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Views and experiences of seeking information and help for vitiligo: a qualitative study of written accounts

Running title: Experiences of seeking information and help for vitiligo

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ABSTRACT (294 words)

Objectives: Vitiligo is a relatively common autoimmune condition causing loss of skin pigment. Around 1 in 100 people in the UK develop vitiligo. It can have a significant impact on quality of life for many of those affected. How people access information and help for vitiligo may influence how they manage such impact. We aimed to explore people's views and experiences of seeking health information and help for vitiligo.

Design: Qualitative analysis of free-text responses to four open-ended questions in an online survey.

Setting: Online survey conducted in the UK between February and March 2016

Participants: A survey link was emailed to 675 members of The Vitiligo Society, a UK-based charity providing information and support for people with vitiligo. One hundred and sixty one members responded to the survey (24%).

Results: Many participants wrote extensive free text, often reporting frustration with help-seeking. They perceived GPs as their primary source of advice but felt that GPs had low awareness of available treatments. Where GPs appeared sympathetic or signposted towards further information this was appreciated, even where people felt their GP had not seemed knowledgeable. Many felt that vitiligo was dismissed by health professionals including GPs and Dermatologists as 'cosmetic', which upset those who experienced substantial impact. Participants expressed concerns about the credibility of online information on vitiligo and the need for reliable, detailed information, as well as a desire for support with managing its psychosocial impact.

Conclusions: Information and help-seeking needs of people with vitiligo currently appear to be poorly met, even amongst members of the Vitiligo Society, who are likely to have received more information than others. People with vitiligo would welcome greater health professional awareness of available vitiligo treatments. Acknowledging the psychosocial impacts of vitiligo and signposting towards credible information are also welcomed.

KEYWORDS

Vitiligo; primary health care; qualitative; patient experience; information; dermatology

STRENGTHS AND LIMITATIONS OF THIS STUDY

- To our knowledge, this is the first qualitative study to explore the help-seeking behaviour of people with vitiligo.
- Our novel study provides valuable insights into the experiences of people with vitiligo in seeking information and treatment about their condition.
- We employed an efficient yet relatively under-utilised method of qualitative data collection to explore an under-researched topic area.
- Members of the Vitiligo Society may not be representative of all people with vitiligo and most of the participants in this study were over 45, which is likely to be unrepresentative of the whole population of people with vitiligo as the condition commonly appears before the age of 20.

INTRODUCTION

Vitiligo is an autoimmune disease where pale white patches progressively develop on the skin due to loss of pigment. Worldwide prevalence ranges between 0.5 and 2% and around 1 in 100 people in the UK develop vitiligo.[1 2] The appearance altering nature of vitiligo can have a significant impact on quality of life, particularly in terms of increased anxiety, lowered self-esteem, relationship difficulties, and it may also negatively affect self-confidence and body image.[3 4] Most vitiligo develops before the age of 20 and may have a profound impact on confidence and self-image at a key time in social development.[5]

The only product currently licensed for use in the treatment of vitiligo is cosmetic camouflage, for which no randomised controlled trials are available. The evidence base for other treatments is also currently poor.[6] A European Guideline has suggested that early treatment of small lesions of recent onset and childhood vitiligo should be treated with a combination of phototherapy and topical agents, such as topical corticosteroids or topical calcineurin inhibitors.[7] 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.

Previous research has highlighted the psychosocial impact of vitiligo and the coping strategies adopted by people living with vitiligo. A survey carried out amongst members of the Vitiligo Society in 2010 showed that over half (56.6%) of respondents felt that vitiligo moderately or severely affected their quality of life.[8] One qualitative interview study carried out with seven white British women, reported a continuous struggle using avoidance, concealment and cognitive strategies to try to deal with the impact of vitiligo.[9] Another qualitative interview study was conducted with seven British women of South Asian descent. All had experienced stigmatisation to some extent. Avoidance and concealment were commonplace, as was a profound impact on their relationships and sense of identity.[10]

How people access and make sense of information, and seek help for vitiligo, is likely to influence how they cope with the psychosocial impacts but there is relatively little research on people's experiences of obtaining information and treatment for vitiligo. Previous quantitative research suggests that people with vitiligo typically want to find a lasting effective treatment but they appear to have difficulty accessing treatment and feel that their condition is dismissed as 'trivial' or 'cosmetic'.[8 11] Members of the Vitiligo Society have reported that they obtain information about vitiligo from non-medical sources, such as the Vitiligo Society (83%) and the internet (25%) rather than from dermatologists (13%) and GPs (7%).[8] Surprisingly few had obtained advice from GPs or dermatologists. Further research is needed to explore whether this relates to difficulties in accessing advice or whether people actively choose to obtain advice elsewhere.

Qualitative methods are well suited to exploring a topic in-depth from the perspective of a particular group of people. Qualitative research that seeks to explore people's experiences of obtaining information about vitiligo and their help seeking behaviour could help to determine whether people with vitiligo expect GPs or Dermatologists to advise them about vitiligo or whether they generally seek information from charities or the internet instead of, or in addition to, consulting. This in turn would enable better understanding of how GPs and Dermatologists can best support people with vitiligo in terms of information provision and/ or signposting to reliable resources. Given the potential insights into people's experiences to be gained by using qualitative methods[12], we incorporated open-ended questions into a quantitative survey about information and help-seeking behaviour in people with vitiligo. We aimed to explore views and experiences of seeking information and help for vitiligo through analysis of the written accounts of survey respondents.

METHODS

This study sought to qualitatively analyse the free text comments within a quantitative survey that focused on exploring sources of information for vitiligo. This qualitative approach has been previously used in other health-related research.[13-15]

Main survey

An anonymous online survey of people with vitiligo was conducted in the UK in February 2016 (response rate 161/675 (24%)). We sought participants through the Vitiligo Society, partly because this had been a successful route for previous research[8] but also because informal advice suggested vitiligo might not be well coded in primary care so recruiting through this route would be problematic. Details about the study and a link to the online survey were emailed to 675 members of the Vitiligo Society. A reminder email was sent out after 2 weeks. The survey link was also made available on the Vitiligo Society website from February to March 2016. In total, 161 people completed some or all of the survey questions and were included in the analysis. Participant characteristics are presented in Table 1. Quantitative survey findings regarding sources of information and help-seeking were similar to those previously reported.[8] This paper focusses on the rich qualitative data obtained from the free text responses to open-ended questions in the survey.

Table 1: Survey Respondents' Characteristics

	Number of participants N=161	**Percentage (%)**
Answered for themselves	151	93.8
Answered on behalf of other person	4	2.5
Missing	6	3.7
Gender :		
Male	55	34.1
Female	98	60.9
Missing	8	5.0
Age :		
5-16 years	2	1.2
16-25 years	8	5.0
26-45 years	27	16.8
46-65 years	73	45.3
More than 65 years	45	28.0
Missing	6	3.7
Portion of skin affected :		
Just a few patches (0-10%)	35	21.7
A fair amount (10-25%)	41	25.5
Quite a lot (25-50%)	33	20.5
Very much (50-80%)	25	15.5
All or nearly all (more than 80%)	19	11.8
Missing	8	5.0
Skin Colour :		
Fair	67	41.6
Medium	75	46.6
Dark	10	6.2
Very dark	1	0.6
Missing	8	5.0
Family with vitiligo :		
Yes	72	44.7
No	82	50.9
Missing	7	4.4
Living :		
UK	147	91.3
Europe	1	0.6
Elsewhere	5	3.1
Missing	8	5.0

Qualitative component

The online survey included four open-ended questions, which allowed participants to respond in more detail (Table 2). The survey dataset was imported into NVivo 10 and responses to the open-ended questions collated for analysis. A total of 495 responses to the open-ended questions (20,728 words) were received from 158 survey respondents (98%). Responses to the open-ended questions ranged from brief comments (one phrase or sentence) to more detailed accounts (a couple of paragraphs). Question 3 (informational needs of people with vitiligo) received the most responses and question 2 (experiences of seeking treatment for vitiligo) received the most detailed comments.

