

**An exploration of men's subjective
experiences of vitiligo: A qualitative
study.**

**A thesis submitted to London Metropolitan University in
partial fulfilment of the requirements for the Professional
Doctorate in Counselling Psychology**

Sarah Jane Khalid BSc, PGDipCBT, PGDipIAPT, MScHealthPsych

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Table of Contents

ABSTRACT	5
REFLEXIVE STATEMENT	6
INTRODUCTION	6
CHAPTER ONE: INTRODUCTION AND LITERATURE REVIEW	10
OVERVIEW	10
DEFINITIONS: COUNSELLING PSYCHOLOGY	10
DEFINITION: VITILIGO	11
HISTORY OF VITILIGO	13
PSYCHODERMATOLOGY	14
THEORETICAL FRAMEWORKS AND PSYCHODERMATOLOGY	15
<i>Biopsychosocial model</i>	15
<i>Diathesis-stress model</i>	16
<i>Stigma model</i>	17
GENDER DIFFERENCE IN APPEARANCE	19
CRITICAL LITERATURE REVIEW	23
INTERVENTIONS	28
RESEARCH RATIONALE	30
RESEARCH AIMS AND QUESTION	31
RELEVANCE TO COUNSELLING PSYCHOLOGY	32
CHAPTER 2	34
METHODOLOGY AND PROCEDURES	34
METHODOLOGY	34
RATIONALE FOR ADOPTING A QUALITATIVE APPROACH	34
OVERVIEW AND RATIONALE OF IPA METHODOLOGY	35
<i>Design</i>	38
<i>Sampling and participants</i>	39
PARTICIPANT DEMOGRAPHICS	39
SEMI STRUCTURED INTERVIEW AND PROCEDURE (APPENDIX D)	40
ETHICAL CONSIDERATIONS	42
VALIDITY	43
TRANSCRIPTION	44
ANALYTIC STRATEGY	46
METHODOLOGICAL REFLEXIVITY	47
CHAPTER THREE: ANALYSIS	50
OVERVIEW	50
SUPERORDINATE THEME ONE: PROCESSING THE VITILIGO DIAGNOSIS	51
<i>Acknowledging the reality of vitiligo</i>	51
<i>Sean (1: 3-7)</i>	53
<i>Feeling unseen at the medical interface</i>	54
<i>Feeling helpless; 'just live with it'</i>	56
SUPERORDINATE THEME TWO: FOCUS ON SELF	59
<i>Living with an unwanted self</i>	60

<i>Managing shame and distress; 'dirty little secret'</i>	61
<i>Perception of self</i>	65
SUPERORDINATE THEME THREE: MANAGING RELATIONSHIPS	69
<i>'Fear of being ridiculed, rejected'</i>	69
<i>Patterns of behaviour</i>	71
CONCLUDING REMARKS	77
CHAPTER FOUR: DISCUSSION	78
OVERVIEW	78
HOW DO MEN EXPERIENCE THEIR VITILIGO?	78
PROCESSING THE VITILIGO DIAGNOSIS	79
FOCUS ON SELF	81
MANAGING RELATIONSHIPS	87
CLINICAL IMPLICATION AND APPLICABILITY TO CoP PRACTICE	91
THE ROLE OF A COUNSELLING PSYCHOLOGIST AND CLINICAL RECOMMENDATIONS	91
METHODOLOGICAL AND PERSONAL REFLEXIVITY	97
LIMITATIONS AND SUGGESTIONS FOR FUTURE RESEARCH	98
CONCLUDING REMARKS	101
REFERENCES	103
LIST OF APPENDICES	122
<i>APPENDIX A: Poster</i>	123
<i>APPENDIX B: Participant information sheet</i>	124
<i>APPENDIX C: Consent form</i>	127
<i>APPENDIX D: Interview schedule</i>	130
<i>APPENDIX D: Written debriefing sheet</i>	133
<i>APPENDIX F: Distress protocol</i>	135
<i>APPENDIX G: List of useful services</i>	138
<i>APPENDIX H: Extract from a transcript</i>	142
<i>APPENDIX I: Master themes</i>	145

ABSTRACT

Vitiligo is a chronic skin disorder, which de-pigments parts or all of the skin. This disfiguring condition presents individual sufferers with many challenges. Studies have shown an adverse psychological impact of living with such a skin condition. However, no studies to date have explored the experience of vitiligo from a purely male perspective. This study sought to provide some preliminary understanding of and insight into men's experience of vitiligo. A qualitative design was employed and the study was conducted using semi-structured interviews with six participants from a white British background who were all members of the Vitiligo Society UK. Three arching themes were found: processing the vitiligo diagnosis, focus on self and managing relationships. These findings are relevant to the theoretical understanding of the psychological impact that skin disorders can have on men. The applicability of these findings for Counselling Psychology practice in the management of vitiligo is discussed and future areas for research are suggested.

Reflexive Statement

Introduction

A reflexive statement has been included in this thesis as it promotes the validity and rigour of this study. It is important, therefore, to begin by describing my experiences and assumptions in order to situate myself with respect to this research, and so enhance its rigour (Willig, 2001). To do so is in keeping with the professional values of a Counselling Psychologist (CoP) as we ‘engage with subjectivity and intersubjectivity, values and beliefs’ (BPS, 2005, p.1). My reflexive statement aims to illustrate how my personal values, experiences and social identity influenced my research, and how it embraces multiple standards of quality, known variously as *validity, credibility, rigour, or trustworthiness*.

Position

Before considering the research it is useful to reflect on my position in relation to its topic (Elliott, Fischer & Rennie, 1999). The following section will outline my professional and personal interest, naming my beliefs and assumptions prior to conducting this research in order to be transparent about how these might have influenced it.

My interest in vitiligo stems from personal and professional experiences. I am from a South Asian heritage, as were my parents. At the age of eleven my GP diagnosed me with vitiligo. I remember my mother in particular showing great concern at the time. We were informed of this dermatological condition, referred to a dermatologist and prescribed sun block. At this point, vitiligo and its trajectory were not fully understood. I remember the patches growing and the looks in my family’s eyes when they looked at my face. My vitiligo covered the right eye area. My mother began a series of alternative therapies in order to reduce the patches. One such treatment involved eating a heavy gram flour chapatti every day, and no fish was allowed in my diet. One of the South Asian myths is that vitiligo develops after eating white foods together, commonly fish with milk. My journey to school with the boys would at times be difficult as I was called all sorts of names, including “ugly.”

As I grew older I was able to use camouflage more skilfully. My recollections of my vitiligo in my teenage years have become blurry and unclear, as I have lived with this dermatological condition for over twenty years. One important aspect that I have learned is that my individuality is more than skin deep; it has taken time for me to learn this. Others, too, accepted the condition, such as family, friends and my partner. I was told repeatedly by GPs and dermatologists that there was no cure. Nevertheless, in my early twenties I looked to the Vitiligo Society hoping for a breakthrough or cure. However, I have now left behind this information-seeking behaviour as I see the beauty of my vitiligo as a part of me, Sarah Jane. Despite this, I believe having this condition has been life changing, and has affected my career, my aspirations, how I perceive others and how I campaign against discrimination due to disfigurement. Perhaps it is this which has led me to choose a qualitative design for the study, so that I might hear the men's accounts. A part of me wondered whether they have had similar negative experiences of living with this. I am aware that, as a result, the literature search may have focused on the negatives, as may the exploration of what the men said in the interviews.

My professional experience in dermatology began during my undergraduate degree in psychology, eight years after I was diagnosed, when I opted to study a subject related to health psychology. After my degree I went on to pursue a Masters in Health Psychology, aiming to carry out research in narrative writing with National Health Service (NHS) patients with vitiligo. Unfortunately, due to time constraints, I was unable to do so, but I planned to return to the subject. I then spent approximately seven years working as an Assistant Clinical Psychologist, Health Psychologist and a Cognitive Behavioural Therapist in various mental health settings. My role predominantly centred on assessment and treatment of adults referred to the primary care service. During my time in primary care as a CBT Psychotherapist I was offered the opportunity to complete a Professional Doctorate in Counselling Psychology. This training allowed me to explore my interest both clinically and in psychodermatology research. I carried out a year-long placement in a psychodermatology clinic using CBT and Schema Focused Therapy. Other potential gaps in research and my literature review showed a notable lack of research within the field of Counselling Psychology, but also within men's lived experiences of

vitiligo. My dermatology placement consolidated my learning as I noticed the high proportion of women who were referred from dermatologists to psychodermatology.

My subsequent training in Counselling Psychology has consisted of a psychodynamic and social constructionist course along with CBT. I have found this to be a richly rewarding experience that has made me question my previous assumptions about what I thought I knew. During this Doctoral Programme I began to reflect on my clinical and personal experiences as if I was looking at life through a different lens. My training has encouraged me to question everything, and to challenge dominant narratives, particularly those that influence my clinical practice. As I became more familiar with this position I began to reflect on my past work in clinical practice, wondering about those who are less able to access mental health services. Much of my previous clinical work has been with individuals of black, minority and ethnic backgrounds. On reflection, I became aware that my predominant aims were to be inclusive and to encourage individuals to access talking therapies, including the male population.

