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**Identifying key components for a psychological intervention for people with vitiligo - a quantitative and qualitative study in the United Kingdom using web-based questionnaires of people with vitiligo and healthcare professionals**

*Running head – Psychological interventions for vitiligo*

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*Abstract*

Background – Psychological interventions are recommended as part of routine management of vitiligo. However the development and effectiveness of such interventions has been rarely addressed. This study aims to identify key components for a psychological intervention for people with vitiligo. This is the first time perspectives of people with vitiligo and healthcare professionals (HCPs) have been directly explored to inform intervention content and delivery.

Objectives – To identify: 1. Which psychological difficulties are highlighted that can be targeted by an intervention; 2. What is important in terms of intervention content and delivery.

Methods – Web-based questionnaires containing both quantitative and qualitative items were completed by people with vitiligo and HCPs. Questionnaires collected data from people with vitiligo on demographics, clinical features, psychological difficulties, and priority areas for psychological interventions, including ideas on delivery and content. HCPs questionnaires collected data on psychological difficulties reported, use of psychological interventions, and suitability within health services. Quantitative data was analysed using descriptive statistics and qualitative data utilised thematic framework analysis.

Results – 100 people with vitiligo (66% female, 92% Caucasian) and 39 HCPs (54% dermatologists) participated. Key areas of difficulty were the impact of vitiligo, coping, issues with appearance/body image and the sun, and medical interactions. Vitiligo on sensitive sites was associated with more psychological impact. Interventions directed at increasing acceptance, confidence and self-esteem, as well as managing embarrassment, were important. These issues could be managed through interventions such as cognitive behavioural therapy, mindfulness, and acceptance and commitment therapy. Both people with vitiligo and HCPs favoured individual interventions.

Conclusion – Vitiligo has significant impact, requiring ongoing psychosocial support. There is a strong need for a psychoeducational intervention with focus on acceptance and managing social impact. The results of this study are the first steps to informing the development of a patient-centred psychological intervention.

## Introduction

Vitiligo is a chronic depigmenting condition affecting approximately 0.5-2% of people worldwide<sup>1</sup>. The psychological impact of vitiligo is significant, with individuals frequently reporting embarrassment, lack of confidence, social anxiety, loss of self-esteem, body image issues, reduced quality of life (QoL), and perceived stigma<sup>2-7</sup>. There is also up to 35% increased risk of psychiatric morbidity (e.g. depression, anxiety)<sup>8</sup>. Psychosocial interventions are now recommended as part of routine management of vitiligo<sup>9,10</sup>. A Priority Setting Partnership<sup>11</sup>, has further highlighted the following research priority within the top ten treatment uncertainties in vitiligo:

*How much do psychological interventions help people with vitiligo?*

Despite the demand, there are few studies that have formally developed and evaluated interventions to address psychological difficulties experienced by people with vitiligo. A Cochrane review of interventions for vitiligo<sup>12</sup> identified only one randomised controlled trial (RCT) that compared cognitive behavioural therapy (CBT) or person-centred therapy with controls<sup>2</sup>. Psychological treatments impacted general health, but there was no difference in psychological variables<sup>2</sup>. This was in contrast to a previous smaller matched study that showed patients benefit from CBT in terms of coping and living with vitiligo<sup>5</sup>. A recent self-help CBT-based intervention showed clinically significant reductions in self-reported anxiety, depression, appearance-related concerns and a change in coping styles in people with vitiligo<sup>13</sup>. Although these studies are limited, they highlight the potential benefits of psychosocial interventions in vitiligo.

Understanding the unmet needs and requirements of people with vitiligo is key to developing interventions<sup>14</sup>. Using a person-centred approach that utilises qualitative research methods, allows exploration of the perspectives and psychosocial factors affecting the target group<sup>15</sup>. This study will inform the first stage in intervention development by exploring the impact of vitiligo and identifying what types of intervention might be acceptable, as well as important areas to target. This information is central to planning interventions to optimise engagement and cost-effectiveness.

To ensure a broad understanding of the target population, both quantitative and qualitative data from people with vitiligo and the healthcare professionals (HCPs) who support them, were collected via web-based questionnaires.