Table 2: Open-ended questions in survey

Questions	No. of responses to each question %	Total no. of words per question
Q1.We would be very interested to learn more about your experience of getting information for vitiligo. *If you are happy to, please can you tell us some more about this?*	**142** (90%)	5,419
Q2. We would be very interested to learn more about your experience of getting treatment for vitiligo. *If you are happy to, please can you tell us some more about this?*	**103** (65%)	6,634
Q3. Are there any aspects of vitiligo that you feel you would like to know more about?	**148** (94%)	3,682
Q4. Is there anything you would like to say that you feel has not been covered already?	**102** (65%)	4,993

Data analysis

An inductive thematic analysis was conducted to explore people's experiences of seeking information and help for vitiligo.[16] One author (EJT) read the comments several times to achieve familiarisation with the data and codes were applied line by line. Codes were derived inductively from the data and grouped together to produce an initial coding frame. Codes were compared to identify similarities and differences. A detailed coding manual was created to ensure transparent and systematic coding of the data. Codes and theme/sub-theme definitions were discussed with, and iteratively developed by, three members of the research team (EJT, MS and IM) to offer diverse inferences and interpretation of the data. A negative case analysis was carried out to ensure that all data was taken into account rather than just selecting data that fitted with the authors' viewpoint. Data saturation could not be determined due to the nature of the method of data collection. Using NVivo enabled a detailed audit trail to be maintained. Ethical approval was granted by the Faculty of Medicine Research Ethics Committee, University of Southampton.

RESULTS

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. Analysis of these data highlighted 3 themes: 1) ***experiences of consulting health professionals for vitiligo***, 2) ***seeking information about vitiligo***, 3) ***perceptions and experiences of vitiligo treatments***. These themes are explored in detail below. All quotes are labelled with a participant ID, gender and age.

Experiences of consulting health professionals for vitiligo

A sense of dissatisfaction and feeling unsupported was apparent in participants' reports about their experiences of consulting health professionals for vitiligo. Participants often seemed disappointed by the response they had received from GPs, who were viewed as their primary source of contact and advice. A common perception amongst participants was that GPs are not generally aware of, or particularly knowledgeable about, vitiligo and as such can only provide limited information and advice to patients.

"None of the GP's I have spoken to have ever offered advice about Vitiligo. They seem to be somewhat in the dark about the problem." ***(Pt36, male, over 65 years)***

Where health professionals appeared sympathetic or where signposting towards further information was offered this was appreciated, even where people felt their GP had not been knowledgeable.

"I have had vitiligo for about 35 years. I am now 70 years old. I have found that, with very few exceptions, GPs know little about the condition. One of my GPs (who "half-retired" a few years ago) was always interested in learning more and asked me if I could provide some information on vitiligo. I gave her some printed material and she was grateful; I know that she read everything which I provided." ***(Pt110, male, over 65 years)***

Many participants felt they had just been left to ‘get on with it’ and learn to accept and manage their vitiligo on their own. For some participants this led them to seeking out alternative treatments not available in the UK. Another dominant perspective in this study was the sense that vitiligo is not taken seriously by medical professionals, both GPs and dermatologists. Many participants felt that their vitiligo was dismissed by health professionals as something inconsequential, i.e. purely cosmetic, which was upsetting to those experiencing substantial psychosocial impact.

“I started my first signs of Vitiligo 30 years ago at the age of 40. I went to my GP who referred me to a consultant. The consultant proved to be absolutely useless in providing any information. He just took one look at me, told me it was something called Vitiligo and told me that it would most likely get worse but wouldn't kill me!!!” ***(Pt71, female, over 65 years)***

“I noticed most doctors don’t know much about vitiligo and really don't seem to care. I felt they had no clue about what a person with vitiligo goes through, Since it's not a matter of life or death, your expected to just accept it. I was very disappointed every time, always left feeling hopeless. I think they should have more to offer, be sympathetic & at least try different things” ***(Pt138, female, 46-65 years)***

Seeking information about vitiligo

Participants commonly reported seeking information from other sources, predominantly online resources, as a result of receiving limited information from health professionals. The Vitiligo Society was viewed as a helpful and trustworthy source of information for participants but many expressed doubts about the reliability and credibility of other online resources about vitiligo. A common concern expressed by the participants related to the credibility of online information on possible treatments for vitiligo. In particular, they expressed doubts about the commercial interests of the websites and about being able to determine the evidence base (safety and efficacy) of certain products and procedures.

“I find it very difficult to find clear and consistent advice on possible treatments for Vitiligo. There are a lot of commercially orientated websites promoting a variety of herbal cures etc but limited proper evidence based medical guidance.” ***(Pt40, male, 26-45 years)***

“The only problem when searching for vitiligo sites is that some websites eventually lead into selling some sort of product which is the new "best treatment". You find that because you are motivated to find some sort of treatment you end up almost believing the hype that they sell.” ***(Pt139, male, 46-65 years)***

A desire for detailed, reliable information about the causes of vitiligo, its progression and possible treatments was widely expressed. Some participants felt it important that such information should come directly from health professionals or other resources perceived to be trustworthy such as NHS Choices. Participants also expressed a desire for information and advice about managing the psychosocial impact of living with vitiligo, particularly advice on learning to cope with social situations and people's reactions to their altered appearance, and how to explain the condition to others.

"I developed vitiligo 42 years ago when I was 2. The GP referred me to a very good dermatologist who explained things clearly as well as, crucially, how to sensibly explain it to other children." ***(Pt11, female 26-45 years)***

"I would like more information on the cause of it and how to deal with being so self-conscious about it - it does affect confidence and forming relationships." ***(Pt130, female, 26-45 years)***

Perceptions and experiences of vitiligo treatments

Experiences of vitiligo treatments expressed by participants were very mixed. Whilst some participants expressed positive experiences of treatment, particularly UV light treatment, many participants appeared to have more negative experiences of seeking and receiving treatment for their vitiligo. A commonly expressed view was that vitiligo treatment is not routinely offered or is poorly available, especially on the NHS, and is limited to particular geographical locations.

"We decided to have light treatment. My main concern was the Vitiligo on my face. The treatment worked well but a few years later it appeared elsewhere on my face so I had more treatment that also worked well. The spread of vitiligo has slowed to almost a stop apart from a couple of new areas on my face." ***(Pt74, male, 46-65 years)***

"There is very little treatment for Vitiligo in the UK. I am at present involved with the Hi-Light trial run by the Univ of Nottingham. This is the first time I have been able to obtain any treatment." ***(Pt102, male, over 65 years)***

Many participants, who had received treatments such as steroid creams and light treatment for their vitiligo, felt they were ineffective in the long-term as the treatments had been unsuccessful in maintaining any areas of re-pigmentation. Participants also reported the perceived difficulties and potential side effects of vitiligo treatment such as concerns about skin thinning with steroid creams, time-consuming nature and inconvenience of hospital-based UV light treatment and the physical side effects of light treatment such as nausea and headaches.

"I was referred to Dermatology and was prescribed PUVA treatment. This helped for a while, but became so time consuming. Progress was very slow. I stopped the treatment and any areas of repigmentation soon reverted back to white skin. So disappointing." ***(Pt156, female, 46-65 years)***

As well as mixed experiences of vitiligo treatments, there were mixed attitudes towards the need to seek vitiligo treatments in the first instance. Some participants reported less experience of treatments because they had not sought these out and had 'accepted' their vitiligo, even though it may have had a profound impact on their lives.