I took a critical realist stance during my training. This is strikingly different from positivism in many of its premises and implications for traditional science (Baert, 1998, p. 192–193). A realist rejects the view of theoretical concepts, which is one of the defining characteristics of positivism (Feyerabend, 1981, p. 176–202; Phillips, 1987, p. 40). Positivists argue that theoretical terms and concepts are merely logical constructions based on, and defined by, observational data; “fictions” that are useful in making predictions but which have no claim to any “reality.” As a realist I see theoretical terms as referring to actual features and properties of a real world (Devitt, 1991). As such, my epistemological standpoint throughout the course of my training is one between critical realism and social constructivism, where value is placed on the process which each individual goes through in order to create meaning from knowledge, within a social context (Vygotsky, 1978). This position also complements my view of myself as a scientist, a reflective-practitioner. I utilise every opportunity to critically reflect on and evaluate my clinical decisions and practice in therapy and research. With my personal and professional experience in mind, I implemented a number of reflexive practices to manage my influence on the research process. Firstly, I made careful use of supervision and peer support groups. Secondly, I kept a reflective journal throughout the doctoral training as my research

idea developed. This enabled me to identify and bracket my feelings and assumptions during the research journey. Finally, I documented my trail of links between the original data and final report. In order to increase data validity, I asked a fellow researcher who is a Clinical Psychologist with experience of qualitative research to generate her own set of themes from two of the transcripts. I then compared these themes against my list of themes. Discrepancies or misalignment were discussed with the fellow researcher and I finalised the definitive set of themes. I then clustered these themes accordingly and selected excerpts from the transcripts to illustrate each theme identified.

By conducting this qualitative research I expected to provide men with vitiligo with an opportunity to voice their experiences, so that I and other professionals might learn from them. It is my intention that this research into men's experience of vitiligo will inform clinical practice and will "ultimately make a positive difference in people's lives" (Kasket, 2012, p.68).

The aim of this thesis is to give an outline of psychodermatology by setting the scene, explaining the physiology of vitiligo itself and critiquing the research carried out so far in this field. I will conclude by highlighting the gaps in research and raise my main research question. In the remaining chapters, the reflexivity sections will be written in the first person, which will present a closer account of the research and personal experiences of the researcher.

CHAPTER ONE: INTRODUCTION AND LITERATURE REVIEW

Overview

This literature review will outline contextual and theoretical issues regarding individuals with vitiligo. Vitiligo will be defined and placed within a historical and political context. Research into the impact of living with vitiligo will be presented, and will then be critically reviewed. Finally, a rationale for the current research study will be discussed and the research questions will be outlined.

The review will be considered throughout from a Counselling Psychology perspective. As such, the following section aims to provide the reader with a brief introduction to Counselling Psychology by outlining the main philosophical principles and values of this profession.

Definitions: Counselling Psychology

Counselling Psychology's definition in this research study will be used according to the definition by the British Psychological Society (BPS, 2005) Division of Counselling Psychology professional practice guidelines. Counselling Psychology is an applied professional psychology strongly influenced by the humanistic tradition, drawing on phenomenological models as well as scientific research. One of the core principles of Counselling Psychology is the subjective experience and the therapeutic relationship, in which unique subjective engagement, empowerment and validation of the individual's difficulties are highly valued and respected.

It is important to understand why Counselling Psychology is distinct when compared with other closely-aligned professions such as Psychotherapy and Clinical Psychology. Counselling Psychology is unique in its relationship to clients' values and beliefs; empathy and respect for personal accounts within the context of the client's social world are important. Counselling Psychologists are also practice led,

with a research base grounded in professional practice values as well as professional knowledge. Lastly, Counselling Psychologists recognise the importance of social contexts, inequalities and discrimination. They endeavour to work in ways that empower and also demonstrate the high standards of anti-discriminatory practice appropriate to the pluralistic nature of society today (p.2, BPS, 2005).

Definition: Vitiligo

Vitiligo refers to an acquired depigmentation disorder, i.e. it is characterised by white spots or patches on the skin and often appears in various patterns of distribution, leaving the individual visibly disfigured. Vitiligo is disfiguring in all races but particularly so in dark-skinned people because of the strong contrast (Schmid-Ott et al., 2007). It affects 1–4% of the world population, (Porter & Beuf, 1991) with no significant difference in its occurrence as regards to the race, age or gender of the individual. Males and females are thought to be equally affected, however some studies report higher incidences of vitiligo among women than men (Ortonne, Mosher & Fitzpatrick, 1983). It is possible that this discrepancy is due to societal norms: it is being more socially acceptable for women to complain about, or seek treatment for, cosmetic disfigurement (Lorber, 1994).

Onset and vitiligo categories

The onset of vitiligo may occur at any age, although statistics suggest that half of all reported cases occur before 20 years of age (Njoo & Westerhof, 2001; Ortonne et al., 1983). There are said to be three categories of vitiligo (Nordlund & Lerner, 1982):

- a) Focal: few patches of depigmentation scattered haphazardly.
- b) Generalised form: skin appears as symmetrical white patches on both sides of the body.
- c) Segmental form: skin condition may affect only one area of the body.

Aetiology

The aetiology of vitiligo is presently unknown. There have been three basic hypotheses proposed to explain the aetiology as follows: (i) autoimmunity, (ii) neurochemical - mediated effects on the melanocyte and (iii) an intrinsic melanocyte defect causing the melanocytes to self-destruct. In the convergence theory, the causal factors of each of the previous three hypotheses act together, or independently, to bring about the destruction of melanocytes (Le Poole et al., 1993). Furthermore, environmental factors, including psychological stress, mechanical stress, friction injury and infections, have been proposed as contributors to vitiligo aetiology (Taieb 2000). There are different potential factors and theories that may explain the cause of vitiligo but none are conclusive and there is also no effective treatment or cure (Al'Abadie, Senior, Bleeh & Gawkrödger, 1994; Moellmann, Klein-Angerer, Scollay, Nordlund & Lerner, 1982; Nordlund & Lerner, 1982; Mandry, Ortiz, Lugo-Somolinos & Sanchez, 1996; Parsad, 2009; Parsad, Dogra, & Kanwar, 2003; Taieb, 2000; Van Geel, Vander Haeghen, Ongenae, & Naeyaert, 2004).

Current guidelines and NHS services

In 2008, detailed guidelines for the diagnosis and management of vitiligo were published in the UK (Gawkrödger et al., 2008). The Cochrane systematic review and expert consensus (2006) was the baseline for the guidelines. It also encompasses patient choice and clinical expertise (Gawkrödger et al., 2008). Current British Association of Dermatologists (BAD) clinical guidelines for the diagnosis and management of vitiligo, recommend NB-UVB, tacrolimus and topical steroids (Gawkrödger et al., 2008). Currently, dermatology services are being restructured within the NHS but it remains unclear how the new services will be shaped. The NHS remains under pressure to be cost efficient and it is likely that “soft” areas of medicine, such as dermatology, will continue to be under-funded. The Vitiligo Society collaborates with the Dermatology Council for England and supports a manifesto, which has been submitted to the government as part of the white paper consultation process. Their key manifesto focuses on defining requirements in skin care. The Dermatology Council demand that all dermatology services should offer a holistic approach across support, treatment and care. The Council also states that in

order to achieve gold standard status, all services must offer access to psycho-social support, including specialist nurses, camouflage services and where appropriate, counselling and psychotherapy. At present, there are a limited number of services across England and Wales offering this. The following section will discuss vitiligo in a historical and social context along with the theoretical paradigms.

History of vitiligo

The earliest reference to vitiligo is thought to be in the Ebers' Papyrus, an Egyptian collection of writings from 1500 - 3000 years ago, which made a distinction between two different types of depigmentation of the skin (Ortonne et al., 1983). The first type had tumours and mutations and the second had only a change in colour. The former was most likely a reference to leprosy and the latter to vitiligo. Another early reference is thought to be in a collection of Japanese Shinto prayers, *Amarakosa*, dating back to 1200 B.C. (Nair, 1978). Furthermore, there are references that have also been made in the Holy Koran and Buddhist scriptures (Ortonne, et al., 1983). White patches were also referred to in ancient Greek literature by both Herodotus (484-425 B. C.) and Aristotle (367-312 B. C.) (Goldman, Moraites & Kitzmiller, 1966). The geographical diversity of these early references highlights the widespread prevalence of vitiligo.

Even today, in countries such as India, vitiligo is considered 'white leprosy' (sweta kusta), and has been since ancient times. The stigma of vitiligo in the subcontinent is so deeply embedded that even today women are chastised and considered unmarriageable. Even the prime minister, Jawaharlal Nehru, ranked malaria, leprosy and vitiligo as the three medical "curses" afflicting his country (Chaturvedi, Singh & Gupta, 2005). Although a clear description of white skin existed among the ancients, the first strong account of leprosy as being distinct from vitiligo was not reported until 1842 (Kaposi, 1883). In historical literature, it is thought that leprosy is referred to as vitiligo. Interestingly, the misleading perception that vitiligo and leprosy are associated remains strong in many parts of the world. Indeed, up until June 1994, the Oxford English Dictionary described Vitiligo as: "a skin disease characterised by the presence of smooth white shining tubercles on the

face, neck and other parts of the body, a species of leprosy" (p.902) thus perpetuating the literal confusion in language. "Vitiligo may have been derived from the Latin *vitium*, meaning 'blemish', or possibly *vitulum*, meaning 'small blemish' (Millington & Levell, 2007, p.990). It is only since the nineteenth-century that vitiligo vulgaris has been used to describe the disease process of acquired melanocyte destruction (Brocq, 1892). It was towards the end of the nineteenth-century that progress was made in the understanding of vitiligo. Both Brocq (1892) and Neumann (1880) observed that episodes of stress can lead to vitiligo and that none of the available treatments of the time made an impact on the trajectory of the disease.