## *Materials and Methods*

Ethical approval was obtained from Queen Mary University of London (QMERC2014/30). This was a cross-sectional study using web-based questionnaires with both quantitative and qualitative response items.

### *Participants and recruitment*

There were two groups of participants eligible to be recruited to the study:

- *People with vitiligo* – over 18 years old, resident within the UK, and with a physician confirmed diagnosis of vitiligo
- *HCPs* – any HCP with experience of working professionally with people with vitiligo

The study was publicised using a standard advert via the websites/social media accounts, or emailing member databases of the following:

- The Vitiligo Society (VS) – official website ([www.vitigosociety.org.uk](http://www.vitigosociety.org.uk)) and Facebook page
- Centre of Evidence-Based Dermatology (CEBD) – database of people with vitiligo who had previously consented to be contacted about vitiligo research
- Psychodermatology Specialist Interest Group (SIG) – database of HCPs with an interest in psychodermatology
- UK Dermatology Clinical Trials Network (UK DCTN) – database of HCPs registered with the UK DCTN

### *Procedures*

Potential participants were directed to an anonymised, self-completed, web-based questionnaire, run through the SurveyMonkey™ platform. This was a study-designed questionnaire beginning with a participant information sheet, contact details for the lead researcher and methods for withdrawal from the study. Informed consent was requested and it was made clear that data collected would be held securely as per the Data Protection Act (1998). Completion of the questionnaire was voluntary and no incentive was offered. The questionnaires were kept open online for 4 weeks, and closed once the final date was reached (full versions provided in ‘Supporting information’).

### *Outcome measures*

The questionnaires were designed to gain an understanding of what should be included in a psychosocial intervention for vitiligo. They were developed based on literature review of the psychosocial difficulties associated with vitiligo<sup>2-8</sup> and consensus discussion using an expert group, including dermatologists with an interest in psychodermatology (AB) or vitiligo (JB), and psychologists (LS, RS, ST), as well as patient and public involvement (MW).

### *People with vitiligo questionnaire -*

There were 5 sections (4 quantitative, 1 qualitative) comprising a total of 15 items including:

- i) Basic socio-demographic data - including region of residence in the UK, age, gender and ethnicity (based on standard categories).
- ii) Clinical information - including age since diagnosis, extent and spread of vitiligo, current and previous treatment.
- iii) Psychosocial impact of vitiligo - 14 areas of life related to psychosocial functioning were rated according to the extent of difficulty experienced.
- iv) Intervention content and delivery - participants were asked to rate the extent they felt 9 areas would be important to address in an intervention, and the preferred mode of delivery.
- v) Free text response items - participants were asked to describe in detail areas of their lives that had been affected by vitiligo and to rank their top three concerns.

### *HCP questionnaire –*

There were 4 sections (3 quantitative, 1 qualitative) comprising a total of 13 items including:

- i) Professional information - including professional roles and experience of working with people with vitiligo.
- ii) Perceived psychosocial impact – the frequency with which people with vitiligo reported 9 psychological difficulties to HCPs.
- iii) Intervention content and delivery - 8 interventions were rated on how useful they would be, and which psychological difficulties they could be utilised for. Further items asked the best way to deliver a psychological intervention using health services.
- iv) Free text response items - HCPs were asked to describe any other psychological difficulties reported, their own experiences of interventions tried, and to rank their top 3 psychological interventions.

### *Analyses*

Quantitative data was primarily presented descriptively. Categorical data was summarised as frequencies, and scale responses were treated as continuous data with mean and standard deviation calculated per item, independent t-tests were used to compare affected and non-affected individuals on psychological outcomes dependent on body site affected.

Qualitative data generated by the research question '*Describe the way vitiligo affects your life, including the things you find difficult to cope with*' was analysed thematically (Fig. 1). Two researchers (AA, LS) independently read through data items to identify patterns of meaning and issues of potential interest<sup>16</sup>. Codes were assigned to data items and collated into overarching themes, which were then reviewed and refined to ensure comparability

and enhance reliability. This process provided a flexible yet rich synthesis across the data set primarily at the semantic level<sup>16</sup>. Analysis was subsequently shared with the study team to verify interpretation of the data.