"I think that vitiligo is a relatively unknown condition. I have never been contacted about treatment or had it offered to me despite having had the condition for many years. You are very much left to get on with it. I can imagine that some people suffer psychologically and I wonder what support they get. I have come to terms with my patches and embrace them rather than disguise them but it can feel quite disheartening at times and I would rather not have them given the choice." (***Pt58, female, 46-65 years)***

DISCUSSION

To our knowledge, this is the first qualitative study of people's experiences seeking information and treatment for vitiligo. We found predominantly negative experiences of help-seeking, concerns about the credibility of online information, and the need for detailed, reliable vitiligo information. Frustration with challenges to help-seeking was often reported, particularly perceived lack of awareness of available treatments amongst GPs. Many felt that vitiligo was often dismissed by health professionals as 'cosmetic', which was upsetting to those experiencing substantial psychosocial impact. Where GPs appeared sympathetic or where signposting towards further information was offered this was appreciated, even where people felt their GP had not seemed knowledgeable. There were very mixed views about the need for treatment and a desire for support with managing the psychosocial impact of vitiligo.

This novel study provides valuable insights into the experiences of people with vitiligo in seeking information and treatment about their condition. We employed an efficient yet relatively under-utilised method of qualitative data collection to explore an under-researched topic area. However, our findings 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. 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.

Most of the participants in this study were over 45, which is likely to be unrepresentative of the whole population of people with vitiligo as the condition commonly appears before the age of 20.[17]

[18] It is likely that most of the participants had had vitiligo for many years and their experience may differ from those more recently diagnosed. Furthermore, by sampling through a patient support group we may have been more likely to receive accounts from people whose needs had not been met by health services, although it is notable that this group still felt that they had many unanswered questions and that they found online information difficult to navigate.

The feeling that vitiligo is dismissed by health professionals as ‘cosmetic’ or ‘trivial’ shows that this is an ongoing concern for people, in common with previous reports,[9 10] and also in line with other skin conditions.[19 20] We found that people can find it difficult to judge the credibility of online information on vitiligo, as in other conditions[21], but it seems surprising in this context where participants are all members of a relevant support group. It is noteworthy that participants still generally view health professionals as an important source of information, which has been noted in other studies[22] but again it seems surprising where participants are members of a support group and many reported negative experiences of consulting. Our finding that people are keen for support with managing the psychosocial impact of living with vitiligo was also found in a recent James Lind Alliance Priority Setting Partnership in the UK, which identified the need for further research into the effectiveness of psychological support for people with vitiligo, either on its own or together with other treatments.[23] The importance of providing people with skin diseases with access to a range of supportive services including psychological support was also acknowledged in a recent report of the All Party Parliamentary Group on Skin.[24] We feel that the varied views and experiences of vitiligo treatments are novel findings, which have implications for further research into how to support people with vitiligo.

Constraints on access to specialists through Primary Care ‘gatekeeping’ or ‘managed care’ may be associated with lower patient satisfaction [25] and respondents in this study expressed frustration with generalist services, perceiving them to have a low level of knowledge about their condition. It is not completely clear whether this represents lack of awareness amongst GPs of available treatments for vitiligo, or lack of provision of services into which they can refer. Access to vitiligo services/treatment is becoming increasingly difficult in many areas of the UK, which is likely to increase people’s frustration with help-seeking and may exacerbate the psychosocial impact experienced by many people with vitiligo.

This paper highlights opportunities for further research into the needs of people with vitiligo, particularly those with a recent diagnosis. There is also a paucity of comparative evidence for effective treatments for vitiligo. Greater evidence is also needed on how best to address the psychosocial impact of living with vitiligo. In an era where people are increasingly obtaining health information online[26], it may be that education and psychological support interventions delivered online may benefit this population. Further research to develop and test web-based behavioural interventions that seek to support people living with vitiligo could also be valuable. Such interventions could include 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.

In conclusion, more can be done to meet the information and help-seeking needs of people with vitiligo. People with vitiligo would welcome greater health professional awareness of the possibility of treating vitiligo, yet recognise that generalist services may not always be able to offer this. People who had been directed towards reliable information were very grateful for this and signposting is viewed as a key role of GPs, which remain the primary source of information for many. Fortunately good online resources for people with vitiligo are available (Box 1). Signposting people with vitiligo towards credible online resources and acknowledging and exploring the potential impact of the condition may allay people's perceptions that distress caused by the condition is not taken seriously.

Box 1: Online resources for people with vitiligo

Website	**URL**
NHS Choices	http://www.nhs.uk/conditions/Vitiligo/Pages/Introduction.aspx Links to the official website of the National Health Service in England. Their section on vitiligo provides information and advice about vitiligo symptoms, causes diagnosis and treatments.
Patient.co.uk	http://patient.info/health/vitiligo-leaflet Links to a general medical information and support website providing information and advice about vitiligo symptoms, causes and treatments.
The Vitiligo Society	http://www.vitiligosociety.org.uk/ Links to The Vitiligo Society website, a UK-based charity providing information and support for people with vitiligo through their regularly update website and newsletter, *Dispatches*.

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Competing interests

The authors have no conflicts of interest to declare.

Authors' contribution

MS, IM and KT designed the study; AS collected the data under supervision of MS and BS; EJT, IM, BS and MS made substantial contributions to the analysis and interpretation of the data; EJT drafted the manuscript; IM, MS, BS, AS and KT critically reviewed and revised the manuscript; all authors gave the final approval of the version to be published.

Data sharing statement

This is a qualitative study and therefore the data generated is not suitable for sharing beyond that contained within the report. Further information can be obtained from the corresponding author.

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ABSTRACT (296 words)

Objectives: Vitiligo is a relatively common autoimmune condition causing loss of skin pigment. Around 1 in 100 people in the UK develop vitiligo. It can have a significant impact on quality of life for many of those affected. How people access information and help for vitiligo may influence how they manage such impact. We aimed to explore people's views and experiences of seeking health information and help for vitiligo.

Design: Qualitative analysis of free-text responses to four open-ended questions in an online survey.

Setting: Online survey conducted in the UK between February and March 2016

Participants: A survey link was emailed to 675 members of The Vitiligo Society, a UK-based charity providing information and support for people with vitiligo. One hundred and sixty one members responded to the survey (24%).

Results: Many participants wrote extensive free text, often reporting frustration with help-seeking. They perceived General Practitioners (GPs) as their primary source of advice but felt that GPs had low awareness of available treatments. Where GPs appeared sympathetic or signposted towards further information this was appreciated, even where people felt their GP had not seemed knowledgeable. Many felt that vitiligo was dismissed by health professionals including GPs and Dermatologists as 'cosmetic', which upset those who experienced substantial impact. Participants expressed concerns about the credibility of online information on vitiligo and the need for reliable, detailed information, as well as a desire for support with managing its psychosocial impact.

Conclusions: Information and help-seeking needs of people with vitiligo currently appear to be poorly met, even amongst members of the Vitiligo Society, who are likely to have received more information than others. People with vitiligo would welcome greater health professional awareness of available vitiligo treatments. Acknowledging the psychosocial impacts of vitiligo and signposting towards credible information are also welcomed.

KEYWORDS

Vitiligo; primary health care; qualitative; patient experience; information; dermatology

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We employed an efficient yet relatively under-utilised method of qualitative data collection to explore an under-researched topic area.

- Conducting an exploratory qualitative analysis of the free text comments within a quantitative survey allowed us to gain novel and valuable insights into, and a greater understanding about, the experiences of people with vitiligo in seeking information and treatment about their condition.

- A limitation of this study was our sampling method. Members of the Vitiligo Society may not be representative of all people with vitiligo, which limits the transferability of our findings. Participants in this study could have had greater impact from vitiligo, been more unsatisfied with the information they had received, or more engaged with seeking treatment and information, than other people with vitiligo.

- Also most of the participants in this study were over 45, which is likely to be unrepresentative of the whole population of people with vitiligo as the condition commonly appears before the age of 20.