In the twentieth-century, research into the cause of vitiligo began to be carried out. While some attributed it to damage of the peripheral nerves (Arnozan, 1922; Dearborn, 1913), others believed the cause to be a genetic predisposition (Merelender & Rywlin, 1940). Perhaps the most convincing argument in the pathogenesis of vitiligo is the autoimmune hypothesis, which is built upon several observations. First, vitiligo is associated with disorders that are considered to have an autoimmune origin, including various autoimmune diseases such as thyroid disease (Ongenaes et al., 2003). Also, the antigen found in vitiligo is seen in autoimmunity. Finally, several of the fairly effective therapies such as ultraviolet A radiation and topical corticosteroids rely on an immunosuppressive effect (Jin et al., 2007). As such, vitiligo has been very much viewed in a medical context in the last and current century. Despite scientific advances in the understanding of the pathogenesis, treatments and cure remain inadequate. Although there is now a consensus that vitiligo is not an infectious disease like leprosy, stigma lives on in societies. Over the past decades, emerging theoretical frameworks have moved from the reductionist medical model to examining wider contributing variables, such as the social and psychological, in order to understand this illness. A new area of psychodermatology has emerged.

Psychodermatology

The skin is the largest and only visible organ of the human body. Its large surface area acts as the barrier between the individual and the outside world. It is also

a major organ of communication socially. Furthermore, skin is a complex organ as it reacts to both internal and external stimuli. Hence, it not only responds to physiological stimuli but also to psychological stimuli such as anxiety, fear, shame and sexual excitement (Van Moffart, 1992). For example feelings of embarrassment can cause blushing. Dermatological conditions, unlike other internal illnesses, are visible to others. As such, there can be social and psychological sequelae from living with such a condition (Bull & Rumsey, 1998). Recent theoretical frameworks have aided understanding of the psychological factors involved in physical health conditions, examining the intricate relationships between biological, psychosocial and environmental variables. The following theoretical frameworks focus on important facets of psychosomatic illness and psychogenesis. These viewpoints continue to evolve as they attempt to embrace new discoveries. The next section will outline the theoretical frameworks for understanding psychodermatology. It is important to detail these theoretical frameworks as they offer an understanding of the experience of individuals with a dermatological condition.

Theoretical frameworks and psychodermatology

Biopsychosocial model

Among the first theories of psychosocial medicine was the biopsychosocial model of illness. The model, which was founded by Engel (1978), puts forward the theory that health and illness are caused by multiple factors. In the words of its founder Engel(1978), “all three levels, biological, psychological, and social, must be taken into account in every health care task” (p. 170). Engel championed his ideas as a fundamental ideology and not only as a scientific proposal. This model was formulated at a time when science itself was evolving from an exclusively analytic, reductionist, and specialised endeavour to a more contextual and cross-disciplinary one (Minuchin, Rosman, & Baker, 1978). Engel’s fundamental ideology tried to reverse the dehumanisation of medicine and disempowerment of clients. His model resonated with those within the medical profession who wished to bring more empathy and compassion into medical practice. Within this model illness is proposed as a result of interacting systems at cellular, tissue, organic, interpersonal and environmental levels (Engel, 1967). The model proposes a holistic view of the

individual, advocating their biological, psychological and contextual determinants as facets of the whole system (Papadopoulos & Bor, 1999).

Diathesis-stress model

The diathesis-stress model (Meehl, 1962) emphasises the relationship between a predisposition to an illness and the environment. This model sits adjacent to the biopsychosocial model. A predisposition toward developing a health condition is termed a diathesis. Whilst a diathesis is perceived as a necessary or contributory cause, alone it is not sufficient to cause the health problem. A more proximal cause, which is termed a stressor, must exist. Lazarus and Folkman (1984) define stress as the response of an individual to demands that he or she perceives as taxing or exceeding his or her personal resources. After a stressful event, the presence of a diathesis can be inferred, when an individual has used maladaptive behaviours (Carson et al., 1998). In this way, dermatological conditions can be understood as a reflection of organ (skin) vulnerability, and any psychological and biological stressors trigger the autonomic system which may be then directed towards the weak organ (Walker & Papadopoulos, 2005).

Every individual is affected by psychosocial and genetic factors that interplay with environmental influences and predisposing factors. Clinical experience suggests that psychological factors play a role in triggering and exacerbating many dermatological diseases (Picardi & Abeni, 2001). In order to understand the visible difference on skin, models of stigma and objectification are important to consider. One of the principle causes of distress for vitiligo sufferers is stigma (Porter & Beuf, 1991). Stigma refers to the relationship between a characteristic possessed by an individual and the devaluation society places on that particular attribute. A stigmatised attribute is one which “renders the person as being unacceptably different from others” (Kent 1999, p.241). Bull and Rumsey (1988) have also shown that, as skin is important for social acceptance, disfigurement leads to both implicit and explicit rejection by others.

Stigma model

In the early 1960s, Goffman (1963) began studying the meaning of stigmatisation, which originated with the ancient Greeks, who used this word to refer to a physical mark on an individual which showed that they were deviant. He described this phenomenon as “enacted stigma” which refers to instances of overt discrimination experienced by stigmatised individuals, and also identified “felt stigma,” which refers to the anticipation of rejection (Jacoby, 1994). The latter has been thought to be more disabling as the individual experiences anxiety regarding rejection and as such withdraws from social interaction (Jacoby, 1994; Scambler & Hopkins, 1986). Goffman’s theory is useful, as it is individualistic in its approach and explains the rejection felt by the clients as a result of their ‘physical mark’ leading to social rejection. However, Porter and Beuf (1991) found that the emphasis he placed on aspects of the stigma as the primary determinant reaction as too simplistic. Coping resources mediate between the stigma itself and adjustment.

More recent theoretical frameworks are offered in understanding body shame and social anxiety models. Accordingly, cognitive-behavioural models have received considerable attention and empirical support in current research and they are the most extensive in terms of considering cognitive, affective and behavioural components. A cognitive conceptualisation for disfigurement has been offered. Kent and Thompson (2002) have proposed a model explaining shame-proneness in individuals distressed by disfigurement. They have argued that experiences of stigmatisation, particularly if this occurs in a repeated fashion in childhood, when there is an early onset of skin disease, can lead to the development of body shame and social anxiety. The possibility that variations in distress associated with disfigurement may be related to early parent-child interactions is consistent with many theories regarding the development of psychopathology. Kent and Thompson (2002) thus suggested that such experiences of stigmatisation can result in the development of negative, maladaptive schemas (Kellet, Humphrey, & Sleeth, 2002).

Individuals that report relatively high levels of emotional neglect during childhood exhibit higher levels of psychiatric symptoms (Campbell-Sills, Cohan & Stein, 2006). Also, the importance of adolescent years in the development of identity and social aspects of the self and in the creation of relationships and the increasing

awareness of sexual attractiveness has been noted (Bernstein, 1997). In theoretical terms, a vicious cycle begins due to maladaptive beliefs triggered causing biases in cognitive process such as worry, which might be associated with increased feelings of shame, anxiety in social situations, proneness to rejecting experiences, depression, avoidance and concealment (Kellet et al., 2002; Kent & Thompson, 2002).

In conclusion, despite references to vitiligo dating back 1500 BC it appears to not yet be truly understood both biologically and treatment wise. The common thread through history is the stigma that individuals face with this dermatological condition and the prevalence of cultures that continue to condemn and isolate individuals with vitiligo (Lesage, 1997). Although the condition itself does not cause pain or physical limitations, individuals report that the power it has over their lives is enormous (Porter & Beuf, 1988; Porter, Beuf, Lerner & Nordlund, 1990). It is important that, as researchers endeavour to find solutions regarding aetiology and curability, the experience of vitiligo is also understood.

Psychodermatology has more recently been gathering further knowledge. Its key objective is to provide support for psychological challenges associated with living with a skin condition and to offer adaptive coping strategies and to promote the endurance required for compliance with medical intervention. While not all dermatological conditions are life threatening, they can cause immense distress (Papadopoulos & Bor, 1999). The principle difficulty in having a dermatological condition is that it can alter physical appearance, which can cause psychological problems. Others may notice the condition in social interactions, which subsequently makes it difficult for the dermatological condition to be a private concern (Papadopoulos & Walker, 2003). As such, the individual may feel like they have lost personal control over their health condition and are left feeling exposed to the public. Furthermore, others may make negative remarks due to an assumption that the dermatological condition is unhygienic or contagious (Kleinman, 1988). In this way, it can predispose others to behave negatively towards the individual with the skin complaint and consequently feelings of stigmatisation may arise within the sufferer.

The often progressive and episodic nature of dermatosis can mean that the individual tends to manage by avoiding social situations; this approach can maintain

anxiety. Accordingly, the physical change in appearance can also affect their self-esteem and body image (Papadopoulos, et al., 1999). Body image is a complex and multi-layered phenomenon, which affects quality of life, emotional regulation, thoughts, attitudes, perceptions and behaviours, and which impacts on relationships (Cash & Hicks, 1990, Cash, 2011). Cash and Pruzinsky (1990) described how body image feelings are particularly pronounced in social contexts. The individual's body image can be influenced by both personal and interpersonal values within a cultural context. More recently, cognitive-behavioural perspectives on body image have been proposed by Cash (2011) considering historical influences such as culture, interpersonal experiences and personality. The model is heuristic and helps organise researcher's thinking about body image and its multidimensionality. Thus it can be said a person's body image refers to the internal representation that they hold regarding their own appearance from internal and external global history and attributions. However, body image as a concept has become popularly synonymous with women because it is assumed that they face greater pressures to be a particular shape and weight in western culture (Lieberman et al. 2001; Ricciardelli & McCabe, 2003; Stice & Whitenton, 2003). As a result, much of the research on body image has focused on distorted body shapes and weight (Grogan, 2008; Wykes & Gunter, 2005) and research into men and women's dermatological conditions and other aspects of male body image has been less prevalent.

