

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Public perceptions of cancer: a qualitative study of the balance of positive and negative beliefs
<b>AUTHORS</b>	Robb, Katie; Simon, Alice; Miles, Anne; Wardle, Jane

### VERSION 1 - REVIEW

<b>REVIEWER</b>	Gozde Ozakinci University of St Andrews, Scotland, UK
<b>REVIEW RETURNED</b>	18-Apr-2014

<b>GENERAL COMMENTS</b>	<p>This qualitative study explores the perceptions of cancer of individuals who have not had a personal history of cancer. I have enjoyed reading this interesting manuscript. I have a few comments and questions that I hope the authors will be able to clarify and answer:</p> <ol style="list-style-type: none"><li>1. I think the authors made a good case of showing the dual nature of cancer fears common among people and how contradictory it could be. The use of heuristics and dual system thinking are good examples of theoretical frameworks. However, I don't think it is very obvious in the manuscript that cancer fears can be related to cancer prevention efforts. I don't think there was enough reports from the participants that these fears would stand in the way of them seeking help if they face potential cancer symptoms (except end of page 6 where p34 mentions finding a lump and its associated fear). I was wondering why the authors did not draw from the 'cancer fatalism' literature and its relation to cancer screening efforts. I would welcome authors' thoughts on that and invite them to make a more convincing case for why cancer fear is relevant to cancer control and risk communication efforts.</li><li>2. I was wondering if the authors have access to occupational status of the participants. Especially if they are coming from a health care professional background or not (as one of the participant was) could have relevance to the study.</li></ol>
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<b>REVIEWER</b>	Mary Wells NMAHP RU, University of Stirling, UK
<b>REVIEW RETURNED</b>	13-May-2014

<b>GENERAL COMMENTS</b>	This is a very well written and interesting paper describing a qualitative study of public perceptions about cancer. There are surprisingly few qualitative studies in this area, and this paper contributes important insights, particularly in relation to the conflicting perceptions and fears that people hold about cancer.
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	<p>However, I have some questions about the approach taken and believe there are a number of areas in which the paper could be significantly strengthened: -</p> <ol style="list-style-type: none"> <li>1) The authors state that they used a 'qualitative methodology to explore public perceptions of cancer, focusing specifically on whether fear and hope were characteristic of different individuals, or one person could hold opposing views'. This sounds as if they had an a priori theory about the co-existence of fear and hope and set out to investigate this. Was this the case or was the existence of fear and hope something that emerged during data collection? I think this is important, as the former suggests a more structured approach and I think requires some discussion of the rationale for this theory. If this was a finding which emerged entirely from a more open discussion about perceptions, the statement above needs to be amended.</li> <li>2) There is very little detail on the community survey and how participants from this were selected. What was the community survey about? Did only 30 people say they could be contacted again? Out of how many? Were the potential participants who were sent a letter a sub-sample of these 30 or was 30 the eventual number who took part. It is hard to tell what was purposive about this sample and it seems that it was more of a convenience sample of people who self-selected. This may be a limitation and should be discussed. Also, although the age range is quite good, the sample is still relatively 'young' and this should be mentioned.</li> <li>3) I am not entirely convinced that 'hope' is the most appropriate label for the findings described. Is it definitely hope? I think it would be helpful if the authors could provide a fuller explanation of what they mean by 'hope' in this context, or alternatively consider whether the participants are describing something other than hope.</li> <li>4) A more inclusive discussion of the literature in this area is required. I would expect some reference to some of the large surveys conducted to elicit public perceptions of cancer, even if these are limited in quality e.g the livestrong global research report and the PACE cancer perception index global survey. There are also other studies in this area that have not been referred to e.g. Keeney et al 2010 (EJCC) and Cho et al 2013 (PsychoOncology)</li> <li>5) It would be helpful if the authors could include some UK/European figures in addition to US figures on page 5.</li> <li>6) The discussion section suggests that Susan Sontag's depiction of cancer has prevailed since 1978, and although I would agree that it is still very influential, a great deal of popular literature on cancer has been published since, and I think it would be helpful to give a flavour of this. I also think a more extensive discussion of media coverage of cancer is warranted. The authors mention Cancer Research UK's campaign and suggest that it could increase the perceived frequency of good outcomes and I am intrigued as to why they think this is the case. In my view the campaign is just as likely to provoke feelings of negativity and fear, and promote the associations Susan Sontag wrote about in the 1970s. I think a more balanced discussion of media and charity depictions of cancer is important here. Finally, I think there are a number of other interesting angles related to the potential of dual processing theory to help understand cancer perceptions and beliefs, not just in relation to the initial response to possible signs and symptoms but also in relation to decision making about cancer treatment and interpretation of experiences. I think these should also be mentioned.</li> </ol>
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## VERSION 1 – AUTHOR RESPONSE