INTRODUCTION

Vitiligo is an autoimmune disease where pale white patches progressively develop on the skin due to loss of pigment. Worldwide prevalence ranges between 0.5 and 2% and around 1 in 100 people in the UK develop vitiligo.[1 2] The appearance altering nature of vitiligo can have a significant impact on quality of life, particularly in terms of increased anxiety, lowered self-esteem, relationship difficulties, and it may also negatively affect self-confidence and body image.[3 4] Most vitiligo develops before the age of 20 and may have a profound impact on confidence and self-image at a key time in social development.[5]

The evidence base for vitiligo treatment is currently poor.[6] A European Guideline has suggested that early treatment of small lesions of recent onset and childhood vitiligo should be treated with a combination of phototherapy and topical agents, such as topical corticosteroids or topical calcineurin inhibitors.[7] 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.

Previous research has highlighted the psychosocial impact of vitiligo and the coping strategies adopted by people living with vitiligo. A survey carried out amongst members of the Vitiligo Society in 2010 showed that over half (56.6%) of respondents felt that vitiligo moderately or severely affected their quality of life.[8] One qualitative interview study carried out with seven white British women, reported a continuous struggle using avoidance, concealment and cognitive strategies to try to deal with the impact of vitiligo.[9] Another qualitative interview study was conducted with seven British women of South Asian descent. All had experienced stigmatisation to some extent. Avoidance and concealment were commonplace, as was a profound impact on their relationships and sense of identity.[10]

How people access and make sense of information, and seek help for vitiligo, is likely to influence how they cope with the psychosocial impacts but there is relatively little research on people's experiences of obtaining information and treatment for vitiligo. Previous quantitative research suggests that people with vitiligo typically want to find a lasting effective treatment but they appear to have difficulty accessing treatment and feel that their condition is dismissed as 'trivial' or 'cosmetic'.[8 11] Members of the Vitiligo Society have reported that they obtain information about vitiligo from non-medical sources, such as the Vitiligo Society (83%) and the internet (25%) rather than from dermatologists (13%) and General Practitioners (GPs) (7%).[8] Surprisingly few had obtained advice from GPs or dermatologists. Further research is needed to explore whether this relates to difficulties in accessing advice or whether people actively choose to obtain advice elsewhere.

Qualitative methods are well suited to exploring a topic in-depth from the perspective of a particular group of people. Qualitative research that seeks to explore people's experiences of obtaining information about vitiligo and their help seeking behaviour could help to determine whether people with vitiligo expect GPs or Dermatologists to advise them about vitiligo or whether they generally seek information from charities or the internet instead of, or in addition to, consulting. This in turn would enable better understanding of how GPs and Dermatologists can best support people with vitiligo in terms of information provision and/ or signposting to reliable resources. Given the potential insights into people's experiences to be gained by using qualitative methods[12], we incorporated open-ended questions into a quantitative survey about information and help-seeking behaviour in people with vitiligo. We aimed to explore views and experiences of seeking information and help for vitiligo through analysis of the written accounts of survey respondents.

METHODS

This study sought to qualitatively analyse the free text comments within a quantitative survey that focused on exploring sources of information for vitiligo, experiences of treatment and information needs. This qualitative approach has been previously used in other health-related research.[13-15] Ethical approval was granted by the Faculty of Medicine Research Ethics Committee, University of Southampton.

Main survey

An anonymous online survey of people with vitiligo was conducted in the UK in February 2016 (response rate 161/675 (24%)). We sought participants through the Vitiligo Society, partly because this had been a successful route for previous research[8] but also because informal advice suggested vitiligo might not be well coded in primary care so recruiting through this route would be problematic. Details about the study and a link to the online survey were emailed to 675 members of the Vitiligo Society. A reminder email was sent out after 2 weeks. The survey link was also made available on the Vitiligo Society website from February to March 2016. Participants provided online informed consent prior to accessing the survey. In total, 161 people completed some or all of the survey questions and were included in the analysis (Table 1). Quantitative survey findings regarding sources of information and help-seeking were similar to those previously reported.[8] This paper focusses on the rich qualitative data obtained from the free text responses to open-ended questions in the survey.

Table 1: Survey Respondents' Characteristics

	Number of participants N=161	**Percentage (%)**
Answered for themselves	151	93.8
Answered on behalf of other person	4	2.5
Missing	6	3.7
Gender :		
Male	55	34.1
Female	98	60.9
Missing	8	5.0
Age :		
5-16 years	2	1.2
16-25 years	8	5.0
26-45 years	27	16.8
46-65 years	73	45.3
More than 65 years	45	28.0
Missing	6	3.7
Portion of skin affected :		
Just a few patches (0-10%)	35	21.7
A fair amount (10-25%)	41	25.5
Quite a lot (25-50%)	33	20.5
Very much (50-80%)	25	15.5
All or nearly all (more than 80%)	19	11.8
Missing	8	5.0
Skin Colour :		
Fair	67	41.6
Medium	75	46.6
Dark	10	6.2
Very dark	1	0.6
Missing	8	5.0
Family with vitiligo :		
Yes	72	44.7
No	82	50.9
Missing	7	4.4
Living :		
UK	147	91.3
Europe	1	0.6
Elsewhere	5	3.1
Missing	8	5.0

Qualitative component

The online survey included four open-ended questions, which allowed participants to respond in more detail (Table 2). The survey dataset was imported into NVivo 10 and responses to the open-ended questions collated for analysis. 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). Responses to the open-ended questions ranged from brief comments (one phrase or sentence) to more detailed accounts (a couple of paragraphs). Question 3 (informational needs of people with vitiligo) received the most responses and question 2 (experiences of seeking treatment for vitiligo) received the most detailed comments.

Table 2: Open-ended questions in survey

Questions	**No. of responses to each question** **%**	**Total no. of words per question**
Q1.We would be very interested to learn more about your experience of getting information for vitiligo. *If you are happy to, please can you tell us some more about this?*	**142** (90%)	5,419
Q2. We would be very interested to learn more about your experience of getting treatment for vitiligo. *If you are happy to, please can you tell us some more about this?*	**103** (65%)	6,634
Q3. Are there any aspects of vitiligo that you feel you would like to know more about?	**148** (94%)	3,682
Q4. Is there anything you would like to say that you feel has not been covered already?	**102** (65%)	4,993

Data analysis

An inductive thematic analysis was conducted to explore people's experiences of seeking information and help for vitiligo.[16] One author (EJT) read the comments several times to achieve familiarisation with the data and codes were applied line by line. Codes were derived inductively from the data and grouped together to produce an initial coding frame. Codes were compared to identify similarities and differences. A detailed coding manual was created to ensure transparent and systematic coding of the data. Codes and theme/sub-theme definitions were discussed with, and iteratively developed by, three members of the research team (EJT, MS and IM) to offer diverse inferences and interpretation of the data. A negative case analysis was carried out to ensure that all data was taken into account rather than just selecting data that fitted with the authors' viewpoint. Data saturation could not be determined due to the nature of the method of data collection. Using NVivo enabled a detailed audit trail to be maintained.

RESULTS

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. Analysis of these data highlighted 3 themes: 1) ***experiences of consulting health professionals for vitiligo***, 2) ***seeking information about vitiligo***, 3) ***perceptions and experiences of vitiligo treatments***. These themes are explored in detail below. All quotes are labelled with a participant ID, gender and age.

Experiences of consulting health professionals for vitiligo

A sense of dissatisfaction and feeling unsupported was apparent in participants' reports about their experiences of consulting health professionals for vitiligo. Participants often seemed disappointed by the response they had received from GPs, who were viewed as their primary source of contact and advice. A common perception amongst participants was that GPs are not generally aware of, or particularly knowledgeable about, vitiligo and as such can only provide limited information and advice to patients.

"None of the GP's I have spoken to have ever offered advice about Vitiligo. They seem to be somewhat in the dark about the problem." ***(Pt36, male, over 65 years)***

Where health professionals appeared sympathetic or where signposting towards further information was offered this was appreciated, even where people felt their GP had not been knowledgeable.