Gender difference in appearance

Throughout classical history there has been considerable interest in appearance dating back to Aphrodite (Powers, 2000) She was a representation of divine beauty that was personified; the importance of beauty was reflected in the ancient Greek's worship of Aphrodite. Attractive people are seen to possess more desirable characteristics and are treated more positively than their less attractive counterparts, a phenomenon that has been labelled the beauty-is-good stereotype (Dion, Berschied & Walster, 1972). Traditionally, more attention has been focussed on the appearance of women. This can be understood from an evolutionary perspective, in terms of beauty being associated with health and fertility. This is one of the Darwinian theories of survival of the fittest in attracting a mate. In this way the

preoccupation with beauty and the pursuit of it are central features of the female sex-role stereotype (Rodin, Silberstein & Striegel-Moore, 1985).

Men's concerns around physical appearance and body image have been ignored up until more recent decades, which perhaps implies that this area has been overlooked. Researchers have investigated sociocultural factors related to appearance and have begun to acknowledge male-female differences in perceptions and behaviours related to their appearance (Bordo, 2003; Fallon & Rozin, 1985). For example, females diet more frequently (Leith, 2006) which is related to their feeling more dissatisfied with their physical appearance than men (Fredrickson & Roberts, 1997). Bodily concern for men is growing as there has been a cultural shift in the portrayal of men's bodies in the popular media in the 1980s when the male body was increasingly used in television advertisements in place of the more traditional image of the female body. Mishkind, Rodin, Silberstein, and Striegel-Moore (1986) argued that men were under increasing pressure to conform to this cultural ideal of the lean, well-toned, muscular build, paralleled by an increasing preoccupation among men with weight and body image:

Advertisements celebrate the young, lean, muscular male body, and men's fashions have undergone significant changes in style both to accommodate and to accentuate changes in men's physiques toward a more muscular and trim body. (p. 545)

By an analysis of male action toys, Pope, Olivardia, Gruber and Borowiecki (1999) have similarly suggested that cultural ideals for the male body have become progressively muscular over time, with many toys of the 1990s exceeding the muscularity of even the largest human bodybuilders. They argue that there has been a cultural shift in attitudes toward the male body during the past thirty years. Muscular men's bodies dominate contemporary style and fashion magazines where once women would have dominated the covers (Nixon, 1996).

The changes in men's behaviours concerning their appearance such as grooming behaviours (for example waxing) as the hairless male body ideal has come back *en vogue* (Luciano, 2001). In addition, western society's attitudes toward men's bodies have prompted research in the role of body-image in men's lives. A study

which investigated college men's satisfaction with their physical appearance, found that 95 percent expressed dissatisfaction with some aspect of their body (Tucker, 1983). Interestingly, when presented with line drawings representing seven body types, more than 70 percent of undergraduate men saw a discrepancy between their own body and their ideal body type. Within the mesomorphic category, a majority selected the hyper-mesomorphic or muscular mesomorphic body as preferred (Tucker, 1983). This physique is the "muscle-man"-type body characterised by well-developed arm and chest muscles and broad shoulders tapering down to a narrow waist. That many men feel bodily dissatisfaction because they do not resemble the mesomorphic or hyper-mesomorphic ideal might not in itself be particularly distressing. The discrepancy between self and ideal is problematic only when men believe that those closest to the ideal reap certain benefits not available to those further away. Research strongly suggests that this is true, both because physical appearance is so important generally in our society and because of the specific benefits that accrue to mesomorphic men such as in dating (Mishkind, et al., 1986). Further reports have shown men revealed dissatisfaction with their chest, waist and weight (Miller, Coffan & Linke, 1980). The male form has become more apparent in popular culture. Due to this, considerable research is being carried out on the effect of this growing visibility of the male form on men's images of their bodies (Mishkind et al., 1986; Mort, 1988; Singleton, Fawkner, White & Foster, 2010). Recent research trends indicate increasing exploration of men's views of themselves and their concerns, such as eating disorders (Andersen, Cohn, & Holbrook, 2000).

It can be argued that men are moving further along the continuum of bodily concern. Western culture places great pressures on life-style change and self-management as the major health-promoting activities (Surgeon General's Report, 1984). It has been indicated that concern with appearance has an impact on men in terms of their health, self-esteem, body image and eating disorders (see Grogan, 1999 for a review). Moreover, the male body is increasingly in the media's eye, targeted by popular culture and advertising, as for example in Gillette razor blade commercials. This challenges traditional masculine icons and invites viewers to become more aware of how they look (Mort, 1988). With this shift in visual culture,

it is important to pose the question of how men feel about their bodies - especially if they live with a chronic health condition which impacts their appearance.

In summary, literature has highlighted how gender has been thought about and researched. Statistics suggest varying prevalence in genders: some report equal prevalence, while others report a higher incidence in women (McBurney, 1979; Wang et al., 2013). These high ratings are different from those reported by other studies (Alkhateeb, Fain, Thody, Bennett & Spritz, 2003; Handa & Kaur, 1999; Lu, Gao, Wang, Jin, Li & Li, 2007) which suggests a bias in data due to recruitment being hospital based rather than community based. This gender discrepancy may be skewed by increased reporting of a cosmetic concern by female patients (Wang et al., 2013). As described, gender appearance is a growing concern for both men and women and vitiligo is a dermatological condition which is known to be psychologically devastating. The next section will critique the research conducted to present day.

Method

As part of reviewing the literature, I have conducted internet searches within specialist databases like PsychINFO. I have further consulted my university library and the local NHS library. Further searches were made through the iterative approach of 'berry-picking' (Bates, 1989) and the 'snowballing technique' (Ridley, 2008). By carrying out internet research, I was able to gain an overview of relevant literature on vitiligo and familiarise myself with the leading research experts in this field. Search terms included 'disfigurement', 'psychological aspects of vitiligo', 'gender', 'ethnicity', and 'quality of life'.

Critical Literature Review

Previous quantitative research has explored the psychological effects of living with vitiligo, taking into consideration factors such as gender, culture and society, which determine the effect of vitiligo in an individual's life (Porter et al., 1978, Papadopoulos et al., 1999). Quantitative research has found that vitiligo causes psychological distress (Baker 1992; Malt & Ugland, 1989), low self-esteem (Papadopoulos, Bor & Legg, 1999), impaired body image and a poorer quality of life (Papadopoulos et al., 1999). Furthermore, those who have vitiligo experience problems predominantly in the area of social interaction e.g. remarks or staring (Parsad et al., 2003). Stigma has been highlighted as one of the principle causes of distress for vitiligo sufferers (Porter & Beuf, 1991). The stigmatisation experienced by individuals with vitiligo can also be a threat to their racial and ethnic identity (Kent & Al'Abadie, 1996; Porter & Beuf, 1994).

Porter and Beuf's study (1991) is important as vitiligo can have profound effects on racial self-esteem, as turning white for a darker skinned individual can have implications in terms of cultural beliefs around punishment for wishing to be white and premarital sexual activity. Although the findings did not identify any significant links between distress experienced by participants with vitiligo and the factors of age, gender and race (black and white ethnic backgrounds), the study shows a lack of interaction effects between variables, which confirms the theoretical importance of covering a range of social aspects in adjustment. Furthermore, their quantitative methodology negated other social and psychological processes that may mitigate the relationships, such as gender. In contrast to these findings, Robinson, Rumsey and Partridge (1996) showed that women experienced more distress than men and both sexes had similar levels of anxiety and avoidance behaviours. Macgregor, (1974) and more recently Martins, Tiggemann and Kirkbride (2007) found that men and women are equally distressed. The difference between them regards how much men will disclose when considering their appearance. The findings mentioned show divergent and inconsistent results which indicate that men and women may appraise disfigurement in different ways.

One of the central studies of understanding individual experience and accounts of living with vitiligo was carried out by Andrew Thompson and colleagues in the UK in which they show that vitiligo is more than just a physical disease (Thompson & Kent, 2001; Thompson, Kent & Smith, 2002). Thompson et al. (2002) carried out a qualitative study examining the experience, impact and ways that patients with vitiligo cope with this condition. Seven white female participants with vitiligo were interviewed for the purpose of gathering qualitative data about their experiences. They found that unlike a quantitative approach, qualitative findings showed the complexity of how individuals manage their disfigurement. Findings suggest that there are on-going struggles with living with this condition, namely the initial reactions to the disfigurement, remarks and intrusive comments made, and the individual's feeling of being different. Participants tried to manage difference through the use of various coping strategies, e.g. behavioural techniques such as avoidance and social concealment, and even confronting people and explaining the condition, which often caused a high level of distress. They also employed cognitive strategies such as hypervigilance towards others' behaviour, attributional analysis and social comparisons between themselves and their condition. They felt the process of acceptance to be a difficult one. Social anxiety strategies were employed to manage others' evaluation of their disfigurement. There appears to be an oscillating process for individuals with vitiligo with regards to their emotions and how they cope with situations, dependent on emotion and context. Therefore, the relationship between appearance and coping is not linear or straightforward as participants often use concealment and avoidance to manage the impressions they make on others, but express much ambivalence in their use (Learly & Kowalski, 1995; Thompson et al., 2003). This research supports earlier findings regarding the different factors discussed (e.g. stigmatisation, low self-esteem) and the effects of societal pressure on self-perception, distress, coping strategies and, consequently, quality of life.

As Thompson et al. (2002) identified, social support was another theme raised by the sufferers of vitiligo. They suggest that social support is important because, firstly, it can act as a buffer to mental health difficulties (i.e. depression and anxiety), and secondly it can reduce the feared consequence of social rejection or

negative impression when clients are exposed to positive interactions in social contexts. Lastly, the authors recognise that significant others can help the individual to move to a position of acceptance regarding their difference and experience positive interactions. Once again this finding suggests that a person's social system can have an enormous impact on their management of vitiligo, as it has the strength to facilitate coping with appropriate support in the same way that it can hinder it with stigmatisation. However, despite its promising outcome, more research is required with other individuals from different races, genders and ages. Also, the findings are specific to women as three men were recruited for the study but in order for the researchers to keep the sample homogenous, the males were not included in the final sample. All the participants in this study were Caucasian and women, therefore to understand vitiligo further, it would be useful to study those from other ethnic backgrounds, and men. Due to these limitations, further research is needed to understand the individual's experience of living with vitiligo.

