PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Views and experiences of seeking information and help for vitiligo: a qualitative study of written accounts
AUTHORS	Teasdale, Emma; Muller, Ingrid; Abdullah Sani, A; Thomas, Kim; Stuart, Beth; Santer, Miriam

VERSION 1 – REVIEW

REVIEWER	XInghua Gao The First Hospital of China Medical University, Shenyang, China
REVIEW RETURNED	23-Jul-2017

GENERAL COMMENTS	The authors made a survey on vitiligo patients, concerning mostly their experience in acquiring information and management of vitiligo conditions. 161 patients answered the open-ended questions. The results mostly are displayed as descriptive rather than analytical. I suggest statistical methods be employed to better describe the study outcomes. As noticed by the authors, most of the res ponders of the survey were over 45 year of age, and they hardly represent the general vitiligo population who are mostly young people. Thus a survey with different age group and comprehensive analysis of the representative cohort is advised.

REVIEWER	Christine Blome University Medical Center Hamburg-Eppendorf, Institute for Health Services Research in Dermatology and Nursing, Germany
REVIEW RETURNED	08-Aug-2017

GENERAL COMMENTS	This is a very interesting, clear, and relevant manuscript on an important topic: experiences and expectations of persons with vitiligo with regards to information about the disease. I would, however, recommend the following changes / additions. 1) References 1 and 2: It would be more helpful to include references to original studies or systematic reviews on vitiligo prevalence. 2) Page 5, line 30: The research question could be formulated more precisely, as the free texts did not only refer to sources of information but also to patients' information needs. 3) No information is given on informed consent and ethics.

	4) It would be helpful to have a brief overview of the survey questions that were included before the free text questions, as Q4 can be understood to refer to content that has not been covered *in the survey* already, instead of *in Q1 to Q3*. 5) Is it correct that text coding was performed by one researcher, with only code and theme definitions being discussed among the coauthors? Was this done with or without recourse to the data (free texts)? 6) Limitations of analyzing written free-text responses should be discussed. Some qualitative literature regards this as not sufficient to understand participants' perspectives in detail as no additional inquiries by the researcher are possible, so limitations of this approach as compared to interview should be described. 7) Page 12, line 24: I am not sure what is meant by "...it seems surprising where participants are members of a support group and many reported negative experiences of consulting". 8) Page 12, line 37: Which implications are meant here? I feel that the statement that the findings have implictaions does not add information without at the same time explaining which implications. The same is true for page 13, line 3 ("This paper highlights opportunities for further research...") - what kind of research? 9) Page 13, line 13-17: It seems like the interventions recommended here are not really linked to / based on the findings of the study. 10) A completed checklist for reports of qualitative research (COREQ or SRQR) would be helpful. MINOR COMMENTS: Abbreviations (e.g., "GP") should be introduced. Are there any barriers to membership of the Vitiligo Society (membership fees), which may be informative with regard to selection bias? Page 7, line 10: It could be made clearer what the 98% refer to (% of survey respondents who also responded to free text questions). Authors' contributions: Initials do not exactly match the names - should not AS read AAS, and should not EST read ET?

REVIEWER	Steven Feldman Wake Forest University School of Medicine USA
REVIEW RETURNED	25-Oct-2017

GENERAL COMMENTS	This is an interesting topic, but I’m not sure that the limitations of potential selection bias have been adequately addressed. Otherwise, this is a well described, concise report of a qualitative study.