"I have had vitiligo for about 35 years. I am now 70 years old. I have found that, with very few exceptions, GPs know little about the condition. One of my GPs (who "half-retired" a few years ago) was always interested in learning more and asked me if I could provide some information on vitiligo. I gave her some printed material and she was grateful; I know that she read everything which I provided." ***(Pt110, male, over 65 years)***

Many participants felt they had just been left to ‘get on with it’ and learn to accept and manage their vitiligo on their own. For some participants this led them to seeking out alternative treatments not available in the UK. Another dominant perspective in this study was the sense that vitiligo is not taken seriously by medical professionals, both GPs and dermatologists. Many participants felt that their vitiligo was dismissed by health professionals as something inconsequential, i.e. purely cosmetic, which was upsetting to those experiencing substantial psychosocial impact.

“I started my first signs of Vitiligo 30 years ago at the age of 40. I went to my GP who referred me to a consultant. The consultant proved to be absolutely useless in providing any information. He just took one look at me, told me it was something called Vitiligo and told me that it would most likely get worse but wouldn't kill me!!!” ***(Pt71, female, over 65 years)***

“I noticed most doctors don’t know much about vitiligo and really don't seem to care. I felt they had no clue about what a person with vitiligo goes through, Since it's not a matter of life or death, your expected to just accept it. I was very disappointed every time, always left feeling hopeless. I think they should have more to offer, be sympathetic & at least try different things” ***(Pt138, female, 46-65 years)***

Seeking information about vitiligo

Participants commonly reported seeking information from other sources, predominantly online resources, as a result of receiving limited information from health professionals. The Vitiligo Society was viewed as a helpful and trustworthy source of information for participants but many expressed doubts about the reliability and credibility of other online resources about vitiligo. A common concern expressed by the participants related to the credibility of online information on possible treatments for vitiligo. In particular, they expressed doubts about the commercial interests of the websites and about being able to determine the evidence base (safety and efficacy) of certain products and procedures.

“I find it very difficult to find clear and consistent advice on possible treatments for Vitiligo. There are a lot of commercially orientated websites promoting a variety of herbal cures etc but limited proper evidence based medical guidance.” ***(Pt40, male, 26-45 years)***

“The only problem when searching for vitiligo sites is that some websites eventually lead into selling some sort of product which is the new "best treatment". You find that because you are motivated to find some sort of treatment you end up almost believing the hype that they sell.” ***(Pt139, male, 46-65 years)***

A desire for detailed, reliable information about the causes of vitiligo, its progression and possible treatments was widely expressed. Some participants felt it important that such information should come directly from health professionals or other resources perceived to be trustworthy such as NHS Choices. Participants also expressed a desire for information and advice about managing the psychosocial impact of living with vitiligo, particularly advice on learning to cope with social situations and people's reactions to their altered appearance, and how to explain the condition to others.

"I developed vitiligo 42 years ago when I was 2. The GP referred me to a very good dermatologist who explained things clearly as well as, crucially, how to sensibly explain it to other children." ***(Pt11, female 26-45 years)***

"I would like more information on the cause of it and how to deal with being so self-conscious about it - it does affect confidence and forming relationships." ***(Pt130, female, 26-45 years)***

Perceptions and experiences of vitiligo treatments

Experiences of vitiligo treatments expressed by participants were very mixed. Whilst some participants expressed positive experiences of treatment, particularly UV light treatment, many participants appeared to have more negative experiences of seeking and receiving treatment for their vitiligo. A commonly expressed view was that vitiligo treatment is not routinely offered or is poorly available, especially on the NHS, and is limited to particular geographical locations.

"We decided to have light treatment. My main concern was the Vitiligo on my face. The treatment worked well but a few years later it appeared elsewhere on my face so I had more treatment that also worked well. The spread of vitiligo has slowed to almost a stop apart from a couple of new areas on my face." ***(Pt74, male, 46-65 years)***

"There is very little treatment for Vitiligo in the UK. I am at present involved with the Hi-Light trial run by the Univ of Nottingham. This is the first time I have been able to obtain any treatment." ***(Pt102, male, over 65 years)***

Many participants, who had received treatments such as steroid creams and light treatment for their vitiligo, felt they were ineffective in the long-term as the treatments had been unsuccessful in maintaining any areas of re-pigmentation. Participants also reported the perceived difficulties and potential side effects of vitiligo treatment such as concerns about skin thinning with steroid creams, time-consuming nature and inconvenience of hospital-based UV light treatment and the physical side effects of light treatment such as nausea and headaches.

"I was referred to Dermatology and was prescribed PUVA treatment. This helped for a while, but became so time consuming. Progress was very slow. I stopped the treatment and any areas of repigmentation soon reverted back to white skin. So disappointing." ***(Pt156, female, 46-65 years)***

As well as mixed experiences of vitiligo treatments, there were mixed attitudes towards the need to seek vitiligo treatments in the first instance. Some participants reported less experience of treatments because they had not sought these out and had 'accepted' their vitiligo, even though it may have had a profound impact on their lives.

"I think that vitiligo is a relatively unknown condition. I have never been contacted about treatment or had it offered to me despite having had the condition for many years. You are very much left to get on with it. I can imagine that some people suffer psychologically and I wonder what support they get. I have come to terms with my patches and embrace them rather than disguise them but it can feel quite disheartening at times and I would rather not have them given the choice." ***(Pt58, female, 46-65 years)***

DISCUSSION

We found predominantly negative experiences of help-seeking, concerns about the credibility of online information, and the need for detailed, reliable vitiligo information. Frustration with challenges to help-seeking was often reported, particularly perceived lack of awareness of available treatments amongst GPs. Many felt that vitiligo was often dismissed by health professionals as 'cosmetic', which was upsetting to those experiencing substantial psychosocial impact. Where GPs appeared sympathetic or where signposting towards further information was offered this was appreciated, even where people felt their GP had not seemed knowledgeable. There were very mixed views about the need for treatment and a desire for support with managing the psychosocial impact of vitiligo.

This study provides valuable insights into the experiences of people with vitiligo in seeking information and treatment about their condition. We employed an efficient yet relatively under-utilised method of qualitative data collection to explore an under-researched topic area. Given the relative anonymity of providing written responses in an online survey, these data may have been more candid than data collected in face-to-face research settings. However, 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.

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

Most of the participants in this study were over 45, which is likely to be unrepresentative of the whole population of people with vitiligo as the condition commonly appears before the age of 20.[17] [18] It is likely that most of the participants had had vitiligo for many years and their experience may differ from those more recently diagnosed. Furthermore, by sampling through a patient support group we may have been more likely to receive accounts from people whose needs had not been met by health services, although it is notable that this group still felt that they had many unanswered questions and that they found online information difficult to navigate.

The feeling that vitiligo is dismissed by health professionals as ‘cosmetic’ or ‘trivial’ shows that this is an ongoing concern for people, in common with previous reports,[9 10] and also in line with other skin conditions.[19 20] We found that people can find it difficult to judge the credibility of online information on vitiligo, as in other conditions[21], but it seems surprising in this context where participants are all members of a relevant support group. We also found that participants still generally view health professionals as an important source of information, which has been noted in other studies[22] Again it seems surprising that our participants, who were 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. Our finding that people are keen for support with managing the psychosocial impact of living with vitiligo was also found in a recent James Lind Alliance Priority Setting Partnership in the UK, which identified the need for further research into the effectiveness of psychological support for people with vitiligo, either on its own or together with other treatments.[23] The importance of providing people with skin diseases with access to a range of supportive services including psychological support was also acknowledged in a recent report of the All Party Parliamentary Group on Skin.[24]

Constraints on access to specialists through Primary Care ‘gatekeeping’ or ‘managed care’ may be associated with lower patient satisfaction [25] and respondents in this study expressed frustration with generalist services, perceiving them to have a low level of knowledge about their condition. It is not completely clear whether this represents lack of awareness amongst GPs of available treatments for vitiligo, or lack of provision of services into which they can refer. Access to vitiligo services/treatment is becoming increasingly difficult in many areas of the UK, which is likely to increase people's frustration with help-seeking and may exacerbate the psychosocial impact experienced by many people with vitiligo.