Thompson et al.'s (2002) study is meritorious as it uses the Interpretative Phenomenological Analysis (IPA) which is specifically designed to explore participants' meaningful experiences with vitiligo. This is different to past studies which used quantitative views rather than the experience of having this skin condition (Conrad, 1990). It has shown the complexity of living with this skin disfigurement and how individuals manage to contain their distress and feeling of difference. The authors acknowledge their limitation regarding the sample used and the potential biases of having a non-disfigured male interviewer, as well as the location in which the interview took place (i.e. in the dermatology clinics in which they had originally been diagnosed). Nonetheless, this study brings to light the possibility of applying clinical interventions, such as social support. If social support is as important as Thompson et al. claim, then clinical interventions like social skills training can increase behavioural coping repertoires. Role-playing around managing stigmatisation can also be of benefit.

Since the appearance of the UK studies (Thompson et al., 2002; Papadopoulos et al., 2004), a more recent qualitative study has been carried out looking at the lived experience of women in Iran with vitiligo (Borimnejad, et al., 2006). This was the first research of its kind in that country. The methodology was

slightly different to previous studies (Kent & Al'Abadie, 1996; Thompson et al., 2002) in that Borimnejad had personally experienced vitiligo and had spent six months prior to the study listening to vitiligo clients' experiences. By holding a hermeneutic position, the first author's personal experience with vitiligo is considered unlikely to interfere with the findings. Borimnejad took an active role in the process of interpretation by initially explaining her experiences to the participants to establish a dialogue of their difficulties in living with vitiligo. Sixteen patients were recruited from dermatology clinics, 13 of which were under thirty years of age and three were aged between 32 and 42.

Four main themes were identified in the analysis: perceiving oneself in a different light, worry of other's perceptions, being influenced by cultural beliefs and accepting and fighting the disease. Participants described how they saw themselves as different, which concurs with previous studies by Thompson et al. (2002) and Thompson, Clarke, Newell, and Gawkrödger (2010). The second theme was cultural beliefs; the various narratives found beliefs around eating certain foods together on the plate, poor personal hygiene, and beliefs around contagion. Some of the participants' frame of understanding comes from their own friends and family and they found that many individuals with the condition were not educated regarding their skin condition. Another salient theme centred on acceptance, which came from being pragmatic or accepting vitiligo as ordained by God. Religion appeared to be an important factor, with some believing God had chosen them to suffer in exchange for other positive outcomes, e.g. meeting good people. However, other participants who had not come to terms with vitiligo described feeling suicidal, sorrowful and even aggressive.

While Borimnejad et al. (2006) provided rich data from an ethnic female group, the study neglects the experiences of men and fails to recruit members of an older age group and female divorcees, as married women that develop vitiligo after marriage are likely to have marital problems and mostly end in divorce (Parsad, Dogra & Kanwar, 2003). It was also unable to elicit differences within religious groups, e.g. Muslims and Christians, and did not give demographic details. This study is meritorious as it builds on previous studies in this area by using a different qualitative methodology which is the hermeneutic phenomenology method. It also

attempts to make recommendations for clinical care, such as psycho-education and psychotherapeutic support. Social support, including social skills training and CBT was identified as being particularly important and these have been further supported (Robinson et al., 1996; Papadopoulos et al., 1999). This study has many positive aspects that outweigh its limitations. It highlights the importance of cultural factors which can determine how individuals with vitiligo cope. For example, accepting this skin condition as a punishment from God helps, whereas the societal pressures on appearance and attractiveness in the western countries can hinder the adjustment process (Altabe & Thompson, 1996; Borimnejad et al., 2006).

One of the latest qualitative studies by Thompson et al. in 2010 has examined the role of ethnicity and culture in exploring the impact and management of vitiligo in British South Asian women in the UK. This study used seven female participants who were of either Pakistani or Indian origin, were between 19 - 52 years old and had lived with vitiligo for five years. The researchers used template analysis, a specific type of thematic analysis, as their qualitative methodology; this iterative approach was particularly suitable in revealing the novel themes of this unexplored area of research. They found that participants described feeling visibly different, in a more pronounced, and therefore problematic, way: a common theme in the qualitative studies discussed so far. Similar to the study by Thompson et al. (2002), it was revealed that coping was made effective by using concealment strategies to manage intrusive reactions by others. Appearance and attractiveness were found to be important to this group as it influenced future marriage prospects (Hughes, Naqvi, Saul, Williamson, Johnson et al., 2009). They were shame-prone as they had experienced stigmatisation to various degrees, leading to internalisation of feelings. They felt that their personal and ethnic identity was spoiled. While this research is the first in the UK to understand the processes of adjustment to vitiligo in a specific ethnic group, it does not draw out the differences between generations or understand male experiences. One potential limitation to this study is that one interview was carried out through e-mail, which questions the quality of the data in terms of the richness of data which may have become lost in translation, in terms of the non-verbal communication. These findings support the theoretical underpinnings of stigmatisation (Scambler & Hopkins, 1986; Jacoby, 1994).

Some of the literature presented above highlights that cognitive and behavioural processes and stressful events can cause or exacerbate the condition. It also identifies cultural beliefs associated and adjustment processes used in living with a chronic dermatological condition. Future research into providing community-based interventions, aimed at raising awareness of social support, treatment and demystifying any negative connotations of vitiligo could be fruitful.

Although the development of interventions often depends on what information is available about the condition, evaluation of an intervention can also bring to light a much better understanding of vitiligo. For example, a successful program lowering distress can highlight what areas of the sufferers' lives are mostly affected by vitiligo. As a result, much research has focused on evaluating the effectiveness of current treatments. The next section will critique emerging research on treating psychological problems in those with vitiligo.

Interventions

Interventions like CBT can help to challenge negative cognitions around appearance. Papadopoulos, Bor and Legg (1999) examined the efficacy of CBT on managing vitiligo as well as looking at the implications of the condition such as self-esteem and quality of life. They had two matched groups (total sample of eight) with vitiligo participants, one group received CBT for eight (one hour) weekly sessions and the other group had no treatment. In both control and treatment group there were two participants each who continued to receive PUVA (light therapy) treatment. Groups were well-matched at baseline for age, sex and ethnicity. The course ran for 8 weeks and then offered a follow-up after 5 months. Traditional CBT was delivered, drawn from Beck (1979). The results showed an improvement in self-esteem, body-image and quality of life compared to the control group. The researchers found that participants held many appearance-related negative thoughts, but that those in the CBT treatment group showed a substantial effect on self-esteem, body-image and quality of life as compared to the control group. They also suggested that their findings had preliminary evidence of an influence of CBT on the progression of vitiligo. A main criticism of this study is its small sample size; more and better-powered studies are needed to establish whether CBT is effective. The researchers

also ran a second study comparing CBT with person-centred therapy which did not support the findings of the first study. This may have been because it was designed to use a group therapy approach rather than individual sessions as in the first therapy, and considering social anxiety is exacerbated in most individuals with vitiligo, it may suggest a limitation to the group format. Overall, the first study furthers the work from Thompson et al.'s (2002) who suggested ideas that can facilitate therapeutic interventions with those with disfigurement.

Papadopoulos, Walker, and Anthis (2004) compared the effectiveness of different interventions. They set up three comparison groups: I) CBT-based group counselling, II) Person-Centred group counselling, III) Control group (no intervention). The study used 44 vitiligo patients recruited through UK dermatology outpatient departments and the UK Vitiligo Society. Participants (13 male, 31 female) were over 18 years of age, with a mean age of 36 years. The first intervention consisted of eight 90 minute weekly sessions of CBT-based group counselling. The second intervention consisted of eight 90 minute weekly sessions of Person-Centred group counselling. The third group was a control group of no intervention. The authors found inconclusive results: therapy groups showed a reduction in post intervention scores on a general health questionnaire, but this was not statistically significant. The inconclusive results may have been due to a number of reasons. The study did not employ a truly random selection process and omitted blinding of participants and assessors. A priori sample size was conducted before the study began and, based on this figure, the sample size used was just below that considered sufficient. The sample chosen was not representative of the vitiligo population as a whole, presenting only mild symptoms; therefore the study was found to have poor validity. The study employed objective and appropriate outcome measures, but the absence of vital statistics (the means for the outcome measures at baseline) meant that the results were not reported in sufficient detail. The groups were, however, comparable at baseline on demographic factors.

Furthermore, the statistical analysis employed by the researchers was not suitable for the study, with no consideration being given to type one errors. Although this is the first controlled trial to be undertaken with vitiligo clients, more rigour is needed when carrying out such a trial. It does show promise in empowering clients to

manage vitiligo. Papadopoulos et al.'s (2004) findings indicate that interventions have some effect on participants' self-reported general health, but the results were not statistically significant. If this study was replicated but amended to account for the weaknesses addressed, then the findings may provide conclusive results that could effectively evaluate the impact of interventions on participants' health.

Papadopoulos et al.'s (2004) study builds on previous findings by examining the effect psychological therapy, using CBT, has on the self-esteem, body image and quality of life of those with vitiligo. CBT was selected as it has been shown to be efficacious for use with body image disturbances in a variety of other studies (e.g. Cash & Hicks, 1990; Cash & Pruzinsky, 1990; Fisher, 1986). At present, there does not appear to be convincing or conclusive evidence for clinical effectiveness for interventions in vitiligo (Papadopoulos et al. 2004; Bessel & Moss, 2007). It is possible that further exploration and understanding of the subjective experience of living with vitiligo is needed. A richer understanding of vitiligo would enable researchers to carry out greater rigour in looking at the effectiveness of the psychological interventions in managing this skin condition. By exploring men's and women's experiences with vitiligo, a greater understanding of vitiligo can be gained. In turn, a greater understanding of these individuals' treatment experiences and treatment needs may be achieved; which can inform professional practice to tailor treatment accordingly and therefore enhance treatment effectiveness.

