I enjoyed reading this well written and thoughtfully designed qualitative study, which makes an important contribution to our understanding of how women interpret and respond to gynaecological symptoms. A novel aspect of the study was the use of a screening questionnaire in non-clinical

settings to gauge whether symptoms had been experienced during the previous three months. The study is clearly underpinned by the Model of Pathways to Treatment (MPT), which provided a framework for interpreting the interview data.

#### Abstract:

1. The conclusions are a bit repetitive of results. What were the broader implications of findings for research and practice?

Response 1. We have edited the abstract to discuss the broader implications in terms of earlier diagnosis and survival.

#### Introduction:

2. In the opening description of the problem context, it could also be relevant to say that routes to early diagnosis of gynaecological cancers are currently limited, with screening only routinely available for cervical but not other forms of gynaecological cancer.

Response 2. We thank the reviewer for this helpful comment and have added this sentence to the introduction referring to the cervical cancer screening programme.

#### Methods:

3. Please confirm that ethical approval for the study was obtained. What did the consent process involve? Were participants offered further information or a helpline number in the event of any concerns or distress raised by the subject matter?

Response 3. Ethical approval was obtained and women were encouraged to seek medical help for persistent symptoms. We have added this to the methods.

4. Please include some examples of non-medical settings that were used to identify and recruit participants.

Response 4. We have now included examples of non-medical settings on p 5.

5. Why were interviews carried out on UCL premises, rather than in women's own homes? Might this have been off-putting for some people, hence the under-representation of certain demographic groups?

Response 5. Women were given the opportunity to participate in the interviews either at UCL or in their own homes, via telephone. We felt that these options provided an opportunity for women to discuss their potentially sensitive symptoms in a neutral location or to do so in the comfort of their own homes, over the telephone, which may have offered a feeling of privacy.

#### Results:

6. Please clarify whether two or three main themes were identified – the text reports three, whereas Box 1 only shows two main themes.

Response 6. Thanks for drawing our attention to this inconsistency – we have clarified that there were 2 main themes.

7. In your reference to Table 1, please add some narrative regarding demographic characteristics of the sample.

Response 7. We have added narrative on p 6.

#### Discussion:

8. The findings relating to women's normalisation and downplaying of gynaecological symptoms put

the meat on the bones of the MPT. The authors may wish to comment on the usefulness of the MPT – a fairly broad and descriptive model of patient appraisal and help seeking intervals.

Response 8. We have discussed the usefulness of MPT under ‘strengths’ in the discussion.

9. It may also be interesting to discuss gender roles/differences in responses to symptoms, with women perhaps more likely than men to minimise symptoms in the face of competing demands and expected caregiving roles. This suggestion is at the authors’ discretion.

Response 9. Although we feel this is a valid point, and draw on the discussion of women’s identity/roles on p17, we think it’s outside the scope of the present study to make comparisons with how men appraise symptoms (also in light of the fact that some evidence suggests men are less likely to seek help for their symptoms than women).

#### Strengths and weaknesses

10. The authors acknowledge that the study sample was primarily white and affluent, which may limit generalisability of findings. I don’t think it’s quite accurate to infer on the basis of one qualitative study (reference 24) that socioeconomic group is not associated with differences in help seeking, when a larger body of evidence suggests that it is.

Response 10. We agree with the reviewer and have edited this sentence to remove this inference.

11. It may also be important to acknowledge that study participants in fact correctly attributed somatic changes to benign conditions (although not feasible to verify/validate self-reported symptoms).

Response 11. We have added a sentence to the discussion to reflect this point.

#### Conclusion

12. The final statement could be strengthened by including a sentence about broader research/practice implications.

Response 12. We had added a final sentence to the conclusion to strengthen this paragraph.

## VERSION 2 – REVIEW

<b>REVIEWER</b>	Julie Evans University of Oxford, UK
<b>REVIEW RETURNED</b>	16-Jun-2015

<b>GENERAL COMMENTS</b>	The authors have addressed the reviewers' comments to my satisfaction.
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<b>REVIEWER</b>	Kate Brain Cardiff University School of Medicine UK
<b>REVIEW RETURNED</b>	09-Jun-2015

<b>GENERAL COMMENTS</b>	Thank you for revising the manuscript as requested. Pending one further minor revision, I am satisfied that the manuscript is acceptable for publication in BMJ Open. On p5, there is some conflation of methods and results - I would suggest that the details of participant response rate should go in results.
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