	1. Don’t ever claim to be first. It is pointless and impossible to prove. And there’s no way to know that it would be true at the time of publication. It seems especially odd to claim to be the first when the Introduction describes previously reported data about obtaining information about vitiligo. 2. The use of a vitiligo society subject population is a major limitation that limits the generalizability of the findings. 3. The lack of any information comparing responders to non-responders is another limitation to the generalizability of the findings. 4. I am not sure that the “only product currently licensed for use in the treatment of vitiligo is cosmetic camouflage” is true. Topical steroids are licensed for steroid-responsive dermatoses, and vitiligo could be considered one. 5. On what basis can the authors conclude that, “Such treatments are unlikely to be used if people with vitiligo do not consult health professionals or do not receive appropriate advice from health professionals,” when they can go to the Internet for information and use over-the-counter hydrocortisone without a prescription? 6. There doesn’t seem to have been any specific hypothesis being tested. 7. Whole sentences aren’t needed to tell the reader there is a table. 8. The claim “The majority of survey respondents (n=158, 98%) completed the open-ended questions, suggesting a high level of enthusiasm to provide written feedback on their experiences of seeking help and information for vitiligo,” seems misleading, as a large majority of people offered the survey did not participate. There was high enthusiasm among the highly enthusiastic, but I don’t think that’s something to get excited about. 9. I wonder if the people who join the Vitiligo Society, especially the ones who chose to participate in this survey, are systematically selected for being unsatisfied with the information their doctor provided. Perhaps the 99% who were very satisfied with the information their doctor provided never join this Society and don’t fill out the survey if they did join. 10. I wonder if we should conclude from the findings that the Vitiligo Society needs to do a better job providing education about vitiligo that meets their members’ needs. 11. I wonder if we should conclude that GP’s should send patients with vitiligo to dermatologists more liberally. 12. I wonder if patients who received good treatments that worked well for them were systematically excluded from the survey (not by the investigators’ efforts but simply by the study methodology). 13. I wonder if it would be more accurate to change, “insights into the experiences of people with vitiligo in seeking information and treatment about their condition,” to “insights into the experiences of unhappy/dissatisfied people with vitiligo in seeking information and treatment about their condition” 14. Useless verbiage such as “It is noteworthy that” can be deleted. 15. It is interesting to me that the authors give a signpost to the Vitiligo Foundation as a credible online resource when their findings of a survey of Vitiligo Foundation members finds that these members are so dissatisfied with the information they’ve received.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Comment: The authors made a survey on vitiligo patients, concerning mostly their experience in acquiring information and management of vitiligo conditions. 161 patients answered the open-ended questions.
The results mostly are displayed as descriptive rather than analytical. I suggest statistical methods be employed to better describe the study outcomes.
As noticed by the authors, most of the res ponders of the survey were over 45 year of age, and they hardly represent the general vitiligo population who are mostly young people. Thus a survey with different age group and comprehensive analysis of the representative cohort is advised.

Response: The purpose of this qualitative study was to analyse the textual data generated in response to open-opened questions within a survey. As our analysis was qualitative, hypothesis testing and statistical methods would be inappropriate.

We agree that the age of the participants is a limitation of the study and further research with different age groups would be beneficial. We have amended the following sentence on page 13 in the discussion to reflect this:
'This paper highlights opportunities for further qualitative and quantitative research exploring and examining the needs of people with vitiligo, particularly younger people with vitiligo and those with a recent diagnosis'

Reviewer: 2
This is a very interesting, clear, and relevant manuscript on an important topic: experiences and expectations of persons with vitiligo with regards to information about the disease. I would, however, recommend the following changes / additions.
1) References 1 and 2: It would be more helpful to include references to original studies or systematic reviews on vitiligo prevalence.

Response: We have amended references 1 & 2 as suggested.

2) Page 5, line 30: The research question could be formulated more precisely, as the free texts did not only refer to sources of information but also to patients' information needs.

3) No information is given on informed consent and ethics.

Response: Details of the ethics approval for the study were provided on page 8, line 10. Given your comment, we have moved this sentence page 5 line 34 at the start of the methods and added details about informed consent (page 5, line 51)

4) It would be helpful to have a brief overview of the survey questions that were included before the free text questions, as Q4 can be understood to refer to content that has not been covered *in the survey* already, instead of *in Q1 to Q3*.

Response: We would be happy to include the survey questions as supplementary materials if this would be welcome to the editorial team

5) Is it correct that text coding was performed by one researcher, with only code and theme definitions being discussed among the co-authors? Was this done with or without recourse to the data (free texts)?

Response: One researcher performed the initial coding of the text. A detailed coding manual (containing code names, code descriptions and data excerpts) was produced, which allowed the research team to review and discuss these codes and definitions with recourse to the data, carry out consistency checks on the text coded to each code and iteratively develop themes (see page 7-8).

6) Limitations of analyzing written free-text responses should be discussed. Some qualitative literature regards this as not sufficient to understand participants' perspectives in detail as no additional inquiries by the researcher are possible, so limitations of this approach as compared to interview should be described.

Response: We have added the following sentence on page 11, line 44 to clarify these study limitations: - ‘ it was not possible in this context to ask participants to expand on or clarify their free-text responses. Being able to clarify and explore further vitiligo patients’ views and experiences in a qualitative interview may have generated richer data that would have enabled a more in-depth qualitative analysis.’

7) Page 12, line 24: I am not sure what is meant by "...it seems surprising where participants are members of a support group and many reported negative experiences of consulting".

Response: We have amended the text as follows to make it clearer:
‘Again it seems surprising that our participants, who are members of a support group and many of whom reported negative experiences of consulting, still wanted health professionals to be the main source of information.’

8) Page 12, line 37: Which implications are meant here? I feel that the statement that the findings have implications does not add information without at the same time explaining which implications. The same is true for page 13, line 3 ("This paper highlights opportunities for further research...") - what kind of research?