### *Results*

One hundred people with vitiligo completed the questionnaire, the majority were female (66%), Caucasian (92%), and had been diagnosed with vitiligo greater than ten years (82%). There was variability in the extent of body surface involved, areas affected, and both past and current treatment for vitiligo. Notably, 79% of participants were not currently receiving treatment and only 5% had ever received any psychological treatment (Table 1).

There were 39 respondents to the HCP questionnaire - 21 dermatologists, 9 psychologists and 9 other HCPs.

### *Psychosocial impact*

Acceptance of vitiligo in relation to its effects on appearance was most problematic for people with vitiligo (Table 2). Acceptance that vitiligo is a long-term condition, managing embarrassment and lacking self-confidence were the next highest rated difficulties. These were also identified within the top concerns. Facial and genital vitiligo had more psychological impact on respondents compared to non-sensitive sites (Table 3)

HCPs reported social anxiety, difficulties with self-esteem, confidence and body image as the issues mentioned most frequently. Other reported difficulties included frustration with lack of therapeutic options, problems with darker skin types, parental concerns if a child has vitiligo, suicidal ideation, skin symptoms, employment issues, body dysmorphophobia, cultural issues and psychosexual problems.

Eighty-three per cent of people with vitiligo provided free text responses about living with vitiligo, this is a high response rate and indicative of an unmet need in this area. Figure 2 summarises the 7 themes and 25 subthemes generated; key themes were (i) impact of vitiligo, (ii) coping with vitiligo, (iii) issues with appearance/body image, (iv) issues with the sun, and (v) medical. The themes are explained further:

### *Impact of Vitiligo*

This was the main theme, commented on by over two thirds of participants. In general, vitiligo impacted life choices, including decisions about education, career and participation in social or physical activities. Significant impact on emotional and psychological well-being was noted. Many reported feelings of depression and anxiety, as well as embarrassment, lack of confidence, self-consciousness, isolation, resentment, low self-esteem and negative

reactions (e.g. feeling 'ugly'). Vitiligo was seen to be an important factor in relationships, particularly of an intimate nature.

### *Coping with Vitiligo*

Nearly half of respondents discussed the way they coped with vitiligo. An important sub-theme was 'acceptance'. Time was a major factor in accepting vitiligo, acceptance increasing with time since diagnosis. Life tended to improve post-acceptance, but it was difficult to acquire. Support from family/spouses/partners was recognised as an important factor in reaching acceptance, as well as involvement with relevant organisations (e.g. VS). Several participants felt 'lucky' theirs was not a 'serious' or 'life-threatening' condition in comparison to other diagnoses (e.g. cancer). Coping with how vitiligo affected identity was a particular challenge.

### *Issues with appearance/body image*

Disguising or hiding vitiligo to 'improve' appearance or to look more 'normal' was reported frequently, most utilising clothing or simply avoiding situations that require exposure (e.g. changing clothes in public areas). In addition, there were high levels of self-consciousness, especially around exposing high impact sites (e.g. face, genitals).

### *Issues with the sun*

These were specifically raised by 44% of people with vitiligo. Avoiding activities that require skin exposure (e.g. swimming) were highlighted. Exposing depigmented skin was a concern, with respondents covering up even in hot weather. Vitiligo being more obvious in the summer and fear of sunburn were particular issues. Several participants commented on the difficulties of maintaining good sun protection and the application of sunscreen, with many having to adapt their behaviour or lifestyles to cope. There were real fears about heightened risk of skin cancer, with some respondents avoiding the sun completely.

### *Medical*

Difficulties with medical interactions and treatments were raised by 42% of participants. There was a general view that the medical profession was unsupportive, with insufficient treatment options, including psychological interventions. Most respondents reported lack of information and support, especially around the time of diagnosis. Several people with vitiligo encountered practical difficulties with treatment (e.g. attending phototherapy), and many that were offered cosmetic camouflage described it as 'messy' and difficult to maintain. In addition, there was resentment at being told to 'cover up' vitiligo.

### *Reaction from others*

Reactions from others were largely negative and included bullying, staring and stigmatisation. Bullying started at a young age with long-lasting impact. Lack of understanding of vitiligo was an important subtheme, many respondents felt ignorance led to negative reactions from the public. There was resentment at having to 'put up' with such reactions.