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. 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. In an era where people are increasingly obtaining health information online[26], it may be that education and psychological support interventions delivered online may beneficial.

In conclusion, more can be done to meet the information and help-seeking needs of people with vitiligo. People with vitiligo would welcome greater health professional awareness of the possibility of treating vitiligo, yet recognise that generalist services may not always be able to offer this. People who had been directed towards reliable information were very grateful for this and signposting is viewed as a key role of GPs, which remain the primary source of information for many. Fortunately good online resources for people with vitiligo are available (Box 1). Signposting people with vitiligo towards credible online resources and acknowledging and exploring the potential impact of the condition may allay people's perceptions that distress caused by the condition is not taken seriously.

Box 1: Online resources for people with vitiligo

Website	URL
NHS Choices	http://www.nhs.uk/conditions/Vitiligo/Pages/Introduction.aspx Links to the official website of the National Health Service in England. Their section on vitiligo provides information and advice about vitiligo symptoms, causes diagnosis and treatments.
Patient.co.uk	http://patient.info/health/vitiligo-leaflet Links to a general medical information and support website providing information and advice about vitiligo symptoms, causes and treatments.
The Vitiligo Society	http://www.vitiligosociety.org.uk/ Links to The Vitiligo Society website, a UK-based charity providing information and support for people with vitiligo through their regularly update website and newsletter, *Dispatches*.

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Competing interests

The authors have no conflicts of interest to declare.

Authors' contribution

MS, IM and KT designed the study; AAS collected the data under supervision of MS and BS; ET, IM, BS and MS made substantial contributions to the analysis and interpretation of the data; ET drafted the manuscript; IM, MS, BS, AAS and KT critically reviewed and revised the manuscript; all authors gave the final approval of the version to be published.

Data sharing statement

This is a qualitative study and therefore the data generated is not suitable for sharing beyond that contained within the report. Further information can be obtained from the corresponding author.

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	N/A
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	N/A
3. Occupation	What was their occupation at the time of the study?	N/A
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	N/A
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	N/A
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods, pg. 5
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods, pg. 5
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods, pg. 5
12. Sample size	How many participants were in the study?	Page 7
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Pages 2 & 5
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods, page 5
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A

16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 6
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	N/A
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	N/A
20. Field notes	Were field notes made during and/or after the inter view or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	N/A
22. Data saturation	Was data saturation discussed?	N/A
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Page 7
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 7
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 7&8
27. Software	What software, if applicable, was used to manage the data?	Page 8
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Pages 8-11
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Pages 8-11
31. Clarity of major themes	Were major themes clearly presented in the findings?	Pages 8-11
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Page 10

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Views and experiences of seeking information and help for vitiligo: a qualitative study of written accounts

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Views and experiences of seeking information and help for vitiligo: a qualitative study of written accounts

Running title: Experiences of seeking information and help for vitiligo

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ABSTRACT (296 words)

Objectives: Vitiligo is a relatively common autoimmune condition causing loss of skin pigment. Around 1 in 100 people in the UK develop vitiligo. It can have a significant impact on quality of life for many of those affected. How people access information and help for vitiligo may influence how they manage such impact. We aimed to explore people's views and experiences of seeking health information and help for vitiligo.

Design: Qualitative analysis of free-text responses to four open-ended questions in an online survey.

Setting: Online survey conducted in the UK between February and March 2016

Participants: A survey link was emailed to 675 members of The Vitiligo Society, a UK-based charity providing information and support for people with vitiligo. One hundred and sixty one members responded to the survey (24%).

Results: Many participants wrote extensive free text, often reporting frustration with help-seeking. They perceived General Practitioners (GPs) as their primary source of advice but felt that GPs had low awareness of available treatments. Where GPs appeared sympathetic or signposted towards further information this was appreciated, even where people felt their GP had not seemed knowledgeable. Many felt that vitiligo was dismissed by health professionals including GPs and Dermatologists as 'cosmetic', which upset those who experienced substantial impact. Participants expressed concerns about the credibility of online information on vitiligo and the need for reliable, detailed information, as well as a desire for support with managing its psychosocial impact.

Conclusions: Information and help-seeking needs of people with vitiligo currently appear to be poorly met, even amongst members of the Vitiligo Society, who are likely to have received more information than others. People with vitiligo would welcome greater health professional awareness of available vitiligo treatments. Acknowledging the psychosocial impacts of vitiligo and signposting towards credible information are also welcomed.

KEYWORDS

Vitiligo; primary health care; qualitative; patient experience; information; dermatology

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We employed an efficient yet relatively under-utilised method of qualitative data collection to explore an under-researched topic area.

- Conducting an exploratory qualitative analysis of the free text comments within a quantitative survey allowed us to gain novel and valuable insights into, and a greater understanding about, the experiences of people with vitiligo in seeking information and treatment about their condition.

- A limitation of this study was our sampling method. Members of the Vitiligo Society may not be representative of all people with vitiligo, which limits the transferability of our findings. Participants in this study could have had greater impact from vitiligo, been more unsatisfied with the information they had received, or more engaged with seeking treatment and information, than other people with vitiligo.

- Also most of the participants in this study were over 45, which is likely to be unrepresentative of the whole population of people with vitiligo as the condition commonly appears before the age of 20.

INTRODUCTION

Vitiligo is an autoimmune disease where pale white patches progressively develop on the skin due to loss of pigment. Worldwide prevalence ranges between 0.5 and 2% and around 1 in 100 people in the UK develop vitiligo.[1 2] The appearance altering nature of vitiligo can have a significant impact on quality of life, particularly in terms of increased anxiety, lowered self-esteem, relationship difficulties, and it may also negatively affect self-confidence and body image.[3 4] Most vitiligo develops before the age of 20 and may have a profound impact on confidence and self-image at a key time in social development.[5]

The evidence base for vitiligo treatment is currently poor.[6] A European Guideline has suggested that early treatment of small lesions of recent onset and childhood vitiligo should be treated with a combination of phototherapy and topical agents, such as topical corticosteroids or topical calcineurin inhibitors.[7] 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.

Previous research has highlighted the psychosocial impact of vitiligo and the coping strategies adopted by people living with vitiligo. A survey carried out amongst members of the Vitiligo Society in 2010 showed that over half (56.6%) of respondents felt that vitiligo moderately or severely affected their quality of life.[8] One qualitative interview study carried out with seven white British women, reported a continuous struggle using avoidance, concealment and cognitive strategies to try to deal with the impact of vitiligo.[9] Another qualitative interview study was conducted with seven British women of South Asian descent. All had experienced stigmatisation to some extent. Avoidance and concealment were commonplace, as was a profound impact on their relationships and sense of identity.[10]

How people access and make sense of information, and seek help for vitiligo, is likely to influence how they cope with the psychosocial impacts but there is relatively little research on people's experiences of obtaining information and treatment for vitiligo. Previous quantitative research suggests that people with vitiligo typically want to find a lasting effective treatment but they appear to have difficulty accessing treatment and feel that their condition is dismissed as 'trivial' or 'cosmetic'.[8 11] Members of the Vitiligo Society have reported that they obtain information about vitiligo from non-medical sources, such as the Vitiligo Society (83%) and the internet (25%) rather than from dermatologists (13%) and General Practitioners (GPs) (7%).[8] Surprisingly few had obtained advice from GPs or dermatologists. Further research is needed to explore whether this relates to difficulties in accessing advice or whether people actively choose to obtain advice elsewhere.

Qualitative methods are well suited to exploring a topic in-depth from the perspective of a particular group of people. Qualitative research that seeks to explore people's experiences of obtaining information about vitiligo and their help seeking behaviour could help to determine whether people with vitiligo expect GPs or Dermatologists to advise them about vitiligo or whether they generally seek information from charities or the internet instead of, or in addition to, consulting. This in turn would enable better understanding of how GPs and Dermatologists can best support people with vitiligo in terms of information provision and/ or signposting to reliable resources. Given the potential insights into people's experiences to be gained by using qualitative methods[12], we incorporated open-ended questions into a quantitative survey about information and help-seeking behaviour in people with vitiligo. We aimed to explore views and experiences of seeking information and help for vitiligo through analysis of the written accounts of survey respondents.