Research rationale

In the past it has been assumed that vitiligo was just a cosmetic condition and psychological understanding was disregarded (Kent, 1996). This review has demonstrated that there is a growing exploration of vitiligo and the impact of this skin condition on day-to-day life. To date, there has been one small, non-randomised study, which showed improvements in body image, self-esteem levels and quality of life through CBT. However, there are few studies to compare this with other skin conditions. There is a lack of rigorous controlled trials in the area of psychological interventions for those with vitiligo, thus making it difficult to draw any conclusions. There has been an expanse of literature exploring the quality of life of individuals with vitiligo (for example, Ongenaie et al., 2003; Parsad et al., 2003; Picardo &

Taieb, 2010) using qualitative methodologies such as the QoL questionnaire. There are merely a handful of studies which examine subjective experiences and meaning of individuals with vitiligo, particularly considering men's experiences. Where research does exist, it is on women's experiences of living with this skin condition in the UK and abroad (for example, Thompson et al., 2002; Borimnejad et al., 2006; Thompson et al., 2010). As Counselling Psychologists are currently practicing within the psychodermatology services, it is hoped that there will be increasingly more positions in the future to offer psychological therapy to clients with dermatological conditions who experience distress. Accordingly, research exploring psychological experiences of men with vitiligo will not only serve to develop an increased understanding of the issues but also address the lack of research from a counselling psychology perspective.

Research aims and question

This study seeks to contribute to the limited literature in general on lived experience of vitiligo in the UK. Specifically, it aims to expand the research base on men's experiences of living with vitiligo in their day-to-day lives, seeking to develop deeper understanding in relation to their context. In doing so, the study's objective is to move vitiligo from being seen as a cosmetic disease, as it is in the medical world, and to understand vitiligo in a phenomenological and psychological context. The critical literature has described how all published qualitative studies carried out so far internationally have used women as participants. The first study by Thompson was not intended to choose women only, but on grounds of homogeneity, they choose to do so. The more recent study looked at South Asian women in particular as research has shown the specific pressures of marriage as being an issue for consideration (Borimnejad et al., Parsad et al., 2003). In addition, research suggests that a key difference in gender is that women are more likely to seek information for their disfigurement (Brown et al., 1988). With prevalence of vitiligo equal to and higher than in men compared to women, men's experiences require exploring (Das et al., 1985; Wang et al., 2013). As Counselling Psychologists are considered to value diversity and equality, it is important that treatment is tailored to men's needs. As a practitioner I do not know their issues or needs and therefore I cannot assume the

same knowledge or insight for men. This proposed research study would continue the work and further research into men's experience of health problems in general (Sabo & Gordon, 1995). The proposed study is original, as no research has been carried out to explore the experiences of men who have vitiligo. Understanding men's subjective experience will enable clinicians to become mindful of possible differences and similarities between genders. Furthermore, it could shape health services at an educational, organisational and policy developing level, by providing psychological support for men with vitiligo.

The aim of the current study was to gain an in-depth understanding of the experience of men with vitiligo, using an Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003; Smith, Flowers & Larkin, 2009). The main research question was: What are men's experiences of living with vitiligo?

Related to this main research question, the following areas of interest were explored: I) how they learned about vitiligo, II) to know what it is like for them and III) what help they have sought, if any.

Relevance to Counselling Psychology

The importance of subjective experience in both men and women is at the core of Counselling Psychology philosophies (BPS, 2005). By learning more about individuals' journeys, research findings will aim to inform professional practitioners and their practice in working with individuals who have vitiligo. In addition, in reviewing the current gaps in the literature on vitiligo in terms of males' experience, it will enhance clinical expertise in this area and identify potential research possibilities. In this way, the recommendations from the research findings will serve to empower men who have vitiligo to be heard and encourage implementation of services to meet this clinical population's needs. By doing so, this research will be in line with the Division of Counselling Psychology's professional values, i.e. "Counselling psychology espouses values that aim to empower clients, and places high priority on anti-discriminatory practice, social and cultural context" (BPS, 2010b, p.1). Furthermore, the main objective of Counselling Psychology research is to support investigation that informs clinical practice (Wheeler, 2003). Thus,

carrying out research within this field would enhance understanding of the subjective experience of vitiligo for all professionals. And by understanding this, future treatment and management can be tailored in an individual way.

The need for counselling and psychological treatment for clients with dermatological conditions is widely acknowledged (Papadopoulos & Bor, 1999). This study has relevance both for dermatologists, psychologists and other related health care professionals. From the dermatologist's perspective, the present study could help educate medical professionals to become aware of the cognitive, emotional and behavioural processes that are happening when a man is diagnosed or seeks treatment for their vitiligo. As such, an awareness of this might guide the treatment that individuals receive in an endeavour to deliver a treatment that is holistic in its approach. From the psychologist's perspective, the findings of this present study can enable new insights into and understanding of how men view, manage and experience their vitiligo on their body. This can have implications for engagement in the psychodermatology services and talking therapy services on offer in primary care. Finally, it is hoped that this study will begin a dialogue with clients and between professionals that could bring new possibilities for collaborative clinical work and research.

CHAPTER 2

METHODOLOGY AND PROCEDURES

Methodology

In order to address the research questions presented at the end of the previous chapter, a qualitative research methodology was used. The aim of this chapter is to outline the justification for using such a methodological approach, highlighting the epistemological position of the research and describing Interpretative Phenomenological Analysis (IPA). The aim is also to describe the data collection procedure.

Rationale for adopting a qualitative approach

Biggerstaff and Thompson (2008) have discussed the value of qualitative research in clinical settings: “essential simplicity, paradoxical complexity and methodological rigour that IPA can offer as a research tool in understanding healthcare and illness from the patient or service user perspective” (p.173). In recent years, qualitative studies on vitiligo have been published (Thompson et al., 2002; Borimnejad et al., 2006; Thompson et al., 2010). Although growing in number, these research studies are comparatively less than the quantitative studies published. Nevonen and Broberg (2000) argue that whilst quantitative findings are valuable they can also be limiting. For example, when using a structured reporting tool, i.e., questionnaires, participants are responding to the specific areas (e.g. illness beliefs) and produce only one part of a wider picture. As this is an exploratory study, qualitative research is appropriate. Such approaches are valuable as they allow for an in-depth detailed study of phenomena which are not easily quantifiable. In addition, such an approach also allows for the emergence of unanticipated findings (Barker, Pistrange & Elliott, 2002).

A qualitative approach was also adopted for the current study in order to remain consistent with the research aims, which considers the context and complexity of men’s experiences of their vitiligo. A qualitative approach that is reflective as well as experiential captured the intricate and dynamic processes of living with a disfiguring skin condition. This study provides meaningful insights into

an area which has been neglected when researching the psychological impact of living with vitiligo.

For many research questions, quantitative methods are neither feasible nor appropriate, yet men's experiences of vitiligo can be considered under a qualitative approach. Indeed, qualitative methodology may be a more appropriate way of exploring an individual's personal perception or account of an event or state, i.e. vitiligo (Smith, Flowers & Larkin, 2009). Under the umbrella of qualitative methods there are various interview formats. Fitzpatrick and Boulton (1994) explain how qualitative analysis requires detailed interviews in order to obtain more detailed information than that available, for instance, in an administered questionnaire. As the subject area of concern was particularly complex, qualitative interviews were used as the methodological approach.

Overview and rationale of IPA methodology

Johnathan Smith developed IPA as a qualitative approach in the mid-1990's (Smith, 1996). IPA has three main theoretical underpinnings; hermeneutic, phenomenological and idiographic in nature (Smith, Flowers & Larkin, 2009). The approach concentrates on the detailed lived experience of the individual and how they interpret their experience (Eatough & Smith, 2008). The phenomenological aspect of IPA is focused on the understanding of what the human lived experience is and the full interpretation of it (Smith et al., 2009). IPA also recognises that meaning-making is contextually bound within a socio-historical framework (Eatough & Smith, 2008). The interpretative aspect of IPA is influenced by hermeneutics, the theory of interpretation. IPA recognises that it is difficult to extract the experiences of the individual given that experiences are subjective. Therefore, the researcher's understanding develops through a process of interpretative engagement (Smith et al., 2009). IPA can therefore be seen as a twofold process; phenomenological, concerned with an individual's lived experience and own perceptions, whilst also being an active process for the researcher who is attempting to understand and interpret the individual's interpretation of their lived experience (Smith & Osborn, 2008). Therefore, an IPA researcher is considered to be engaged in a double hermeneutic in

which they are attempting to make sense of the participant trying to make sense of their own experience (Smith et al., 2009). Additionally, as Smith et al. (2009) have highlighted, a further double hermeneutic exists in IPA in which the researcher adopts both a curious and empathic stance. The researcher aims to adopt their participant's position and understand their journey, whilst also taking a different more inquiring perspective of their participant. In doing so, the notion of the researcher standing in the participant's shoes whilst also standing alongside their participant is engendered (Smith et al., 2009). Finally IPA is idiographic by nature and committed to exploring in detail the particular instances of lived experience (Smith et al., 2009). In focusing on the particular rather than the universal, knowledge is acquired through understanding meaning, as opposed to ascertaining a causal relationship.

IPA was considered the most appropriate method to address the research questions, which consider the individual's lived experiences, and the way said individuals make sense of them and give them meaning (Chapman & Smith, 2002; Eatough & Smith, 2008).