### *Other*

Dealing with vitiligo as a teenager was a struggle. There were real concerns about 'passing it on' to children. The uncertainty of progression, especially spread to high impact sites, was difficult to deal with. People with vitiligo also have their own ideas about possible triggers and associations, but feel this is not taken seriously by HCPs.

### *Intervention delivery and content*

Of nine strategies suggested to help coping, people with vitiligo indicated (i) dealing with embarrassment, (ii) increasing confidence and self-esteem, (iii) coping with social situations and anxiety, (iv) understanding the condition and its impact, and (v) acceptance were the most important areas for interventions to target (Table 4).

People with vitiligo indicated an overall preference for individual interventions (58%), however group (42%), guided (34%) and self-help (34%) interventions also appeared acceptable. HCPs had a clear preference for individual (68%), followed by group-based interventions (58%).

CBT was indicated by HCPs as the most useful intervention, followed by mindfulness and acceptance and commitment therapy (ACT). Interventions incorporating patient education were also suggested. CBT, mindfulness and ACT were also the top three interventions for a number of psychological difficulties (e.g. depression, anxiety, body image issues, acceptance).

HCPs indicated CBT, ACT, psychodynamic, family and behavioural therapy, as well as training on social skills and coping strategies, as previously used psychological interventions. Cosmetic camouflage was also used as a form of psychological intervention. A number of HCPs referred to psychologists or support groups. The majority did not have personal experience of delivering psychological interventions. One HCP had prescribed psychotropic medication to manage the psychological impact of vitiligo.



## *Discussion*

The findings of this study show significant psychological and emotional impact of vitiligo. Acceptance, coping with embarrassment and lack of self-confidence are particularly difficult for people with vitiligo, in line with HCPs' experiences and previous research<sup>2-7</sup>.

The qualitative themes reveal the widespread effect of vitiligo. Impact on life choices, relationships, emotional and psychological well-being highlights the importance of ongoing psychosocial support. Acceptance is a key factor in coping, which is facilitated by time and significant others. People with vitiligo also modify their appearance in response to body image issues, especially in public situations. The general lack of awareness and psychological impact of people's reactions towards vitiligo, are a source of distress. There is a great deal of uncertainty about disease progression, triggers and genetics of vitiligo. In addition, there is disappointment at the paucity of research and lack of cure.

Coping with day-to-day issues, such as clothing choices and skin exposure, are especially difficult. Our study has revealed a high level of sun-specific problems (e.g. practicalities of sun protection, concerns regarding skin cancer) that add to the growing literature detailing the unmet needs of this patient group. These concerns provide a new level of awareness that has significant implications for intervention content.

The lack of education and understanding highlighted suggests that earlier intervention using a psychoeducational approach may be the first step to improving psychological well-being. There is a window of opportunity around the time of diagnosis when people with vitiligo feel most discontented.

Cosmetic camouflage is a common intervention, however it did not appear to be acceptable to a number of respondents as they resented being told to 'cover up'. This is in contrast to previous studies that suggest the use of cosmetic camouflage improves QoL<sup>17,18</sup>. The use of camouflage may be hindering acceptance, although for some it remains an important aspect of management.

There was variability in the extent and areas affected by vitiligo (Table 1). For the majority of areas involved, there was little difference between those who were affected and not affected on each of the items of psychological impact (Table 3). The exception to this were individuals with genital involvement, who found it significantly more difficult to manage impact within personal relationships and discussing with friends, as well as impact on self-confidence, and managing depression and anxiety (Table 3). Individuals who had facial involvement also found personal relationships significantly more difficult to manage (Table 3). Interestingly, people with less areas affected by vitiligo had greater difficulty understanding the condition. This finding may suggest that the more surface area involved, the greater the individual's search is for understanding vitiligo. It should be noted however, that individuals were able to indicate more than one body area affected, hence findings should be treated with caution.

HCPs indicated that CBT, mindfulness and ACT could be useful methods of intervention delivery. Along with strategies to deal with embarrassment, increasing confidence and self-esteem, targeting acceptance and the impact of vitiligo (social and personal) adds a new dimension to intervention development. This can be further explored during the next phase of our exploratory work.