METHODS

This study sought to qualitatively analyse the free text comments within a quantitative survey that focused on exploring sources of information for vitiligo, experiences of treatment and information needs. This qualitative approach has been previously used in other health-related research.[13-15] Ethical approval was granted by the Faculty of Medicine Research Ethics Committee, University of Southampton.

Main survey

An anonymous online survey of people with vitiligo was conducted in the UK in February 2016 (response rate 161/675 (24%)). We sought participants through the Vitiligo Society, partly because this had been a successful route for previous research[8] but also because informal advice suggested vitiligo might not be well coded in primary care so recruiting through this route would be problematic. Details about the study and a link to the online survey were emailed to 675 members of the Vitiligo Society. A reminder email was sent out after 2 weeks. The survey link was also made available on the Vitiligo Society website from February to March 2016. Participants provided online informed consent prior to accessing the survey. In total, 161 people completed some or all of the survey questions and were included in the analysis (Table 1). Quantitative survey findings regarding sources of information and help-seeking were similar to those previously reported.[8] This paper focusses on the rich qualitative data obtained from the free text responses to open-ended questions in the survey.

Table 1: Survey Respondents' Characteristics

	Number of participants N=161	**Percentage (%)**
Answered for themselves	151	93.8
Answered on behalf of other person	4	2.5
Missing	6	3.7
Gender :		
Male	55	34.1
Female	98	60.9
Missing	8	5.0
Age :		
5-16 years	2	1.2
16-25 years	8	5.0
26-45 years	27	16.8
46-65 years	73	45.3
More than 65 years	45	28.0
Missing	6	3.7
Portion of skin affected :		
Just a few patches (0-10%)	35	21.7
A fair amount (10-25%)	41	25.5
Quite a lot (25-50%)	33	20.5
Very much (50-80%)	25	15.5
All or nearly all (more than 80%)	19	11.8
Missing	8	5.0
Skin Colour :		
Fair	67	41.6
Medium	75	46.6
Dark	10	6.2
Very dark	1	0.6
Missing	8	5.0
Family with vitiligo :		
Yes	72	44.7
No	82	50.9
Missing	7	4.4
Living :		
UK	147	91.3
Europe	1	0.6
Elsewhere	5	3.1
Missing	8	5.0

Qualitative component

The online survey included four open-ended questions, which allowed participants to respond in more detail (Table 2). The survey dataset was imported into NVivo 10 and responses to the open-ended questions collated for analysis. 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). Responses to the open-ended questions ranged from brief comments (one phrase or sentence) to more detailed accounts (a couple of paragraphs). Question 3 (informational needs of people with vitiligo) received the most responses and question 2 (experiences of seeking treatment for vitiligo) received the most detailed comments.

Table 2: Open-ended questions in survey

Questions	**No. of responses to each question** **%**	**Total no. of words per question**
Q1.We would be very interested to learn more about your experience of getting information for vitiligo. *If you are happy to, please can you tell us some more about this?*	**142** (90%)	5,419
Q2. We would be very interested to learn more about your experience of getting treatment for vitiligo. *If you are happy to, please can you tell us some more about this?*	**103** (65%)	6,634
Q3. Are there any aspects of vitiligo that you feel you would like to know more about?	**148** (94%)	3,682
Q4. Is there anything you would like to say that you feel has not been covered already?	**102** (65%)	4,993

Data analysis

An inductive thematic analysis was conducted to explore people's experiences of seeking information and help for vitiligo.[16] One author (ET) read the comments several times to achieve familiarisation with the data and codes were applied line by line. Codes were derived inductively from the data and grouped together to produce an initial coding frame. Codes were compared to identify similarities and differences. 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 (ET, MS and IM) to offer diverse inferences and interpretation of the data. A negative case analysis was carried out to ensure that all data was taken into account rather than just selecting data that fitted with the authors' viewpoint.

Data saturation could not be determined due to the nature of the method of data collection. Using NVivo enabled a detailed audit trail to be maintained.

RESULTS

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. Analysis of these data highlighted 3 themes: 1) ***experiences of consulting health professionals for vitiligo**,* 2) ***seeking information about vitiligo***, 3) ***perceptions and experiences of vitiligo treatments***. These themes are explored in detail below. All quotes are labelled with a participant ID, gender and age.

Experiences of consulting health professionals for vitiligo

A sense of dissatisfaction and feeling unsupported was apparent in participants' reports about their experiences of consulting health professionals for vitiligo. Participants often seemed disappointed by the response they had received from GPs, who were viewed as their primary source of contact and advice. A common perception amongst participants was that GPs are not generally aware of, or particularly knowledgeable about, vitiligo and as such can only provide limited information and advice to patients.

"None of the GP's I have spoken to have ever offered advice about Vitiligo. They seem to be somewhat in the dark about the problem." ***(Pt36, male, over 65 years)***

Where health professionals appeared sympathetic or where signposting towards further information was offered this was appreciated, even where people felt their GP had not been knowledgeable.

"I have had vitiligo for about 35 years. I am now 70 years old. I have found that, with very few exceptions, GPs know little about the condition. One of my GPs (who "half-retired" a few years ago) was always interested in learning more and asked me if I could provide some information on vitiligo. I gave her some printed material and she was grateful; I know that she read everything which I provided." ***(Pt110, male, over 65 years)***

Many participants felt they had just been left to 'get on with it' and learn to accept and manage their vitiligo on their own. For some participants this led them to seeking out alternative treatments not available in the UK. Another dominant perspective in this study was the sense that vitiligo is not taken seriously by medical professionals, both GPs and dermatologists. Many participants felt that their vitiligo was dismissed by health professionals as something inconsequential, i.e. purely cosmetic, which was upsetting to those experiencing substantial psychosocial impact.

"I started my first signs of Vitiligo 30 years ago at the age of 40. I went to my GP who referred me to a consultant. The consultant proved to be absolutely useless in providing any information. He just took one look at me, told me it was something called Vitiligo and told me that it would most likely get worse but wouldn't kill me!!!" ***(Pt71, female, over 65 years)***

"I noticed most doctors don't know much about vitiligo and really don't seem to care. I felt they had no clue about what a person with vitiligo goes through, Since it's not a matter of life or death, your expected to just accept it. I was very disappointed every time, always left feeling hopeless. I think they should have more to offer, be sympathetic & at least try different things" ***(Pt138, female, 46-65 years)***

Seeking information about vitiligo

Participants commonly reported seeking information from other sources, predominantly online resources, as a result of receiving limited information from health professionals. The Vitiligo Society was viewed as a helpful and trustworthy source of information for participants but many expressed doubts about the reliability and credibility of other online resources about vitiligo. A common concern expressed by the participants related to the credibility of online information on possible treatments for vitiligo. In particular, they expressed doubts about the commercial interests of the websites and about being able to determine the evidence base (safety and efficacy) of certain products and procedures.

"I find it very difficult to find clear and consistent advice on possible treatments for Vitiligo. There are a lot of commercially orientated websites promoting a variety of herbal cures etc but limited proper evidence based medical guidance." ***(Pt40, male, 26-45 years)***

"The only problem when searching for vitiligo sites is that some websites eventually lead into selling some sort of product which is the new "best treatment". You find that because you are motivated to find some sort of treatment you end up almost believing the hype that they sell." ***(Pt139, male, 46-65 years)***

A desire for detailed, reliable information about the causes of vitiligo, its progression and possible treatments was widely expressed. Some participants felt it important that such information should come directly from health professionals or other resources perceived to be trustworthy such as NHS Choices. Participants also expressed a desire for information and advice about managing the psychosocial impact of living with vitiligo, particularly advice on learning to cope with social situations and people's reactions to their altered appearance, and how to explain the condition to others.