Response to Dr Gozde Ozakinci:

“This qualitative study explores the perceptions of cancer of individuals who have not had a personal history of cancer. I have enjoyed reading this interesting manuscript.”

Thank you, we are glad you enjoyed the paper and found it interesting.

“I have a few comments and questions that I hope the authors will be able to clarify and answer:”

1. “I was wondering why the authors did not draw from the ‘cancer fatalism’ literature and its relation to cancer screening efforts. I would welcome authors’ thoughts on that and invite them to make a more convincing case for why cancer fear is relevant to cancer control and risk communication efforts.”

Thank you for this helpful suggestion, we have now added a brief discussion of this to paragraphs 3 and 4 of the Discussion.

2. “I was wondering if the authors have access to occupational status of the participants. Especially if they are coming from a health care professional background or not (as one of the participant was) could have relevance to the study.”

Yes, we did record occupational status and this is something we considered. However, there were only two participants from a health care professional background (retired nurses) one of whom we mention in the paper. The other occupations were quite diverse including eight people who responded ‘retired’ which makes interpretation of the impact of occupational status on perceptions more ambiguous.

Response to Professor Mary Wells:

“This is a very well written and interesting paper describing a qualitative study of public perceptions about cancer. There are surprisingly few qualitative studies in this area, and this paper contributes important insights, particularly in relation to the conflicting perceptions and fears that people hold about cancer.”

Thank you. We are glad you found the paper interesting and agree that the paper contributes important insights.

“However, I have some questions about the approach taken and believe there are a number of areas in which the paper could be significantly strengthened:”

1) “The authors state that they used a ‘qualitative methodology to explore public perceptions of cancer, focusing specifically on whether fear and hope were characteristic of different individuals, or one person could hold opposing views’. This sounds as if they had an a priori theory about the co-existence of fear and hope and set out to investigate this. Was this the case or was the existence of fear and hope something that emerged during data collection? I think this is important, as the former suggests a more structured approach and I think requires some discussion of the rationale for this theory. If this was a finding which emerged entirely from a more open discussion about perceptions, the statement above needs to be amended.”

We have now amended this statement.

2) “There is very little detail on the community survey and how participants from this were selected. What was the community survey about? Did only 30 people say they could be contacted again? Out of how many? Were the potential participants who were sent a letter a sub-sample of these 30 or was 30 the eventual number who took part. It is hard to tell what was purposive about this sample and it seems that it was more of a convenience sample of people who self-selected. This may be a limitation and should be discussed.”

We have now clarified this in the Methods, the start of the Results and noted the limitation of this approach in the Discussion.

“Also, although the age range is quite good, the sample is still relatively ‘young’ and this should be mentioned.”

We now include this point in the limitations section of the Discussion.

3) “I am not entirely convinced that ‘hope’ is the most appropriate label for the findings described. Is it definitely hope? I think it would be helpful if the authors could provide a fuller explanation of what they mean by ‘hope’ in this context, or alternatively consider whether the participants are describing something other than hope.”

On reflection, we agree and have amended our use of the word hope, including in the title.

4) “A more inclusive discussion of the literature in this area is required. I would expect some reference to some of the large surveys conducted to elicit public perceptions of cancer, even if these are limited in quality e.g the livestrong global research report and the PACE cancer perception index global survey. There are also other studies in this area that have not been referred to e.g. Keeney et al 2010 (EJCC) and Cho et al 2013 (PsychoOncology).”