Although individual interventions were favoured, it is encouraging that participants are willing to consider other delivery methods, which may be more economically feasible (e.g. group or guided interventions). Of note, a higher number of HCPs suggested the need for individual interventions. This may be because they perceived more complex psychological needs of people with vitiligo.

The cross-sectional nature of the questionnaires with self-selected populations is a possible limitation of the current study. Vitiligo respondents were predominantly female, Caucasian and had been diagnosed for more than 10 years. This may not be reflective of the broader population with vitiligo. Those individuals who responded may also experience a greater psychological burden. The psychological and emotional impacts reported by this study are however in keeping with previous reports<sup>2-7</sup>, and support the need for interventional work.

In view of the small percentage of ethnic minority participants, these findings should be validated in this population. Ethnic minority individuals with vitiligo living in the UK may be less engaged with patient support networks, and this may be fuelled by cultural or language limitations. Future studies should engage further with ethnic minority groups.

A further limitation may be the study-designed element of the questionnaire. We developed a questionnaire specifically for the study rather than use a standardised quality of life measure. This qualitative aspect allowed greater probing of the factors that influence quality of life in vitiligo specifically. Validated questionnaires (e.g. Dermatology Life Quality Index, Hospital Anxiety and Depression Scale) could have been included, however the purpose of the study was not to measure prevalence of psychological morbidity or quantitative assessment of impact, but rather to guide intervention development. We were conscious of participant burden and for this reason elected not to incorporate additional validated measures.

Respondents to the professional survey were mainly dermatologists, likely a reflection of the membership of the UK DCTN and Psychodermatology SIG. The inclusion criteria emphasised that only HCPs with experience of treating vitiligo should respond. The mainstay of care remains within dermatology departments, thus the views of dermatologists are essential in intervention development.

A strength of this study was the ability for respondents to supply free text responses. This was used to a great extent by nearly all participants giving not only rich data for analysis, but also heightening awareness of the unmet needs of people with vitiligo.

The number of respondents in both groups was small, which potentially makes generalising the results more difficult. However, no previous research has explored ideas on intervention content and delivery directly with people with vitiligo and HCPs; making this study particularly valuable. Often there is a tendency with psychological interventions to take 'off the peg' approaches (e.g. CBT) without considering whether this approach best meets the needs of the population. The data, although limited, adds important information to support the provision of psychological services for this patient group.

Current guidelines recommend not only psychological assessment of people with vitiligo, but also propose engaging in psychological interventions<sup>9,10</sup>. Without established therapeutic interventions however, there is little in the way of support once need is recognised. Applying the findings of this study will allow the values and perspectives of this patient group to be translated directly into intervention development.

To our knowledge, this study is the first attempt at developing a patient-directed psychological intervention for vitiligo. The quantitative and qualitative analyses support interventions that incorporate basic self-management and education, as well as focus on acceptance and managing the social impact of vitiligo as areas of priority.

In conclusion, we now have preliminary data which can be used to work towards developing a psycho-educational intervention. The next phase will incorporate focus group work with people with vitiligo and HCPs, as well as in-depth discussion about intervention format, delivery and content. Eventual interventions will benefit from robust testing through a RCT.

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Number of respondents (N)	100	
Sex ratio (F:M)	2.3:1	
Ethnicity	White	92%
	Mixed/multiple ethnic groups	2%
	Asian/Asian British	2%
	Black/African/Caribbean/black British	0%
	other	4%
Marital status	Single, never married	16%
	Married/domestic partnership	74%
	Widowed	2%
	Divorced	4%
	Separated	3%
	Prefer not to say	1%
Time since diagnosis (years)	<1	2%
	1-2	1%
	3-5	3%
	5-10	12%
	>10	82%
Body surface area involved (%)	0-10	18%
	10-25	32%
	25-50	22%
	50-80	13%
	80-100	13%
	Don't know	2%
Area affected	Face/neck	82%
	Trunk	65%
	Arms	78%
	Hands	84%
	Legs	78%
	Feet	79%
	Genitals	68%
	Prefer not to say	1%
	Other	11%
Past treatment for vitiligo	Steroid cream/ointment	27%
	Other cream/ointment	3%
	Phototherapy	25%
	Combination (phototherapy+topical)	10%
	Systemic steroid	2%
	Other tablets	2%
	Cosmetic camouflage	39%
	Psychological treatments	4%
	Other treatment	7%
	None	38%
Current treatment for vitiligo	Steroid cream/ointment	1%
	Other cream/ointment	3%
	Phototherapy	1%
	Combination (phototherapy+topical)	1%
	Systemic steroid	0%
	Other tablets	0%
	Cosmetic camouflage	16%
	Psychological treatments	1%
	Other treatment	1%
	None	79%

