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

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

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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 reported¹¹ 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

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3 dermatologists. Further research is needed to explore whether this relates to difficulties in accessing
4 advice or whether people actively choose to obtain advice elsewhere.
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7 Qualitative methods are well suited to exploring a topic in-depth from the perspective of a particular
8 group of people. Qualitative research that seeks to explore people's experiences of obtaining
9 information about vitiligo and their help seeking behaviour could help to determine whether people
10 with vitiligo expect GPs or Dermatologists to advise them about vitiligo or whether they generally
11 seek information from charities or the internet instead of, or in addition to, consulting. This in turn
12 would enable better understanding of how GPs and Dermatologists can best support people with
13 vitiligo in terms of information provision and/ or signposting to reliable resources. Given the
14 potential insights into people's experiences to be gained by using qualitative methods¹², we
15 incorporated open-ended questions into a quantitative survey about information and help-seeking
16 behaviour in people with vitiligo. We aimed to explore views and experiences of seeking
17 information and help for vitiligo through analysis of the written accounts of survey respondents.
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28 **METHODS**

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

40 An anonymous online survey of people with vitiligo was conducted in the UK in February 2016
41 (response rate 161/675 (24%)). We sought participants through the Vitiligo Society, partly because
42 this had been a successful route for previous research⁸ but also because informal advice suggested
43 vitiligo might not be well coded in primary care so recruiting through this route would be
44 problematic. Details about the study and a link to the online survey were emailed to 675 members
45 of the Vitiligo Society. A reminder email was sent out after 2 weeks. The survey link was also made
46 available on the Vitiligo Society website from February to March 2016. In total, 161 people
47 completed some or all of the survey questions and were included in the analysis. Participant
48 characteristics are presented in Table 1. Quantitative survey findings regarding sources of
49 information and help-seeking were similar to those previously reported.⁸ This paper focusses on the
50 rich qualitative data obtained from the free text responses to open-ended questions in the survey.
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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. <i>If you are happy to, please can you tell us some more about this?</i>	142 (90%)	5,419
Q2. We would be very interested to learn more about your experience of getting treatment for vitiligo. <i>If you are happy to, please can you tell us some more about this?</i>	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,

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3 and iteratively developed by, three members of the research team (EJT, MS and IM) to offer diverse
4 inferences and interpretation of the data. A negative case analysis was carried out to ensure that all
5 data was taken into account rather than just selecting data that fitted with the authors' viewpoint.
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7 Data saturation could not be determined due to the nature of the method of data collection. Using
8 NVivo enabled a detailed audit trail to be maintained. Ethical approval was granted by the Faculty of
9
10 Medicine Research Ethics Committee, University of Southampton.
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13 14 15 16 RESULTS

17
18 The majority of survey respondents (n=158, 98%) completed the open-ended questions, suggesting a
19 high level of enthusiasm to provide written feedback on their experiences of seeking help and
20 information for vitiligo. Analysis of these data highlighted 3 themes: 1) **experiences of consulting**
21 **health professionals for vitiligo**, 2) **seeking information about vitiligo**, 3) **perceptions and**
22 **experiences of vitiligo treatments**. These themes are explored in detail below. All quotes are
23
24 labelled with a participant ID, gender and age.
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30 31 Experiences of consulting health professionals for vitiligo

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33 A sense of dissatisfaction and feeling unsupported was apparent in participants' reports about their
34 experiences of consulting health professionals for vitiligo. Participants often seemed disappointed
35 by the response they had received from GPs, who were viewed as their primary source of contact
36 and advice. A common perception amongst participants was that GPs are not generally aware of, or
37 particularly knowledgeable about, vitiligo and as such can only provide limited information and
38
39 advice to patients.
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43 *"None of the GP's I have spoken to have ever offered advice about Vitiligo. They seem to be somewhat in the*
44 *dark about the problem." (Pt36, male, over 65 years)*
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48 Where health professionals appeared sympathetic or where signposting towards further information
49 was offered this was appreciated, even where people felt their GP had not been knowledgeable.
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52 *"I have had vitiligo for about 35 years. I am now 70 years old. I have found that, with very few exceptions, GPs*
53 *know little about the condition. One of my GPs (who "half-retired" a few years ago) was always interested in*
54 *learning more and asked me if I could provide some information on vitiligo. I gave her some printed material*
55 *and she was grateful; I know that she read everything which I provided." (Pt110, male, over 65 years)*
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3 Many participants felt they had just been left to 'get on with it' and learn to accept and manage their
4 vitiligo on their own. For some participants this led them to seeking out alternative treatments not
5 available in the UK. Another dominant perspective in this study was the sense that vitiligo is not
6 taken seriously by medical professionals, both GPs and dermatologists. Many participants felt that
7 their vitiligo was dismissed by health professionals as something inconsequential, i.e. purely
8 cosmetic, which was upsetting to those experiencing substantial psychosocial impact.
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13 *"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
14 consultant. The consultant proved to be absolutely useless in providing any information. He just took one look
15 at me, told me it was something called Vitiligo and told me that it would most likely get worse but wouldn't kill
16 me!!!" (Pt71, female, over 65 years)*
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19 *"I noticed most doctors don't know much about vitiligo and really don't seem to care. I felt they had no clue
20 about what a person with vitiligo goes through, Since it's not a matter of life or death, your expected to just
21 accept it. I was very disappointed every time, always left feeling hopeless. I think they should have more to
22 offer, be sympathetic & at least try different things" (Pt138, female, 46-65 years)*
23