IPA was chosen over Grounded Theory as grounded theorists set out to generate a theoretical level account of a particular phenomenon, and this often requires sampling on a rather large scale (Smith et al., 2009). In addition, a grounded theory approach aims towards a more conceptual explanatory level in which individual accounts are drawn on to illustrate the theoretical claim. Grounded theorists sample until they achieve theoretical saturation, i.e. until there are no new connections between categories and all responses fit into one. IPA offers a greater interpretative and contextual account that is not exhaustive. In fact, it reveals underlying phenomena that grounded theory methods would not account for.

Grounded theory does propose the same idiographic focus as IPA. Within the process of IPA analysis, the researcher analyses each individual account as well as interpreting the group's experiences as a whole. IPA is concerned with the details and nuances of personal experiences (Smith, Flowers & Larkin, 2009), which are in accord with the present study's aims.

IPA is a recent development in qualitative analysis. Jonathan Smith developed IPA in the mid-1990s, and his rationale was to redress the neglect of personal accounts and subjective experiences. The main crux of IPA is the notion of individuals as “self-interpreting animals” (Taylor, 1985, p.45) and it is a phenomenological approach in which the main aim is a detailed exploration of how individuals make sense of their personal and social worlds. Accordingly, “the main currency for an IPA study is the meanings particular experiences, events, states hold for participants” (Smith & Osborn, 2008, p.51).

IPA was chosen since it is consistent with the research objectives of this study, which is committed to the examination of how people make sense of their major life experiences (Smith et al., 2009). The phenomenological approach is focused on “exploring experience in its own terms rather than attempting to reduce it to ‘predefined or overly abstract categories’” (Smith et al., 2009, p.1). IPA’s epistemological underpinnings originate from both phenomenology and hermeneutic inquiry. Phenomenology is concerned with the way things appear to us in terms of experience; how, as individuals, we perceive and talk about objects and events. Husserl (1970) was the first to write about this approach. Heidegger (1962) furthered the examination and emphasised the nature of human experience, which takes place within a situated context in the world and accordingly requires an interpretative component to be understood. The researcher is therefore said to have an active role in the process, since their own experiences and conceptions influence the interpretation of the participant’s experience.

IPA has gained momentum within the field of health psychology and its value has been demonstrated in many clinical health psychology research papers (e.g. Chapman, 2002; Collins and Nicholson, 2002; Dunne & Quayle, 2001). IPA is concerned with both the phenomenological and social constructionist theories. Accordingly, IPA deals with the individuals’ experience of living with vitiligo but also with the researcher’s own interpretation of their experiences in order to make sense of the data. This approach is in line with the researcher’s own epistemological position which gives primacy to experience (Holloway & Todres, 2003), and is concerned with understanding the individual’s everyday experience of reality, in great detail, so as to gain an understanding of the phenomenon in question (McLeod,

2001). Lastly, it can be argued that IPA is not only compatible with the research aims, but also with the field of Counselling Psychology. Counselling Psychology stems from America where the originators of Counselling saw individuals' subjective experience as paramount (Strawbridge & Woolfe, 2005). It has been built on humanist values that seek to understand the subjective processes between the self and the other.

Within the Division of Counselling Psychology and the Professional Practice Guidelines (British Psychological Society, 2005) many points accord with the philosophy of IPA. The exploration of participant's experiences, understandings and perceptions (Brocki & Wearden, 2006) are consistent with Counselling Psychology's professional commitment to "engage with subjectivity and intersubjectivity, values and beliefs" (BPS, 2005, p.1). Both the Division of Counselling Psychology and IPA aim to give individuals a voice to express their experiences and to tell their story by contextualising it from a psychological perspective (Larkin, Watts & Clifton, 2006).

Design

The study employed a qualitative research design. A purposive sample of participants was used in keeping with IPA requirements to have a small and homogenous sample. Semi-structured interviews were employed, which were audio-recorded, transcribed verbatim and then analysed using IPA (Smith & Osborn, 2003; Smith et al. 2009).

Sampling and participants

The study advertisement clearly stipulated that the requirements were men aged 18 and above, and only those formally diagnosed with vitiligo. The literature suggests that vitiligo onset occurs before 20 years of age (Ortonne, Mosher, & Fitzpatrick, 1983; Njoo & Westerhof, 2001). All participants were members of the Vitiligo Society. Criteria for inclusion in the research included:

- Diagnosis of vitiligo for more than three years so that participants had lived experience of their condition
- The vitiligo is visible
- Age 18 years old and over
- Not diagnosed with any severe and enduring mental illnesses
- No obvious intellectual impairment
- Completion of an informed consent form

Contact was established with the Vitiligo Society, where the manager offered to assist in the recruitment of participants. A meeting took place to discuss how best to recruit members. Recruitment material such as an information sheet and an advert (See Appendix A) were placed in their quarterly magazine, "Dispatches". As part of the proposal for the study, both materials had ethical approval from the University. During the recruitment process twelve men contacted the researcher requesting further details. A total of six men were recruited as they met the research criteria. The interviews were conducted in university rooms in London.

Participant demographics

The demographics for the six participants are described in brief for the purpose of contextualising the men's experiences by situating the sample and allowing assessment of the relevance of findings (Elliott et al., 1999). The demographics are presented as whole rather than individual details to ensure

confidentiality and anonymity. The demographic information was collected at the beginning and during the interviews via a questionnaire.

Six men between the ages of 42 and 60 were recruited. Their ethnic background was White-British with their first language being English. It was the author's intention to include participants from other backgrounds, however it was not feasible given their availability during the recruitment process. All participants stated they were heterosexual and all were married. Four were in employment, of which two were self-employed, one was retired and one unemployed. All six participants confirmed that they had a formal diagnosis of vitiligo from a medical professional and had been living with their dermatological condition from 30 – 54 years.

Table 1: Participant information

Participant pseudonym	Age range in years
Ben	40-50
Mark	50-60
Sean	60-70
Tom	40-50
John	50-60
Peter	50-60

Semi structured interview and procedure (Appendix D)

A semi-structured interview was designed to obtain qualitative data from participants concerning their experiences of vitiligo. There were seven open-ended questions which focused on their initial diagnosis, their treatment and their views on their vitiligo at present. The interviews were audio recorded and transcribed. Any personal identifiers were deleted to maintain confidentiality. During the interview process, provisions were made for the researcher's safety, and suitable interview rooms were provided within the University. An administrative member was notified as the participants entered and left the building. This ensured safety and security when carrying out interviews.

Semi-structured interviews allow the researcher to engage in dialogue in a creative and flexible manner (Smith & Osborn, 2008). The questions were adjusted

with each individual depending on their responses and consequently the interviews took unanticipated courses, enabling new information about the participant's vitiligo to be unravelled.

The researcher emailed participants an information sheet and consent form before the interview so that any questions could be answered. Upon arrival, each participant was given the opportunity to ask questions or raise concerns regarding the research, had they not done so previously via email correspondence. Participants were informed that they could withdraw from the study at any time up until two weeks after the interview. It was emphasised to participants that the information they provided was confidential and anonymous, that the researcher was the only person with access to the tapes recordings and that these would be kept in a locked cabinet and in a secure file on a personal computer. The data would be anonymised and stored for five years and then destroyed appropriately after this duration. Informed written consent was then gained from participants who agreed to these conditions (Appendix C).

The researcher verbally asked participants for demographic information and consent. The nature of the interview was also explained, i.e. that questions would be asked, that the researcher was interested in their experiences and that there was no right or wrong answer to the questions. Participants were then asked to complete the forms. The questions were simply phrased and open ended, and were rephrased when necessary. Prompts were also used when appropriate. In line with the aims of IPA, the schedule did not lead the direction of the interviews, functioning, instead, as a guide for them. This enabled the researcher to follow up on participants' responses and concerns in a more curious and detailed fashion (Smith & Dunworth, 2003). In this way, the participant was able to talk freely about their personal experience of living with vitiligo. The ordering of the questions varied according to the flow of conversation and pacing was important to enable participants to have enough time to reply in full.

Interviews lasted from 45 to 75 minutes, after which participants were asked if they had any further comments or questions. The participants were verbally debriefed at the end of the interview and were given a debriefing information sheet

(see Appendix E). The participants were again thanked for their co-operation in the study and given a gift voucher for Marks and Spencer. The interviews were transferred to a locked file on a laptop and the audio-recorder was locked in a cabinet after use at the researcher's home. They will be destroyed in 5 years.

A pilot study was conducted with the first participant to pre-test the interview schedule, in order to practice the wording of questions and judge how participants responded to what was being asked. The pilot study served as a rehearsal for delivery, content and any problems that might arise. Following the pilot study, minor amendments were made to the wording of questions in the interview schedule. All subsequent participants went through the same amended interview schedule, with the same procedural and ethical considerations. The pilot study's data was also included in the final analysis.

Ethical considerations

Ethical approval was obtained from the Department of Psychology at the University of London Metropolitan Research Ethics Committee in August 2011. In accordance with the British Psychological Society Code of Conduct, Ethical Principles and Guidelines (2005), the researcher reflected on and gave full consideration and reflection to the ethical implications of this study.

Gaining approval from the Vitiligo Society was reliant on approval from the Department of Psychology research and ethics committee. Once this was gained, the researcher was able to gain access to the members of the society. Information regarding the study was provided to the Society, along with the advert which was then placed in Dispatches magazine. The members who expressed interest and who met the inclusion criteria were then sent written information regarding the study so that they had full knowledge of what it entailed and were able to give informed consent.