Response: We have removed the text on page 12, line 37 and added the following text to pag3 13, line 3 clarify this point: ‘This paper highlights opportunities for further qualitative and quantitative research exploring and examining the needs of people with vitiligo, particularly younger people with vitiligo and those with a recent diagnosis There is also a paucity of comparative evidence for effective treatments for vitiligo. In addition to quantitative research examining the effectiveness of treatments, greater evidence is also needed on how best to address the psychosocial impact of living with vitiligo.’

9) Page 13, line 13-17: It seems like the interventions recommended here are not really linked to / based on the findings of the study.

Response: We have revised this sentence to include ‘education and psychological intervention’ rather than ‘web-based behavioural intervention’ (see below)
In this study people’s support needs included advice on managing social situations and explaining the condition to others, learning how to use camouflage, as well as clear and up-to-date information about the pros and cons of available treatments. Further research to develop and test education and psychological support interventions that seek to address the information and support needs of people with vitiligo are likely to be valuable.’

10) A completed checklist for reports of qualitative research (COREQ or SRQR) would be helpful.

Response: We have completed the COREQ as suggested.

1) Abbreviations (e.g., "GP") should be introduced.

Response: We have added ‘General Practitioner’ to the first reference of GP in the abstract (page 2) and the first reference of GP in the main text (page 4, line 56)

2) Are there any barriers to membership of the Vitiligo Society (membership fees), which may be informative with regard to selection bias(page 12)

‘Members of the Vitiligo Society pay an annual membership fee (£26), which may be a barrier to membership for some people.’

3) Page 7, line 10: It could be made clearer what the 98% refer to (% of survey respondents who also responded to free text questions).

Response: We have added the following text to clarify this:
‘A total of 495 responses to the open-ended questions (20,728 words) were received from 158 of the 161 survey respondents (98% of respondents completed the free-text questions in addition the other survey questions).’

4) Authors' contributions: Initials do not exactly match the names - should not AS read AAS, and should not EST read ET?

Response: We have corrected the authors’ initials accordingly

Reviewer: 3

This is an interesting topic, but I’m not sure that the limitations of potential selection bias have been adequately addressed. Otherwise, this is a well described, concise report of a qualitative study.

1. Don’t ever claim to be first. It is pointless and impossible to prove. And there’s no way to know that it would be true at the time of publication. It seems especially odd to claim to be the first when the Introduction describes previously reported data about obtaining information about vitiligo.

Response: We acknowledge that this is not possible to know and have removed the sentence on page 11, line 22.

2. The use of a vitiligo society subject population is a major limitation that limits the generalizability of the findings.

Response: 2) We accept that this is a limitation of the study and have added further text to expand the limitations section of the discussion as follows:
Our findings also need to be seen in the context of our sampling method. People with vitiligo who are members of the Vitiligo Society may not be representative of all people with vitiligo and the response rate for our survey, which was carried out entirely online, was lower than the previous survey amongst Vitiligo Society members 8, which was carried out by post. We did not compare responders to non-responders and so cannot be sure that our participants are different in some way to those who did not respond to the survey. This may mean that participants in this study had greater impact from vitiligo, or were more engaged with seeking treatment and information, than other people with vitiligo and limits the transferability of the findings.’

3. The lack of any information comparing responders to non-responders is another limitation to the generalizability of the findings.
Response: Please see the response above.

4. I am not sure that the "only product currently licensed for use in the treatment of vitiligo is cosmetic camouflage" is true. Topical steroids are licensed for steroid-responsive dermatoses, and vitiligo could be considered one.

Response: It is our understanding that camouflage is the only product 'specifically licensed' for vitiligo in the UK. However, clinical guidelines certainly recommend topical steroids for vitiligo. We have therefore removed this sentence to be clearer (page 4, line 18).

5. On what basis can the authors conclude that, "Such treatments are unlikely to be used if people with vitiligo do not consult health professionals or do not receive appropriate advice from health professionals," when they can go to the Internet for information and use over-the-counter hydrocortisone without a prescription?

Response: We have amended this sentence as follows:
'Such treatments are less likely to be used if people with vitiligo do not consult health professionals or do not receive appropriate advice from health professionals. '

6. There doesn't seem to have been any specific hypothesis being tested.

Response: The purpose of this qualitative study was to analyse the textual data generated in response to open-opened questions within a survey to enhance our understanding people's experiences of seeking help and information for vitiligo. As our analysis was qualitative, hypothesis testing and statistical methods would be inappropriate.

7. Whole sentences aren't needed to tell the reader there is a table.

Response: We have amended page 5, line 53 to reflect this.