24 25 26 27 **Seeking information about vitiligo**

28
29 Participants commonly reported seeking information from other sources, predominantly online
30 resources, as a result of receiving limited information from health professionals. The Vitiligo Society
31 was viewed as a helpful and trustworthy source of information for participants but many expressed
32 doubts about the reliability and credibility of other online resources about vitiligo. A common
33 concern expressed by the participants related to the credibility of online information on possible
34 treatments for vitiligo. In particular, they expressed doubts about the commercial interests of the
35 websites and about being able to determine the evidence base (safety and efficacy) of certain
36 products and procedures.
37

38
39 *"I find it very difficult to find clear and consistent advice on possible treatments for Vitiligo. There are a lot of
40 commercially orientated websites promoting a variety of herbal cures etc but limited proper evidence based
41 medical guidance." (Pt40, male, 26-45 years)*
42

43
44 *"The only problem when searching for vitiligo sites is that some websites eventually lead into selling some sort
45 of product which is the new "best treatment". You find that because you are motivated to find some sort of
46 treatment you end up almost believing the hype that they sell." (Pt139, male, 46-65 years)*
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53 A desire for detailed, reliable information about the causes of vitiligo, its progression and possible
54 treatments was widely expressed. Some participants felt it important that such information should
55 come directly from health professionals or other resources perceived to be trustworthy such as NHS
56 Choices. Participants also expressed a desire for information and advice about managing the
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3 psychosocial impact of living with vitiligo, particularly advice on learning to cope with social
4 situations and people's reactions to their altered appearance, and how to explain the condition to
5 others.
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9 *"I developed vitiligo 42 years ago when I was 2. The GP referred me to a very good dermatologist who*
10 *explained things clearly as well as, crucially, how to sensibly explain it to other children." (Pt11, female 26-45*
11 *years)*

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13 *"I would like more information on the cause of it and how to deal with being so self-conscious about it - it does*
14 *affect confidence and forming relationships." (Pt130, female, 26-45 years)*
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16 17 18 **Perceptions and experiences of vitiligo treatments**

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20 Experiences of vitiligo treatments expressed by participants were very mixed. Whilst some
21 participants expressed positive experiences of treatment, particularly UV light treatment, many
22 participants appeared to have more negative experiences of seeking and receiving treatment for
23 their vitiligo. A commonly expressed view was that vitiligo treatment is not routinely offered or is
24 poorly available, especially on the NHS, and is limited to particular geographical locations.
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29 *"We decided to have light treatment. My main concern was the Vitiligo on my face. The treatment worked well*
30 *but a few years later it appeared elsewhere on my face so I had more treatment that also worked well. The*
31 *spread of vitiligo has slowed to almost a stop apart from a couple of new areas on my face." (Pt74, male, 46-65*
32 *years)*
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35 *"There is very little treatment for Vitiligo in the UK. I am at present involved with the Hi-Light trial run by the*
36 *Univ of Nottingham. This is the first time I have been able to obtain any treatment." (Pt102, male, over 65*
37 *years)*
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40 Many participants, who had received treatments such as steroid creams and light treatment for their
41 vitiligo, felt they were ineffective in the long-term as the treatments had been unsuccessful in
42 maintaining any areas of re-pigmentation. Participants also reported the perceived difficulties and
43 potential side effects of vitiligo treatment such as concerns about skin thinning with steroid creams,
44 time-consuming nature and inconvenience of hospital-based UV light treatment and the physical
45 side effects of light treatment such as nausea and headaches.
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51 *"I was referred to Dermatology and was prescribed PUVA treatment. This helped for a while, but became so*
52 *time consuming. Progress was very slow. I stopped the treatment and any areas of repigmentation soon*
53 *reverted back to white skin. So disappointing." (Pt156, female, 46-65 years)*
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3 As well as mixed experiences of vitiligo treatments, there were mixed attitudes towards the need to
4 seek vitiligo treatments in the first instance. Some participants reported less experience of
5 treatments because they had not sought these out and had 'accepted' their vitiligo, even though it
6 may have had a profound impact on their lives.
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10 *"I think that vitiligo is a relatively unknown condition. I have never been contacted about treatment or had it*
11 *offered to me despite having had the condition for many years. You are very much left to get on with it. I can*
12 *imagine that some people suffer psychologically and I wonder what support they get. I have come to terms*
13 *with my patches and embrace them rather than disguise them but it can feel quite disheartening at times and I*
14 *would rather not have them given the choice."* (Pt58, female, 46-65 years)
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17 18 19 **DISCUSSION**