Table 1. Demographics and clinical information for people with vitiligo

Table 2. Likert scale responses to psychological difficulties experienced by people with vitiligo ( $\pi$ , SD)

Responses to statements about what people find difficult because of vitiligo (0 = never, 10 = always)  <i>'We would like to know which of the following you find difficult because of your vitiligo'</i>	I find it difficult to accept the way the vitiligo makes me look	5.80 (3.30)
	I find it difficult to accept that vitiligo is a long term condition	4.93 (3.74)
	I feel depressed and low in spirits because of the vitiligo	3.90 (3.44)
	I feel anxious because of the vitiligo	3.52 (3.42)
	I find it difficult to deal with social situations because of the vitiligo	3.92 (3.30)
	Having vitiligo embarrasses me	4.79 (3.67)
	I find it difficult to discuss vitiligo with my friends	3.39 (3.59)
	I find it difficult to discuss vitiligo within my personal and/or intimate relationships	2.55 (3.35)
	I find it difficult to manage other people's reactions to the vitiligo	3.87 (3.39)
	I find it difficult to manage negative thoughts I have about the vitiligo	3.84 (3.61)
	I lack self-confidence because of the vitiligo	4.32 (3.88)
	I do not really understand my condition	2.58 (3.27)
	I find it difficult to cope with treatments for my condition	2.15 (3.18)
	I find it difficult to keep regular appointments for treatment of my vitiligo	1.30 (2.87)

		Face NA=15 A = 80	Trunk NA= 32 A=63	Arms NA=21 A=74	Hands NA=14 A=81	Legs NA=19 A=76	Feet NA=18 A=77	Genitals NA=30 A=65
I find it difficult to accept way I look	Not affected	4.53 ±3.314	5.84±3.37	5.33±3.58	5.29±3.50	5.68±3.64	4.78±3.77	4.73±3.25
	Affected	6.04 ±3.29	5.78±3.32	5.93±3.26	5.89±3.35	5.83±3.26	6.04±2.19	6.29±3.26* (p=0.033)
I find it difficult to accept that vitiligo is a long term condition	Not affected	4.33±3.98	5.09±3.72	4.48±4.30	5.36±4.13	5.63±4.02	5.11±3.88	4.80±3.67
	Affected	5.04±3.75	4.84±3.83	5.05±3.64	4.85±3.74	4.75±3.72	4.88±3.78	4.98±3.85
I feel depressed and low in spirits because of vitiligo	Not affected	2.79±2.61	4.13±3.71	4.35±3.70	3.79±3.73	4.58±3.86	3.47±3.63	2.59±2.54
	Affected	4.10±3.55	3.79±3.33	3.78±3.39	3.93±3.42	3.73±3.33	4.00±3.42	4.49±3.61* (p=0.005)
I feel anxious because of vitiligo	Not affected	2.27±2.68	3.88±3.59	3.71±3.61	3.57±3.90	4.26±3.83	3.06±3.47	2.40±2.47
	Affected	3.75±3.48	3.33±3.31	3.46±3.36	3.51±3.33	3.33±3.28	3.62±3.40	4.03±3.65* (p=0.013)
I find it difficult to deal with social situations because of vitiligo	Not affected	2.73±2.37	4.13±3.43	3.76±3.63	3.71±3.60	3.95±3.29	3.56±3.67	2.43±2.47
	Affected	4.14±3.41	3.81±3.26	3.96±3.23	3.95±3.27	3.91±3.33	4.00±2.23	4.60±3.43* (p=0.001)
Having vitiligo embarrasses me	Not affected	3.73±3.71	4.59±3.60	4.33±3.92	4.64±4.11	4.74±3.68	4.50±4.10	3.77±3.47
	Affected	4.99±3.65	4.89±3.72	4.92±3.61	4.81±3.61	4.80±3.68	4.86±3.59	5.26±3.68
I find it difficult to discuss vitiligo with my friends	Not affected	2.19±3.19	3.85±3.70	2.59±3.62	3.20±4.00	2.60±3.28	3.26±3.66	2.42±2.90
	Affected	3.63±3.65	3.14±3.55	3.65±3.58	3.42±3.55	3.59±3.67	3.42±3.61	3.85±3.83* (p=0.046)
I find it difficult to discuss vitiligo within my personal and/or intimate relationships	Not affected	1.06±2.21	2.91±3.23	2.14±3.40	2.73±3.88	2.05±3.25	2.53±3.61	1.58±2.38
	Affected	2.86±3.48* (p=0.012)	2.36±3.44	2.68±3.36	2.52±3.28	2.69±3.40	2.56±3.32	3.03±3.67* (p=0.024)
I find it difficult to manage other people's reactions to vitiligo	Not affected	2.75±3.32	4.09±3.07	3.48±3.72	3.36±3.90	3.74±3.56	3.28±3.32	2.97±2.93
	Affected	4.18±3.37	3.85±3.56	4.07±3.30	4.04±3.31	3.99±3.37	4.09±3.41	4.40±3.51* (p=0.043)