"I developed vitiligo 42 years ago when I was 2. The GP referred me to a very good dermatologist who explained things clearly as well as, crucially, how to sensibly explain it to other children." ***(Pt11, female 26-45 years)***

"I would like more information on the cause of it and how to deal with being so self-conscious about it - it does affect confidence and forming relationships." ***(Pt130, female, 26-45 years)***

Perceptions and experiences of vitiligo treatments

Experiences of vitiligo treatments expressed by participants were very mixed. Whilst some participants expressed positive experiences of treatment, particularly UV light treatment, many participants appeared to have more negative experiences of seeking and receiving treatment for their vitiligo. A commonly expressed view was that vitiligo treatment is not routinely offered or is poorly available, especially on the NHS, and is limited to particular geographical locations.

"We decided to have light treatment. My main concern was the Vitiligo on my face. The treatment worked well but a few years later it appeared elsewhere on my face so I had more treatment that also worked well. The spread of vitiligo has slowed to almost a stop apart from a couple of new areas on my face." ***(Pt74, male, 46-65 years)***

"There is very little treatment for Vitiligo in the UK. I am at present involved with the Hi-Light trial run by the Univ of Nottingham. This is the first time I have been able to obtain any treatment." ***(Pt102, male, over 65 years)***

Many participants, who had received treatments such as steroid creams and light treatment for their vitiligo, felt they were ineffective in the long-term as the treatments had been unsuccessful in maintaining any areas of re-pigmentation. Participants also reported the perceived difficulties and potential side effects of vitiligo treatment such as concerns about skin thinning with steroid creams, time-consuming nature and inconvenience of hospital-based UV light treatment and the physical side effects of light treatment such as nausea and headaches.

"I was referred to Dermatology and was prescribed PUVA treatment. This helped for a while, but became so time consuming. Progress was very slow. I stopped the treatment and any areas of repigmentation soon reverted back to white skin. So disappointing." ***(Pt156, female, 46-65 years)***

As well as mixed experiences of vitiligo treatments, there were mixed attitudes towards the need to seek vitiligo treatments in the first instance. Some participants reported less experience of treatments because they had not sought these out and had ‘accepted’ their vitiligo, even though it may have had a profound impact on their lives.

“I think that vitiligo is a relatively unknown condition. I have never been contacted about treatment or had it offered to me despite having had the condition for many years. You are very much left to get on with it. I can imagine that some people suffer psychologically and I wonder what support they get. I have come to terms with my patches and embrace them rather than disguise them but it can feel quite disheartening at times and I would rather not have them given the choice.” ***(Pt58, female, 46-65 years)***

DISCUSSION

We found predominantly negative experiences of help-seeking, concerns about the credibility of online information, and the need for detailed, reliable vitiligo information. Frustration with challenges to help-seeking was often reported, particularly perceived lack of awareness of available treatments amongst GPs. Many felt that vitiligo was often dismissed by health professionals as ‘cosmetic’, which was upsetting to those experiencing substantial psychosocial impact. Where GPs appeared sympathetic or where signposting towards further information was offered this was appreciated, even where people felt their GP had not seemed knowledgeable. There were very mixed views about the need for treatment and a desire for support with managing the psychosocial impact of vitiligo.

This study provides valuable insights into the experiences of people with vitiligo in seeking information and treatment about their condition. We employed an efficient yet relatively under-utilised method of qualitative data collection to explore an under-researched topic area. Given the relative anonymity of providing written responses in an online survey, these data may have been more candid than data collected in face-to-face research settings. However, 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.

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

Most of the participants in this study were over 45, which is likely to be unrepresentative of the whole population of people with vitiligo as the condition commonly appears before the age of 20.[17] [18] It is likely that most of the participants had had vitiligo for many years and their experience may differ from those more recently diagnosed. Furthermore, by sampling through a patient support group we may have been more likely to receive accounts from people whose needs had not been met by health services, although it is notable that this group still felt that they had many unanswered questions and that they found online information difficult to navigate.

The feeling that vitiligo is dismissed by health professionals as ‘cosmetic’ or ‘trivial’ shows that this is an ongoing concern for people, in common with previous reports,[9 10] and also in line with other skin conditions.[19 20] We found that people can find it difficult to judge the credibility of online information on vitiligo, as in other conditions[21], but it seems surprising in this context where participants are all members of a relevant support group. We also found that participants still generally view health professionals as an important source of information, which has been noted in other studies[22] Again it seems surprising that our participants, who were 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. Our finding that people are keen for support with managing the psychosocial impact of living with vitiligo was also found in a recent James Lind Alliance Priority Setting Partnership in the UK, which identified the need for further research into the effectiveness of psychological support for people with vitiligo, either on its own or together with other treatments.[23] The importance of providing people with skin diseases with access to a range of supportive services including psychological support was also acknowledged in a recent report of the All Party Parliamentary Group on Skin.[24]

Constraints on access to specialists through Primary Care ‘gatekeeping’ or ‘managed care’ may be associated with lower patient satisfaction [25] and respondents in this study expressed frustration with generalist services, perceiving them to have a low level of knowledge about their condition. It is not completely clear whether this represents lack of awareness amongst GPs of available treatments for vitiligo, or lack of provision of services into which they can refer. Access to vitiligo services/treatment is becoming increasingly difficult in many areas of the UK, which is likely to increase people's frustration with help-seeking and may exacerbate the psychosocial impact experienced by many people with vitiligo.

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. 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. In an era where people are increasingly obtaining health information online[26], it may be that education and psychological support interventions delivered online may beneficial.

In conclusion, more can be done to meet the information and help-seeking needs of people with vitiligo. People with vitiligo would welcome greater health professional awareness of the possibility of treating vitiligo, yet recognise that generalist services may not always be able to offer this. People who had been directed towards reliable information were very grateful for this and signposting is viewed as a key role of GPs, which remain the primary source of information for many. Fortunately good online resources for people with vitiligo are available (Box 1). Signposting people with vitiligo towards credible online resources and acknowledging and exploring the potential impact of the condition may allay people's perceptions that distress caused by the condition is not taken seriously.

Box 1: Online resources for people with vitiligo

Website	**URL**
NHS Choices	http://www.nhs.uk/conditions/Vitiligo/Pages/Introduction.aspx Links to the official website of the National Health Service in England. Their section on vitiligo provides information and advice about vitiligo symptoms, causes diagnosis and treatments.
Patient.co.uk	http://patient.info/health/vitiligo-leaflet Links to a general medical information and support website providing information and advice about vitiligo symptoms, causes and treatments.
The Vitiligo Society	http://www.vitiligosociety.org.uk/ Links to The Vitiligo Society website, a UK-based charity providing information and support for people with vitiligo through their regularly update website and newsletter, *Dispatches*.

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Competing interests

The authors have no conflicts of interest to declare.

Authors' contribution

MS, IM and KT designed the study; AAS collected the data under supervision of MS and BS; ET, IM, BS and MS made substantial contributions to the analysis and interpretation of the data; ET drafted the manuscript; IM, MS, BS, AAS and KT critically reviewed and revised the manuscript; all authors gave the final approval of the version to be published.

Data sharing statement

This is a qualitative study and therefore the data generated is not suitable for sharing beyond that contained within the report. Further information can be obtained from the corresponding author.

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	N/A
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	N/A
3. Occupation	What was their occupation at the time of the study?	N/A
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	N/A
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	N/A
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods, pg. 5
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods, pg. 5
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods, pg. 5
12. Sample size	How many participants were in the study?	Page 7
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Pages 2 & 5
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods, page 5
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A

16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 6
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	N/A
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	N/A
20. Field notes	Were field notes made during and/or after the inter view or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	N/A
22. Data saturation	Was data saturation discussed?	N/A
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Page 7
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 7
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 7&8
27. Software	What software, if applicable, was used to manage the data?	Page 8
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Pages 8-11
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Pages 8-11
31. Clarity of major themes	Were major themes clearly presented in the findings?	Pages 8-11
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Page 10