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21 To our knowledge, this is the first qualitative study of people's experiences seeking information and
22 treatment for vitiligo. We found predominantly negative experiences of help-seeking, concerns
23 about the credibility of online information, and the need for detailed, reliable vitiligo information.
24 Frustration with challenges to help-seeking was often reported, particularly perceived lack of
25 awareness of available treatments amongst GPs. Many felt that vitiligo was often dismissed by
26 health professionals as 'cosmetic', which was upsetting to those experiencing substantial
27 psychosocial impact. Where GPs appeared sympathetic or where signposting towards further
28 information was offered this was appreciated, even where people felt their GP had not seemed
29 knowledgeable. There were very mixed views about the need for treatment and a desire for support
30 with managing the psychosocial impact of vitiligo.
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40 This novel study provides valuable insights into the experiences of people with vitiligo in seeking
41 information and treatment about their condition. We employed an efficient yet relatively under-
42 utilised method of qualitative data collection to explore an under-researched topic area. However,
43 our findings need to be seen in the context of our sampling method. People with vitiligo who are
44 members of the Vitiligo Society may not be representative of all people with vitiligo and the
45 response rate for our survey, which was carried out entirely online, was lower than the previous
46 survey amongst Vitiligo Society members⁸, which was carried out by post. This may mean that
47 participants in this study had greater impact from vitiligo, or were more engaged with seeking
48 treatment and information, than other people with vitiligo.
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55 Most of the participants in this study were over 45, which is likely to be unrepresentative of the
56 whole population of people with vitiligo as the condition commonly appears before the age of 20.¹⁷
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3 ¹⁸ It is likely that most of the participants had had vitiligo for many years and their experience may
4 differ from those more recently diagnosed. Furthermore, by sampling through a patient support
5 group we may have been more likely to receive accounts from people whose needs had not been
6 met by health services, although it is notable that this group still felt that they had many
7 unanswered questions and that they found online information difficult to navigate.
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14 The feeling that vitiligo is dismissed by health professionals as 'cosmetic' or 'trivial' shows that this is
15 an ongoing concern for people, in common with previous reports,^{9,10} and also in line with other skin
16 conditions.^{19,20} We found that people can find it difficult to judge the credibility of online information
17 on vitiligo, as in other conditions²¹, but it seems surprising in this context where participants are all
18 members of a relevant support group. It is noteworthy that participants still generally view health
19 professionals as an important source of information, which has been noted in other studies²² but
20 again it seems surprising where participants are members of a support group and many reported
21 negative experiences of consulting. Our finding that people are keen for support with managing the
22 psychosocial impact of living with vitiligo was also found in a recent James Lind Alliance Priority
23 Setting Partnership in the UK, which identified the need for further research into the effectiveness of
24 psychological support for people with vitiligo, either on its own or together with other treatments.²³
25 The importance of providing people with skin diseases with access to a range of supportive services
26 including psychological support was also acknowledged in a recent report of the All Party
27 Parliamentary Group on Skin.²⁴ We feel that the varied views and experiences of vitiligo treatments
28 are novel findings, which have implications for further research into how to support people with
29 vitiligo.
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42 Constraints on access to specialists through Primary Care 'gatekeeping' or 'managed care' may be
43 associated with lower patient satisfaction²⁵ and respondents in this study expressed frustration
44 with generalist services, perceiving them to have a low level of knowledge about their condition. It is
45 not completely clear whether this represents lack of awareness amongst GPs of available treatments
46 for vitiligo, or lack of provision of services into which they can refer. Access to vitiligo
47 services/treatment is becoming increasingly difficult in many areas of the UK, which is likely to
48 increase people's frustration with help-seeking and may exacerbate the psychosocial impact
49 experienced by many people with vitiligo.
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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 online²⁶, 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.vitigosociety.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, <i>Dispatches</i> .

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

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8 **Views and experiences of seeking information and help for vitiligo: a**
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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.

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3 Qualitative methods are well suited to exploring a topic in-depth from the perspective of a particular
4 group of people. Qualitative research that seeks to explore people's experiences of obtaining
5 information about vitiligo and their help seeking behaviour could help to determine whether people
6 with vitiligo expect GPs or Dermatologists to advise them about vitiligo or whether they generally
7 seek information from charities or the internet instead of, or in addition to, consulting. This in turn
8 would enable better understanding of how GPs and Dermatologists can best support people with
9 vitiligo in terms of information provision and/ or signposting to reliable resources. Given the
10 potential insights into people's experiences to be gained by using qualitative methods¹², we
11 incorporated open-ended questions into a quantitative survey about information and help-seeking
12 behaviour in people with vitiligo. We aimed to explore views and experiences of seeking
13 information and help for vitiligo through analysis of the written accounts of survey respondents.
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23 **METHODS**

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25 This study sought to qualitatively analyse the free text comments within a quantitative survey that
26 focused on exploring sources of information for vitiligo, experiences of treatment and information
27 needs. This qualitative approach has been previously used in other health-related research.¹³⁻¹⁵
28
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30 Ethical approval was granted by the Faculty of Medicine Research Ethics Committee, University of
31 Southampton.
32
33

34 **Main survey**

35
36 An anonymous online survey of people with vitiligo was conducted in the UK in February 2016
37 (response rate 161/675 (24%)). We sought participants through the Vitiligo Society, partly because
38 this had been a successful route for previous research⁸ but also because informal advice suggested
39 vitiligo might not be well coded in primary care so recruiting through this route would be
40 problematic. Details about the study and a link to the online survey were emailed to 675 members
41 of the Vitiligo Society. A reminder email was sent out after 2 weeks. The survey link was also made
42 available on the Vitiligo Society website from February to March 2016. Participants provided online
43 informed consent prior to accessing the survey. In total, 161 people completed some or all of the
44 survey questions and were included in the analysis (Table 1). Quantitative survey findings regarding
45 sources of information and help-seeking were similar to those previously reported.⁸ This paper
46 focusses on the rich qualitative data obtained from the free text responses to open-ended questions
47 in the survey.
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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. <i>If you are happy to, please can you tell us some more about this?</i>	142 (90%)	5,419
Q2. We would be very interested to learn more about your experience of getting treatment for vitiligo. <i>If you are happy to, please can you tell us some more about this?</i>	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

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3 inferences and interpretation of the data. A negative case analysis was carried out to ensure that all
4 data was taken into account rather than just selecting data that fitted with the authors' viewpoint.
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6 Data saturation could not be determined due to the nature of the method of data collection. Using
7
8 NVivo enabled a detailed audit trail to be maintained.
9