I find it difficult to manage negative thoughts I have about vitiligo	Not affected	2.86±3.61	4.31±3.58	4.33±3.86	4.00±3.98	4.47±3.60	3.39±3.58	2.45±2.77
	Affected	4.01±3.61	3.58±3.66	3.69±3.55	3.81±3.67	3.67±3.62	3.95±3.63	4.48±3.79* (p=0.005)
I lack self-confidence because of vitiligo	Not affected	3.31±3.65	4.61±4.01	4.05±4.28	2.47±3.60	4.00±4.0	2.68±3.57	2.77±3.27
	Affected	4.39±3.85	4.00±3.73	4.26±3.70	4.54±3.79	4.27±3.79	4.59±3.80	4.91±3.89* (p=0.007)
I do not really understand my condition	Not affected	3.07±3.73	3.38±3.55	3.95±4.33	4.57±4.27	3.05±3.76	4.06±3.99	2.40±3.35
	Affected	2.49±3.20	2.16±3.07	2.18±2.81* (p=0.028)	2.23±2.96	2.46±3.15	2.23±3.00	2.67±3.26
I find it difficult to cope with treatments for my condition	Not affected	4.00±2.74	3.93±2.62	3.88±3.56	4.17±3.31	3.50±1.64	3.00±2.90	3.30±2.98
	Affected	3.42±2.98	3.26±3.10	3.39±2.81	3.37±2.89	3.49±3.11	3.57±2.96	3.55±2.95
I find it difficult to keep regular appointments for treatment of vitiligo	Not affected	4.00±0.00	4.86±3.34	5.75±3.95	2.50±2.12	4.00±0.0	5.00±5.66	3.63±3.34
	Affected	3.33±3.31	2.62±2.84	2.81±2.74	3.50±3.26	3.37±3.22	3.22±2.96	3.25±3.14

NA – not affected, A – Affected. \* p<0.05, \*\*p<0.01

Table 3. Independent t-test analysis to compare affected and non-affected individuals on psychological outcomes dependent on body site

Table 4. Likert scale responses by people with vitiligo to inclusion of particular strategies in a psychological intervention ( $\mu$ , SD)

Responses to importance of inclusion of different strategies in a psychological intervention (0=not important, 10=very important)  <i>'If you were to be offered a choice of strategies to help you cope with your vitiligo, how important is it for the following to be included?'</i>	Learning to accept vitiligo	6.01 (3.85)
	Understanding the condition and the impact it can have on me	6.29 (3.54)
	Managing the impact of vitiligo on mood	5.80 (3.68)
	Coping with social situations and feelings of anxiety	6.56 (3.51)
	Overcoming embarrassment and dealing with other people's reactions	6.66 (3.50)
	The effect vitiligo has on my on relationships	4.56 (3.90)
	Coping with negative or unhelpful thoughts	5.46 (3.87)
	Increasing my confidence and self-esteem	6.62 (3.73)
	Coping with stress in relation to having vitiligo	5.71 (3.83)