Thank you for these suggestions. We have now cited the Livestrong and PACE reports and the Keeney et al. (2010) and Cho et al. (2013) papers.

5) “It would be helpful if the authors could include some UK/European figures in addition to US figures on page 5.”

We have now included UK-based figures.

6) “The discussion section suggests that Susan Sontag’s depiction of cancer has prevailed since 1978, and although I would agree that it is still very influential, a great deal of popular literature on cancer has been published since, and I think it would be helpful to give a flavour of this.”

We cited the Sontag (1978) book because we believe it was a seminal piece of work in the field and it remains influential as the Professor Wells agrees. Our purpose in mentioning it was to reflect on whether perceptions of cancer had changed in the intervening years. We agree that there has been a great deal of popular literature since then, indeed when we searched Amazon books using the word ‘cancer’ 59,548 results were returned! We now cite two more recent books from the popular literature by Mukherjee and Jain which we feel provides a bit more of a flavour of the popular literature.

“I also think a more extensive discussion of media coverage of cancer is warranted. The authors mention Cancer Research UK’s campaign and suggest that it could increase the perceived frequency of good outcomes and I am intrigued as to why they think this is the case. In my view the campaign is just as likely to provoke feelings of negativity and fear, and promote the associations Susan Sontag wrote about in the 1970s. I think a more balanced discussion of media and charity depictions of cancer is important here.”

Professor Wells makes a very good point here. We suggested that the Cancer Research UK campaign could increase the perceived frequency of good outcomes because it depicted people surviving cancer and getting on with their lives which we felt would provide concrete examples of cancer not being a death sentence. However, the campaign may also provoke feelings of negativity and fear as Professor Wells suggests. Without knowing the impact of the campaign on people’s beliefs we propose removing this comment from the Discussion. We also believe it would not be helpful to comment on charity depictions of cancer in this paper because of the ambiguity of their impact on the public and presenting a balanced description of charity campaigns we feel is beyond the scope of this paper. We have however followed Professor Well’s suggestion and included a brief account of media depictions of cancer in the Discussion.

“Finally, I think there are a number of other interesting angles related to the potential of dual processing theory to help understand cancer perceptions and beliefs, not just in relation to the initial response to possible signs and symptoms but also in relation to decision making about cancer

treatment and interpretation of experiences. I think these should also be mentioned.”  
We agree and have now included this point in the Discussion.

#### VERSION 2 – REVIEW

<b>REVIEWER</b>	Mary Wells NMAHP Research Unit, University of Stirling, UK
<b>REVIEW RETURNED</b>	18-Jun-2014

<b>GENERAL COMMENTS</b>	The revisions have more than adequately addressed previous comments. The only thing that perhaps needs clarification is how the 30 people who took part in interviews were selected from the 67 who agreed to be contacted. The re-wording of the methods section now gives the impression that 67 people were included in the study, so it then comes as a surprise that only 30 took part in interviews. This just needs some minor re-wording to make it clear that 30 were selected from the 67 (if possible with reasons for selection)
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#### VERSION 2 – AUTHOR RESPONSE

Response to Professor Mary Wells:

“The revisions have more than adequately addressed previous comments.”

Thank you. We welcome your feedback and feel your suggestions have strengthened our paper.

“The only thing that perhaps needs clarification is how the 30 people who took part in interviews were selected from the 67 who agreed to be contacted. The re-wording of the methods section now gives the impression that 67 people were included in the study, so it then comes as a surprise that only 30 took part in interviews. This just needs some minor re-wording to make it clear that 30 were selected from the 67 (if possible with reasons for selection.”

We have now included the following sentence in the Methods:

‘Of the 67 people invited, 30 agreed to be interviewed and are described in this analysis.’

So rather than us ‘selecting’ from the 67, the final sample was determined by those who agreed to participate. We have also changed the word ‘selected’ (in the first sentence of the Methods) to ‘invited’ which we hope will further clarify how the sample was obtained.