14 RESULTS

16 The majority of survey respondents (n=158, 98%) completed the open-ended questions, suggesting
17 that those who responded to the survey were highly motivated to provide written feedback on their
18 experiences of seeking help and information for vitiligo. Analysis of these data highlighted 3 themes:
19
20 1) **experiences of consulting health professionals for vitiligo**, 2) **seeking information about vitiligo**,
21
22 3) **perceptions and experiences of vitiligo treatments**. These themes are explored in detail below.
23

24 All quotes are labelled with a participant ID, gender and age.
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29 Experiences of consulting health professionals for vitiligo

30
31 A sense of dissatisfaction and feeling unsupported was apparent in participants' reports about their
32 experiences of consulting health professionals for vitiligo. Participants often seemed disappointed
33 by the response they had received from GPs, who were viewed as their primary source of contact
34 and advice. A common perception amongst participants was that GPs are not generally aware of, or
35 particularly knowledgeable about, vitiligo and as such can only provide limited information and
36
37 advice to patients.
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41 *"None of the GP's I have spoken to have ever offered advice about Vitiligo. They seem to be somewhat in the*
42 *dark about the problem."* (Pt36, male, over 65 years)
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46 Where health professionals appeared sympathetic or where signposting towards further information
47 was offered this was appreciated, even where people felt their GP had not been knowledgeable.
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51 *"I have had vitiligo for about 35 years. I am now 70 years old. I have found that, with very few exceptions, GPs*
52 *know little about the condition. One of my GPs (who "half-retired" a few years ago) was always interested in*
53 *learning more and asked me if I could provide some information on vitiligo. I gave her some printed material*
54 *and she was grateful; I know that she read everything which I provided."* (Pt110, male, over 65 years)
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3 Many participants felt they had just been left to 'get on with it' and learn to accept and manage their
4 vitiligo on their own. For some participants this led them to seeking out alternative treatments not
5 available in the UK. Another dominant perspective in this study was the sense that vitiligo is not
6 taken seriously by medical professionals, both GPs and dermatologists. Many participants felt that
7 their vitiligo was dismissed by health professionals as something inconsequential, i.e. purely
8 cosmetic, which was upsetting to those experiencing substantial psychosocial impact.
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13 *"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*
14 *consultant. The consultant proved to be absolutely useless in providing any information. He just took one look*
15 *at me, told me it was something called Vitiligo and told me that it would most likely get worse but wouldn't kill*
16 *me!!!" (Pt71, female, over 65 years)*
17

18
19 *"I noticed most doctors don't know much about vitiligo and really don't seem to care. I felt they had no clue*
20 *about what a person with vitiligo goes through, Since it's not a matter of life or death, your expected to just*
21 *accept it. I was very disappointed every time, always left feeling hopeless. I think they should have more to*
22 *offer, be sympathetic & at least try different things" (Pt138, female, 46-65 years)*
23

24 25 26 **Seeking information about vitiligo**

27
28 Participants commonly reported seeking information from other sources, predominantly online
29 resources, as a result of receiving limited information from health professionals. The Vitiligo Society
30 was viewed as a helpful and trustworthy source of information for participants but many expressed
31 doubts about the reliability and credibility of other online resources about vitiligo. A common
32 concern expressed by the participants related to the credibility of online information on possible
33 treatments for vitiligo. In particular, they expressed doubts about the commercial interests of the
34 websites and about being able to determine the evidence base (safety and efficacy) of certain
35 products and procedures.
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41
42 *"I find it very difficult to find clear and consistent advice on possible treatments for Vitiligo. There are a lot of*
43 *commercially orientated websites promoting a variety of herbal cures etc but limited proper evidence based*
44 *medical guidance." (Pt40, male, 26-45 years)*
45

46
47 *"The only problem when searching for vitiligo sites is that some websites eventually lead into selling some sort*
48 *of product which is the new "best treatment". You find that because you are motivated to find some sort of*
49 *treatment you end up almost believing the hype that they sell." (Pt139, male, 46-65 years)*
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52 A desire for detailed, reliable information about the causes of vitiligo, its progression and possible
53 treatments was widely expressed. Some participants felt it important that such information should
54 come directly from health professionals or other resources perceived to be trustworthy such as NHS
55 Choices. Participants also expressed a desire for information and advice about managing the
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3 psychosocial impact of living with vitiligo, particularly advice on learning to cope with social
4 situations and people's reactions to their altered appearance, and how to explain the condition to
5 others.
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8 *"I developed vitiligo 42 years ago when I was 2. The GP referred me to a very good dermatologist who*
9 *explained things clearly as well as, crucially, how to sensibly explain it to other children." (Pt11, female 26-45*
10 *years)*
11

12 *"I would like more information on the cause of it and how to deal with being so self-conscious about it - it does*
13 *affect confidence and forming relationships." (Pt130, female, 26-45 years)*
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16 17 **Perceptions and experiences of vitiligo treatments**

18
19 Experiences of vitiligo treatments expressed by participants were very mixed. Whilst some
20 participants expressed positive experiences of treatment, particularly UV light treatment, many
21 participants appeared to have more negative experiences of seeking and receiving treatment for
22 their vitiligo. A commonly expressed view was that vitiligo treatment is not routinely offered or is
23 poorly available, especially on the NHS, and is limited to particular geographical locations.
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28 *"We decided to have light treatment. My main concern was the Vitiligo on my face. The treatment worked well*
29 *but a few years later it appeared elsewhere on my face so I had more treatment that also worked well. The*
30 *spread of vitiligo has slowed to almost a stop apart from a couple of new areas on my face." (Pt74, male, 46-65*
31 *years)*
32