Figure 1. Phases of thematic analysis (adapted from Braun & Clarke, 2006)<sup>16</sup>

*Familiarisation with data*

Read data to become familiar with content

Identify interesting aspects in the data that may form the basis of repeated patterns



*Generating initial codes*

Assign numerical codes to potential patterns



*Searching for themes*

Collate codes into potential themes until theme saturation (when no more themes can be generated)

Create different levels of themes (e.g. main theme, sub-themes)



*Reviewing themes*

Have a good idea of what the themes are, how they fit together and the overall story they tell about the data



*Defining and naming themes*

Generate clear definitions and names for each theme



*Producing the report*

Relate the analysis back to the research question and literature

Produce a report of the analysis

Figure 2. Themes and subthemes generated from free text responses from PWV about what they find difficult to cope with and how vitiligo affects their lives (including examples of free text comments from data extraction)

Issues with appearance/body image	<ul style="list-style-type: none"> <li>Practical 'I make different decisions on what I will wear because of exposing the white patches' (P050)</li> <li>Body image 'I feel ugly - I cannot wear the clothes I want to as I have to hide it' (P030)</li> </ul>
Issues with the sun	<ul style="list-style-type: none"> <li>Practical 'It is a nuisance as I have to use sunscreen every day, which is time consuming!... Need to wear hat, keep out of sun, etc. A bit limiting sometimes!!' (P022)</li> <li>Skin cancer 'There is always the anxiety about skin cancer lurking at the back of my mind' (P070)</li> </ul>
Coping with vitiligo	<ul style="list-style-type: none"> <li>Acceptance 'I wish I didn't have it, but I could have something life threatening, so I shouldn't bother as much about it as I do' (P050)</li> <li>Help from others 'My husband and children have been my camouflage' (P006)</li> <li>Impact on identity 'I am more defined by my vitiligo than by my cancer!' (P063)</li> <li>Dealing with others 'When people stare at me I stare back and sometimes can't even resist but pose the question: is there something you want to ask?' (P048)</li> </ul>
Impact of vitiligo	<ul style="list-style-type: none"> <li>Life choices 'I had to change my career prospects due to vitiligo, I cannot go into teaching as I had studied for, this is disappointing' (P025)</li> <li>Relationships 'My husband is supportive despite the fact that I do not want any intimacy as a result of my vitiligo' (P083)</li> <li>Psychological 'I have numerous moments when I just break down in tears as I find the condition distressing and extremely hard to live with' (P036)</li> <li>Emotional 'Self-consciousness all the time, low self esteem' (P016)</li> </ul>
Medical	<ul style="list-style-type: none"> <li>Response from medical profession 'The hardest thing for me is the lack of understanding &amp; help from doctors' (P001)</li> <li>Treatment 'I find the daily routine of applying creams time consuming and frustrating' (P067)</li> </ul>
Reaction from others	<ul style="list-style-type: none"> <li>Bullying 'Making comments like I had a horrible disease and was a freak' (P053)</li> <li>Staring 'Wherever I go people will not let me pass without a second glance at me' (P060)</li> <li>Lack of listening/understanding 'I feel exceptionally let down and it feels as though nobody ever listens' (P036)</li> <li>Negative comments 'I have been asked if I should be allowed to work with children' (P015)</li> <li>Stigma 'I find cultural events very hard to attend due to the stigma attached to vitiligo' (P025)</li> <li>Society 'Social structures are so much about perception over substance and it took me a long time to come to terms with the change in my appearance' (P063)</li> </ul>
Other	<ul style="list-style-type: none"> <li>Issues when growing up 'As a child/teenager my vitiligo affected me quite a lot' (P053)</li> <li>Genetic 'My main concern these days is whether my children will develop it' (P062)</li> <li>Autoimmune diseases 'I have developed hypothyroidism and am developing other autoimmune conditions' (P026)</li> <li>Progression of disease 'Always worried it will spread to my face and the uncertainty' (P047)</li> <li>Triggers 'I believe, for me, the trigger for vitiligo and subsequently hyperthyroidism, was the menopause' (P001)</li> </ul>