8. The claim "The majority of survey respondents (n=158, 98%) completed the open-ended questions, suggesting a high level of enthusiasm to provide written feedback on their experiences of seeking help and information for vitiligo," seems misleading, as a large majority of people offered the survey did not participate. There was high enthusiasm among the highly enthusiastic, but I don't think that's something to get excited about.

Response: We wanted to reflect on the amount of textual data provided by this survey, which is not always the case in quantitative surveys. However, we do acknowledge your point and have amended the sentence (page 8) as follows:
'The majority of survey respondents (n=158, 98%) completed the open-ended questions, suggesting that those who responded to the survey were highly motivated to provide written feedback on their experiences of seeking help and information for vitiligo.'

9. I wonder if the people who join the Vitiligo Society, especially the ones who chose to participate in this survey, are systematically selected for being unsatisfied with the information their doctor provided. Perhaps the 99% who were very satisfied with the information their doctor provided never join this Society and don't fill out the survey if they did join.

Response: We have amended the discussion (page 11, line 53) to further acknowledge the limitations of our sample.

‘This may mean that participants in this study had greater impact from vitiligo, were more unsatisfied with the information they had received, or were more engaged with seeking treatment and information, than other people with vitiligo and limits the transferability of the findings.’

10. I wonder if we should conclude from the findings that the Vitiligo Society needs to do a better job providing education about vitiligo that meets their members’ needs.

Response: The Vitiligo Society was commonly viewed as a helpful and trustworthy source of information for participants. We did not compare our participants with people who are not members of the Vitiligo Society and it is possible that non-members would have even greater unmet informational needs. We have made no changes to the text.

11. I wonder if we should conclude that GP’s should send patients with vitiligo to dermatologists more liberally.

Response: Although we agree this is a possibility, there were also negative comments about Dermatologists and treatments that had not worked, so we cannot really conclude this from the data.

12. I wonder if patients who received good treatments that worked well for them were systematically excluded from the survey (not by the investigators’ efforts but simply by the study methodology).

Response: We did find some positive experiences of treatment in the data so we cannot really conclude this and have made no changes to the text

13. I wonder if it would be more accurate to change, “insights into the experiences of people with vitiligo in seeking information and treatment about their condition,” to “insights into the experiences of unhappy/dissatisfied people with vitiligo in seeking information and treatment about their condition”

Response: As we did not compare our participants with people who are not members of the Vitiligo Society, we cannot really say whether they were more satisfied or not. So we have made no changes to this text.

14. Useless verbiage such as “It is noteworthy that” can be deleted.

Response: This has been deleted as suggested.

15. It is interesting to me that the authors give a signpost to the Vitiligo Foundation as a credible online resource when their findings of a survey of Vitiligo Foundation members finds that these members are so dissatisfied with the information they’ve received.

Response: We found that participants were dissatisfied with information received from health professionals and had concerns around the credibility of online information on vitiligo and would like to see reliable, detailed, easily accessible information from a trustworthy source. Participants generally appeared to feel that the Vitiligo Society had been their main source of credible online information.

VERSION 2 – REVIEW

REVIEWER	Christine Blome University Medical Center Hamburg-Eppendorf, Institute for Health Services Research in Dermatology and Nursing, Germany
REVIEW RETURNED	28-Nov-2017

GENERAL COMMENTS	Thank you for addressing my comments and questions; at this point, I have only two minor comments: Reference #1: The year is missing. On comment #5: “which allowed the research team to review and discuss these codes and definitions with recourse to the data” – I would suggest to explicitly state in the manuscript that the review was performed with recourse to the data, as this was not clear from the text – at least for me.

REVIEWER	Steven Feldman Wake Forest School of Medicine USA I have received lots of support from many companies but none with specific relevance to this manuscript.
REVIEW RETURNED	28-Nov-2017

GENERAL COMMENTS	The authors were very responsive to the critique.

VERSION 2 – AUTHOR RESPONSE

Reviewer: 2

Thank you for addressing my comments and questions; at this point, I have only two minor comments:

1. Reference #1: The year is missing.
2. On comment #5: “which allowed the research team to review and discuss these codes and definitions with recourse to the data” – I would suggest to explicitly state in the manuscript that the review was performed with recourse to the data, as this was not clear from the text – at least for me.

Thank you for your comments

1) We have added the year to this reference.

2) We have added the following text to page 7 to clarify this:

A detailed coding manual (containing code names, code descriptions and data excerpts) was created to ensure transparent and systematic coding of the data. Codes and theme/sub-theme definitions were discussed with recourse to the data, and iteratively developed by three members of the research team (EJT, MS and IM) to offer diverse inferences and interpretation of the data.