33 *"There is very little treatment for Vitiligo in the UK. I am at present involved with the Hi-Light trial run by the*
34 *Univ of Nottingham. This is the first time I have been able to obtain any treatment." (Pt102, male, over 65*
35 *years)*
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40 Many participants, who had received treatments such as steroid creams and light treatment for their
41 vitiligo, felt they were ineffective in the long-term as the treatments had been unsuccessful in
42 maintaining any areas of re-pigmentation. Participants also reported the perceived difficulties and
43 potential side effects of vitiligo treatment such as concerns about skin thinning with steroid creams,
44 time-consuming nature and inconvenience of hospital-based UV light treatment and the physical
45 side effects of light treatment such as nausea and headaches.
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50 *"I was referred to Dermatology and was prescribed PUVA treatment. This helped for a while, but became so*
51 *time consuming. Progress was very slow. I stopped the treatment and any areas of repigmentation soon*
52 *reverted back to white skin. So disappointing." (Pt156, female, 46-65 years)*
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3 As well as mixed experiences of vitiligo treatments, there were mixed attitudes towards the need to
4 seek vitiligo treatments in the first instance. Some participants reported less experience of
5 treatments because they had not sought these out and had 'accepted' their vitiligo, even though it
6 may have had a profound impact on their lives.
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10 *"I think that vitiligo is a relatively unknown condition. I have never been contacted about treatment or had it*
11 *offered to me despite having had the condition for many years. You are very much left to get on with it. I can*
12 *imagine that some people suffer psychologically and I wonder what support they get. I have come to terms*
13 *with my patches and embrace them rather than disguise them but it can feel quite disheartening at times and I*
14 *would rather not have them given the choice."* (Pt58, female, 46-65 years)
15

16 17 18 **DISCUSSION**

19
20 We found predominantly negative experiences of help-seeking, concerns about the credibility of
21 online information, and the need for detailed, reliable vitiligo information. Frustration with
22 challenges to help-seeking was often reported, particularly perceived lack of awareness of available
23 treatments amongst GPs. Many felt that vitiligo was often dismissed by health professionals as
24 'cosmetic', which was upsetting to those experiencing substantial psychosocial impact. Where GPs
25 appeared sympathetic or where signposting towards further information was offered this was
26 appreciated, even where people felt their GP had not seemed knowledgeable. There were very
27 mixed views about the need for treatment and a desire for support with managing the psychosocial
28 impact of vitiligo.
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37 This study provides valuable insights into the experiences of people with vitiligo in seeking
38 information and treatment about their condition. We employed an efficient yet relatively under-
39 utilised method of qualitative data collection to explore an under-researched topic area. Given the
40 relative anonymity of providing written responses in an online survey, these data may have been
41 more candid than data collected in face-to-face research settings. However, it was not possible in
42 this context to ask participants to expand on or clarify their free-text responses. Being able to clarify
43 and explore further vitiligo patients' views and experiences in a qualitative interview may have
44 generated richer data that would have enabled a more in-depth qualitative analysis.
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51 Our findings also need to be seen in the context of our sampling method. People with vitiligo who
52 are members of the Vitiligo Society may not be representative of all people with vitiligo. Members
53 of the Vitiligo Society pay an annual membership fee (£26), which may be a barrier to membership
54 for some people. The response rate for our survey, which was carried out entirely online, was lower
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3 than the previous survey amongst Vitiligo Society members⁸, which was carried out by post. We did
4 not compare responders to non-responders and so cannot be sure that our participants are different
5 in some way to those who did not respond to the survey. This may mean that participants in this
6 study had greater impact from vitiligo, were more unsatisfied with the information they had
7 received, or were more engaged with seeking treatment and information, than other people with
8 vitiligo and limits the transferability of the findings
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13 Most of the participants in this study were over 45, which is likely to be unrepresentative of the
14 whole population of people with vitiligo as the condition commonly appears before the age of 20.¹⁷
15
16¹⁸ It is likely that most of the participants had had vitiligo for many years and their experience may
17 differ from those more recently diagnosed. Furthermore, by sampling through a patient support
18 group we may have been more likely to receive accounts from people whose needs had not been
19 met by health services, although it is notable that this group still felt that they had many
20 unanswered questions and that they found online information difficult to navigate.
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28 The feeling that vitiligo is dismissed by health professionals as 'cosmetic' or 'trivial' shows that this is
29 an ongoing concern for people, in common with previous reports,^{9 10} and also in line with other skin
30 conditions.^{19 20} We found that people can find it difficult to judge the credibility of online information
31 on vitiligo, as in other conditions²¹, but it seems surprising in this context where participants are all
32 members of a relevant support group. We also found that participants still generally view health
33 professionals as an important source of information, which has been noted in other studies²² Again it
34 seems surprising that our participants, who were members of a support group and many of whom
35 reported negative experiences of consulting, still wanted health professionals to be the main source
36 of information. Our finding that people are keen for support with managing the psychosocial impact
37 of living with vitiligo was also found in a recent James Lind Alliance Priority Setting Partnership in the
38 UK, which identified the need for further research into the effectiveness of psychological support for
39 people with vitiligo, either on its own or together with other treatments.²³ The importance of
40 providing people with skin diseases with access to a range of supportive services including
41 psychological support was also acknowledged in a recent report of the All Party Parliamentary Group
42 on Skin.²⁴
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53 Constraints on access to specialists through Primary Care 'gatekeeping' or 'managed care' may be
54 associated with lower patient satisfaction²⁵ and respondents in this study expressed frustration
55 with generalist services, perceiving them to have a low level of knowledge about their condition. It is
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3 not completely clear whether this represents lack of awareness amongst GPs of available treatments
4 for vitiligo, or lack of provision of services into which they can refer. Access to vitiligo
5 services/treatment is becoming increasingly difficult in many areas of the UK, which is likely to
6 increase people's frustration with help-seeking and may exacerbate the psychosocial impact
7 experienced by many people with vitiligo.
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14 This paper highlights opportunities for further qualitative and quantitative research exploring and
15 examining the needs of people with vitiligo, particularly younger people with vitiligo and those with
16 a recent diagnosis. There is also a paucity of comparative evidence for effective treatments for
17 vitiligo. In addition to quantitative research examining the effectiveness of treatments, greater
18 evidence is also needed on how best to address the psychosocial impact of living with vitiligo. In this
19 study people's support needs included advice on managing social situations and explaining the
20 condition to others, learning how to use camouflage, as well as clear and up-to-date information
21 about the pros and cons of available treatments. Further research to develop and test education and
22 psychological support interventions that seek to address the information and support needs of
23 people with vitiligo are likely to be valuable. In an era where people are increasingly obtaining health
24 information online²⁶, it may be that education and psychological support interventions delivered
25 online may be beneficial.
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34 In conclusion, more can be done to meet the information and help-seeking needs of people with
35 vitiligo. People with vitiligo would welcome greater health professional awareness of the possibility
36 of treating vitiligo, yet recognise that generalist services may not always be able to offer this. People
37 who had been directed towards reliable information were very grateful for this and signposting is
38 viewed as a key role of GPs, which remain the primary source of information for many. Fortunately
39 good online resources for people with vitiligo are available (Box 1). Signposting people with vitiligo
40 towards credible online resources and acknowledging and exploring the potential impact of the
41 condition may allay people's perceptions that distress caused by the condition is not taken seriously.
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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, <i>Dispatches</i> .

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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		
<i>Personal Characteristics</i>		
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
<i>Relationship with participants</i>		
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		
<i>Theoretical framework</i>		
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
<i>Participant selection</i>		
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
<i>Setting</i>		
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
<i>Data collection</i>		
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		
<i>Data analysis</i>		
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
<i>Reporting</i>		
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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8 **Views and experiences of seeking information and help for vitiligo: a**
9 **qualitative study of written accounts**
10

11 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.

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2
3 Qualitative methods are well suited to exploring a topic in-depth from the perspective of a particular
4 group of people. Qualitative research that seeks to explore people's experiences of obtaining
5 information about vitiligo and their help seeking behaviour could help to determine whether people
6 with vitiligo expect GPs or Dermatologists to advise them about vitiligo or whether they generally
7 seek information from charities or the internet instead of, or in addition to, consulting. This in turn
8 would enable better understanding of how GPs and Dermatologists can best support people with
9 vitiligo in terms of information provision and/ or signposting to reliable resources. Given the
10 potential insights into people's experiences to be gained by using qualitative methods¹², we
11 incorporated open-ended questions into a quantitative survey about information and help-seeking
12 behaviour in people with vitiligo. We aimed to explore views and experiences of seeking
13 information and help for vitiligo through analysis of the written accounts of survey respondents.
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23 **METHODS**

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25 This study sought to qualitatively analyse the free text comments within a quantitative survey that
26 focused on exploring sources of information for vitiligo, experiences of treatment and information
27 needs. This qualitative approach has been previously used in other health-related research.¹³⁻¹⁵
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30 Ethical approval was granted by the Faculty of Medicine Research Ethics Committee, University of
31 Southampton.
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33

34 **Main survey**

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36 An anonymous online survey of people with vitiligo was conducted in the UK in February 2016
37 (response rate 161/675 (24%)). We sought participants through the Vitiligo Society, partly because
38 this had been a successful route for previous research⁸ but also because informal advice suggested
39 vitiligo might not be well coded in primary care so recruiting through this route would be
40 problematic. Details about the study and a link to the online survey were emailed to 675 members
41 of the Vitiligo Society. A reminder email was sent out after 2 weeks. The survey link was also made
42 available on the Vitiligo Society website from February to March 2016. Participants provided online
43 informed consent prior to accessing the survey. In total, 161 people completed some or all of the
44 survey questions and were included in the analysis (Table 1). Quantitative survey findings regarding
45 sources of information and help-seeking were similar to those previously reported.⁸ This paper
46 focusses on the rich qualitative data obtained from the free text responses to open-ended questions
47 in the survey.
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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. <i>If you are happy to, please can you tell us some more about this?</i>	142 (90%)	5,419
Q2. We would be very interested to learn more about your experience of getting treatment for vitiligo. <i>If you are happy to, please can you tell us some more about this?</i>	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.

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3 Data saturation could not be determined due to the nature of the method of data collection. Using
4 NVivo enabled a detailed audit trail to be maintained.
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10 11 **RESULTS**

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13 The majority of survey respondents (n=158, 98%) completed the open-ended questions, suggesting
14 that those who responded to the survey were highly motivated to provide written feedback on their
15 experiences of seeking help and information for vitiligo. Analysis of these data highlighted 3 themes:
16
17 1) *experiences of consulting health professionals for vitiligo*, 2) *seeking information about vitiligo*,
18
19 3) *perceptions and experiences of vitiligo treatments*. These themes are explored in detail below.
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21 All quotes are labelled with a participant ID, gender and age.
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26 **Experiences of consulting health professionals for vitiligo**

27
28 A sense of dissatisfaction and feeling unsupported was apparent in participants' reports about their
29 experiences of consulting health professionals for vitiligo. Participants often seemed disappointed
30 by the response they had received from GPs, who were viewed as their primary source of contact
31 and advice. A common perception amongst participants was that GPs are not generally aware of, or
32 particularly knowledgeable about, vitiligo and as such can only provide limited information and
33
34 advice to patients.
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38 *"None of the GP's I have spoken to have ever offered advice about Vitiligo. They seem to be somewhat in the*
39 *dark about the problem."* (Pt36, male, over 65 years)
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43 Where health professionals appeared sympathetic or where signposting towards further information
44 was offered this was appreciated, even where people felt their GP had not been knowledgeable.
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47 *"I have had vitiligo for about 35 years. I am now 70 years old. I have found that, with very few exceptions, GPs*
48 *know little about the condition. One of my GPs (who "half-retired" a few years ago) was always interested in*
49 *learning more and asked me if I could provide some information on vitiligo. I gave her some printed material*
50 *and she was grateful; I know that she read everything which I provided."* (Pt110, male, over 65 years)
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54 Many participants felt they had just been left to 'get on with it' and learn to accept and manage their
55 vitiligo on their own. For some participants this led them to seeking out alternative treatments not
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3 available in the UK. Another dominant perspective in this study was the sense that vitiligo is not
4 taken seriously by medical professionals, both GPs and dermatologists. Many participants felt that
5 their vitiligo was dismissed by health professionals as something inconsequential, i.e. purely
6 cosmetic, which was upsetting to those experiencing substantial psychosocial impact.
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10 *"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*
11 *consultant. The consultant proved to be absolutely useless in providing any information. He just took one look*
12 *at me, told me it was something called Vitiligo and told me that it would most likely get worse but wouldn't kill*
13 *me!!!" (Pt71, female, over 65 years)*
14

15 *"I noticed most doctors don't know much about vitiligo and really don't seem to care. I felt they had no clue*
16 *about what a person with vitiligo goes through, Since it's not a matter of life or death, your expected to just*
17 *accept it. I was very disappointed every time, always left feeling hopeless. I think they should have more to*
18 *offer, be sympathetic & at least try different things" (Pt138, female, 46-65 years)*
19
20

21 22 23 **Seeking information about vitiligo**

24 Participants commonly reported seeking information from other sources, predominantly online
25 resources, as a result of receiving limited information from health professionals. The Vitiligo Society
26 was viewed as a helpful and trustworthy source of information for participants but many expressed
27 doubts about the reliability and credibility of other online resources about vitiligo. A common
28 concern expressed by the participants related to the credibility of online information on possible
29 treatments for vitiligo. In particular, they expressed doubts about the commercial interests of the
30 websites and about being able to determine the evidence base (safety and efficacy) of certain
31 products and procedures.
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34 *"I find it very difficult to find clear and consistent advice on possible treatments for Vitiligo. There are a lot of*
35 *commercially orientated websites promoting a variety of herbal cures etc but limited proper evidence based*
36 *medical guidance." (Pt40, male, 26-45 years)*
37

38 *"The only problem when searching for vitiligo sites is that some websites eventually lead into selling some sort*
39 *of product which is the new "best treatment". You find that because you are motivated to find some sort of*
40 *treatment you end up almost believing the hype that they sell." (Pt139, male, 46-65 years)*
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48 A desire for detailed, reliable information about the causes of vitiligo, its progression and possible
49 treatments was widely expressed. Some participants felt it important that such information should
50 come directly from health professionals or other resources perceived to be trustworthy such as NHS
51 Choices. Participants also expressed a desire for information and advice about managing the
52 psychosocial impact of living with vitiligo, particularly advice on learning to cope with social
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3 situations and people's reactions to their altered appearance, and how to explain the condition to
4 others.

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

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

13 14 15 16 **Perceptions and experiences of vitiligo treatments**

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

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

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31
32 *"There is very little treatment for Vitiligo in the UK. I am at present involved with the Hi-Light trial run by the*
33 *Univ of Nottingham. This is the first time I have been able to obtain any treatment."* **(Pt102, male, over 65**
34 **years)**

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

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

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55 As well as mixed experiences of vitiligo treatments, there were mixed attitudes towards the need to
56 seek vitiligo treatments in the first instance. Some participants reported less experience of

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3 treatments because they had not sought these out and had 'accepted' their vitiligo, even though it
4 may have had a profound impact on their lives.
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7 *"I think that vitiligo is a relatively unknown condition. I have never been contacted about treatment or had it*
8 *offered to me despite having had the condition for many years. You are very much left to get on with it. I can*
9 *imagine that some people suffer psychologically and I wonder what support they get. I have come to terms*
10 *with my patches and embrace them rather than disguise them but it can feel quite disheartening at times and I*
11 *would rather not have them given the choice."* (Pt58, female, 46-65 years)
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13 14 15 **DISCUSSION**

16
17 We found predominantly negative experiences of help-seeking, concerns about the credibility of
18 online information, and the need for detailed, reliable vitiligo information. Frustration with
19 challenges to help-seeking was often reported, particularly perceived lack of awareness of available
20 treatments amongst GPs. Many felt that vitiligo was often dismissed by health professionals as
21 'cosmetic', which was upsetting to those experiencing substantial psychosocial impact. Where GPs
22 appeared sympathetic or where signposting towards further information was offered this was
23 appreciated, even where people felt their GP had not seemed knowledgeable. There were very
24 mixed views about the need for treatment and a desire for support with managing the psychosocial
25 impact of vitiligo.
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34 This study provides valuable insights into the experiences of people with vitiligo in seeking
35 information and treatment about their condition. We employed an efficient yet relatively under-
36 utilised method of qualitative data collection to explore an under-researched topic area. Given the
37 relative anonymity of providing written responses in an online survey, these data may have been
38 more candid than data collected in face-to-face research settings. However, it was not possible in
39 this context to ask participants to expand on or clarify their free-text responses. Being able to clarify
40 and explore further vitiligo patients' views and experiences in a qualitative interview may have
41 generated richer data that would have enabled a more in-depth qualitative analysis.
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47 Our findings also need to be seen in the context of our sampling method. People with vitiligo who
48 are members of the Vitiligo Society may not be representative of all people with vitiligo. Members
49 of the Vitiligo Society pay an annual membership fee (£26), which may be a barrier to membership
50 for some people. The response rate for our survey, which was carried out entirely online, was lower
51 than the previous survey amongst Vitiligo Society members⁸, which was carried out by post. We did
52 not compare responders to non-responders and so cannot be sure that our participants are different
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3 in some way to those who did not respond to the survey. This may mean that participants in this
4 study had greater impact from vitiligo, were more unsatisfied with the information they had
5 received, or were more engaged with seeking treatment and information, than other people with
6 vitiligo and limits the transferability of the findings
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10 Most of the participants in this study were over 45, which is likely to be unrepresentative of the
11 whole population of people with vitiligo as the condition commonly appears before the age of 20.¹⁷
12
13 ¹⁸ It is likely that most of the participants had had vitiligo for many years and their experience may
14 differ from those more recently diagnosed. Furthermore, by sampling through a patient support
15 group we may have been more likely to receive accounts from people whose needs had not been
16 met by health services, although it is notable that this group still felt that they had many
17 unanswered questions and that they found online information difficult to navigate.
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24 The feeling that vitiligo is dismissed by health professionals as 'cosmetic' or 'trivial' shows that this is
25 an ongoing concern for people, in common with previous reports,^{9 10} and also in line with other skin
26 conditions.^{19 20} We found that people can find it difficult to judge the credibility of online information
27 on vitiligo, as in other conditions²¹, but it seems surprising in this context where participants are all
28 members of a relevant support group. We also found that participants still generally view health
29 professionals as an important source of information, which has been noted in other studies²² Again it
30 seems surprising that our participants, who were members of a support group and many of whom
31 reported negative experiences of consulting, still wanted health professionals to be the main source
32 of information. Our finding that people are keen for support with managing the psychosocial impact
33 of living with vitiligo was also found in a recent James Lind Alliance Priority Setting Partnership in the
34 UK, which identified the need for further research into the effectiveness of psychological support for
35 people with vitiligo, either on its own or together with other treatments.²³ The importance of
36 providing people with skin diseases with access to a range of supportive services including
37 psychological support was also acknowledged in a recent report of the All Party Parliamentary Group
38 on Skin.²⁴
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49 Constraints on access to specialists through Primary Care 'gatekeeping' or 'managed care' may be
50 associated with lower patient satisfaction²⁵ and respondents in this study expressed frustration
51 with generalist services, perceiving them to have a low level of knowledge about their condition. It is
52 not completely clear whether this represents lack of awareness amongst GPs of available treatments
53 for vitiligo, or lack of provision of services into which they can refer. Access to vitiligo
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3 services/treatment is becoming increasingly difficult in many areas of the UK, which is likely to
4 increase people's frustration with help-seeking and may exacerbate the psychosocial impact
5 experienced by many people with vitiligo.
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10 This paper highlights opportunities for further qualitative and quantitative research exploring and
11 examining the needs of people with vitiligo, particularly younger people with vitiligo and those with
12 a recent diagnosis. There is also a paucity of comparative evidence for effective treatments for
13 vitiligo. In addition to quantitative research examining the effectiveness of treatments, greater
14 evidence is also needed on how best to address the psychosocial impact of living with vitiligo. In this
15 study people's support needs included advice on managing social situations and explaining the
16 condition to others, learning how to use camouflage, as well as clear and up-to-date information
17 about the pros and cons of available treatments. Further research to develop and test education and
18 psychological support interventions that seek to address the information and support needs of
19 people with vitiligo are likely to be valuable. In an era where people are increasingly obtaining health
20 information online²⁶, it may be that education and psychological support interventions delivered
21 online may be beneficial.
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30 In conclusion, more can be done to meet the information and help-seeking needs of people with
31 vitiligo. People with vitiligo would welcome greater health professional awareness of the possibility
32 of treating vitiligo, yet recognise that generalist services may not always be able to offer this. People
33 who had been directed towards reliable information were very grateful for this and signposting is
34 viewed as a key role of GPs, which remain the primary source of information for many. Fortunately
35 good online resources for people with vitiligo are available (Box 1). Signposting people with vitiligo
36 towards credible online resources and acknowledging and exploring the potential impact of the
37 condition may allay people's perceptions that distress caused by the condition is not taken seriously.
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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.vitigosociety.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, <i>Dispatches</i> .

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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

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2
3 the manuscript; IM, MS, BS, AAS and KT critically reviewed and revised the manuscript; all authors
4 gave the final approval of the version to be published.
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9 **Data sharing statement**

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

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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		
<i>Personal Characteristics</i>		
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
<i>Relationship with participants</i>		
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		
<i>Theoretical framework</i>		
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
<i>Participant selection</i>		
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
<i>Setting</i>		
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
<i>Data collection</i>		
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		
<i>Data analysis</i>		
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
<i>Reporting</i>		
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