Consent forms were signed once the participants, who had met the researcher, understood the study, and once all their relevant questions had been addressed. The consent form clearly explained and reiterated the study's aims, its anonymity, the

conditions of withdrawal and the researcher and supervisor's details. Participants were assured that there were no right or wrong answers and that they could refuse to answer any question. All signed forms such as consent forms were kept in a locked cabinet at the researcher's home and will be destroyed once it has been completed.

In considering the potential risks posed to participants in the study, the physical or emotional harm anticipated was no different to those posed by ordinary life. However, the researcher wrote a distress protocol as a precaution (Appendix F). In addition, the researcher handed over support information and contact details of relevant resources (Appendix G) along with the debrief form. The debrief form outlined the opportunity for participants to learn more about the research study and the importance of carrying out the interviews, and explained confidentiality. It also re-iterated the right to withdraw, and explained that declining to participate up to two weeks after the interview would carry no penalty. It also emphasised that the participants information and interview data would be destroyed.

Validity

With a recent rise in the use of qualitative research methods in psychology, a debate has begun regarding the quality and validity of this type of research (See Elliott, et al., 1999; Yardley, 2000). The varied methods in qualitative research and associated epistemologies have given rise to broadly different traditions and procedures. This diversity has made it difficult to effectively demonstrate the value and validity of these methodologies (Yardley, 2000). For this reason Yardley (2000) has recommended four key criteria for assessing the validity of qualitative research, which will be considered in the present IPA study.

Sensitivity to context is the first criterion (Yardley, 2000). Choosing IPA as the methodological approach offered sensitivity to the particular features of the participants' accounts (Smith et al., 2009). Interviews were conducted sensitively, using empathy and warmth, so that participants and the researcher could build a working alliance. In this way, it reflects core values of CoP, in terms of subjectivity and intersubjectivity (Division of Counselling Psychology, BPS, 2005). The issue of sensitivity was also considered at the analysis and discussion stage, with reflections upon how the men's views were expressed. In an effort to show sensitivity to the

data the researcher endeavoured to suggest alternative interpretations throughout, and to pay close attention to the intricacies of the men's accounts. Furthermore, sensitivity to context was in mind during the analysis process as the researcher devoted disciplined attention to and immense care of the data. Similarly, sensitivity was shown in the results chapter, by carefully choosing selected extracts and offering 'interpretations as possible readings grounded in the data and contextualising the report in relevant existing literature' (Shinebourne, 2011, p.27).

Another criterion that Yardley (2008) proposes for validity is commitment and rigour. Commitment was shown by the researcher's engagement and depth in the analytical process. The researcher endeavoured to convey sufficient details regarding the sampling technique as well as the rationale for the sample used and thus demonstrated that it is purposive and homogenous in nature, and appropriate to the selected group (Meyrick, 2006).

In addition, Yardley writes of the importance of coherence and transparency. Coherence can be described as the common thread of the design and analysis and how it relates to the study as whole (Yardley, 2008). Transparency refers to the reader understanding what has been carried out in the study and the rationale behind it (Yardley, 2008). The researcher endeavoured to give a clear description of the research which led to the development of the research questions in a comprehensive and explicit manner.

The last criterion requires consideration when taking account of validity is important (Yardley, 2008). The researcher endeavoured to focus on the meaning, context and intricacy of men's lived experience of their vitiligo and has revealed a rich, contextual and interpretative understanding of their subjective experience. The results and applicability in clinical practice of this understanding will be presented in the final chapter.

Transcription

Each interview was transcribed verbatim by the researcher, paying heed to significant non-verbal behaviour such as gestures, laughter and noticeably long pauses (Smith & Dunworth, 2003). For the purpose of the analysis, the transcripts included all false starts and extraneous words to reflect the original dialogue with

participants. Any identifying features of participants, such as names or identifying places, were changed at the time of transcription in order to maintain anonymity and confidentiality.

Analytic strategy

IPA seeks to understand the intricacies and meaning of the individual's world by understanding their narrative (Smith & Osborn, 2008). In order for this process to occur, the researcher engaged in an interpretative relationship with each of the transcripts. The initial stage in the analysis was interpreting the issues arising from each individual transcript as these are idiographic in nature (Smith & Osborn, 2008). All transcripts were formatted in landscape with a margin on the left-hand side for themes, and a margin on the right hand side for notes and comments. All transcripts were line and page numbered for ease of reference throughout the analysis.

Each recording was listened to and the transcripts were repeatedly read. Carrying out this process was useful as the individuals voice became stronger and easier to recall on subsequent readings (Smith & Dunworth, 2003). Notes were made regarding initial ideas, which were inserted in the right-hand margin of the text. These notes captured the researcher's curiosity, speculations and associations, as well as summaries of the narrative and links to other aspects of the men's accounts. Basic preliminary interpretations were also noted. The researcher aimed to remain near to the text and its meaning (Langdridge, 2007; Smith & Dunworth, 2003).

Slowly emerging sub-themes were then identified and developed from the initial notes, and noted in the left-hand margin. The wording of the sub-themes encapsulated the essence of the quote. Again, the transcript was re-read several times in order to ensure that the emerging sub-themes were still embedded in the original text, and that they genuinely represented the men's narrative. The preliminary sub-theme labels reflected a broader level of meaning for each participant's narrative. In this way the process began to move onto a higher level of abstraction and became more interpretative than purely recording notes (Smith & Dunworth, 2003). That said, the sub-themes were not set in stone at this point of the analysis. See extract from a transcript in Appendix H

The next stage involved drawing together these preliminary emergent themes according to connections and similarities, which produced the superordinate themes. These were arranged in a table which showed superordinate themes together with their sub-themes and quotation references. This allowed a reference point for each theme to be traced back to the original transcribed data (Appendix I).

All of these stages were applied to each of the transcripts, until they were all analysed. Tables of superordinate themes were created for all transcripts and examinations of the patterns across participant's transcripts were conducted. These examinations involved redefining and reconfiguring some of the superordinate themes and returning to the transcripts repeatedly. It was at this point that master themes were constructed from the superordinate themes until the final version was established (Appendix I). The themes from the table were then written up in a narrative account.

In summary, this section outlined the cyclical process in IPA, whereby the researcher conducts several iterative stages with the data.

Methodological reflexivity

Reflexivity may be defined as both a central component of being human (i.e. the capacity to position the self) and also as the ability to consider intersubjective dynamics and to reflect on these between researcher and research findings (Finlay & Gough, 2003; Hutchinson & Wilson, 1994). The researcher's involvement in the study requires consideration: they have implicated themselves in the research at the level of interpretative engagement with data (Willig, 2008). Thus, it becomes a three-way interaction between the researcher, the participants and the analytical process. By reflecting upon the methodology in this way, I attempt to create transparency and to add validity to the analysis of the study. During the research process, I became aware of pre-conceived ideas, which may have influenced the direction of my research. When reflected on, I tried to bracket them where possible.

One of my initial presuppositions was that men with vitiligo would not be able to express their emotions during the interview, and that they would present a 'macho' image of how they manage their anxieties and low mood. I thought I would struggle to elicit their experiences and be able to explore their meanings by using various prompts and cues. I was aware of how my personal upbringing influenced my view of what a man 'should' be like i.e. men are not allowed to be 'weak' in South Asian culture. Additionally, the literature on gender differences I read during the years of my undergraduate and postgraduate studies also shaped my beliefs,

which influenced my presupposition. For example, Maccoby and Jacklin (1987) conclusions that there are gender differences in verbal, mathematical and spatial abilities and in aggression are well established. Furthermore in research I learned the term “alpha bias” as the dominant bias in psychological research on gender. This is evidenced in the Freudian theory, Parson’s gender role theory and the feminist psychodynamic theories of Chodorow (Hare-Mustin & Marecek, 1988). All these approaches portray men and women having different identities and roles; typically women as emotional, expressive and relationship-orientated and men as rational and instrumental. Thus, this shaped my understanding of how men may present in my research study. Importantly, I was reminded through supervision of how I needed to remain in a position where I held openness and curiosity to explore different perspectives throughout the research (Kasket, 2012). As such, I reviewed some of the wordings of the questions, as I realised that I may have encouraged clients to talk more about their negative aspects of their experiences when writing up my draft interview schedule. It is possible that I may have been projecting some of my negative assumptions on how difficult they may finding their vitiligo, so I made sure the questions were neutral and did not have any loaded questions.

Reflecting on the interview process, a number of aspects stood out. Firstly, many of the participants had seen a picture of me in the society’s ‘Dispatches’ magazine, where I presented both my research and clinical practice and also participated as a ‘model’ in a camouflage session for my vitiligo patches. This was in aid of one of the vitiligo support days for members of the society. I believe that this level of participation may have enabled the participants in a way to feel more open with me during our interview sessions. They may not have seen me as a non-vitiligo ‘normal person’, but rather as someone they could identify with and who could possibly empathise with them. Having seen my facial vitiligo on ‘display’ on the day they may have made the assumption I was comfortable and confident. Two of the participants mentioned on the day of the interview that they had seen me presenting my research at a society talk. This may have been encouraging for some participants but also off-putting to others, namely those who did not feel confident at all and therefore may have created a bias in the participant sample. It is possible that the participants may have viewed me as a ‘role-model’ being both a sufferer and a professional when I presented talking therapies in managing emotional responses to

their vitiligo. Furthermore, it is possible that they were invested in generating research and awareness of the impact on their day-to-day life and this could have affected social desirability in the interviews. Participants commented post-interview on how helpful the process itself had been, almost therapeutic. This created a tension between the ‘clinician’ and the ‘researcher’ in me as a Counselling Psychologist Trainee. I found it to be a struggle as for many years I have practiced as a therapist, but as a researcher I still felt like a novice. Reflecting upon this, I had several new insights about the interview process: motivational investments, social desirability and an awareness of own beliefs and language used with participants.

Keeping a reflexive journal and taking time to reflect was helpful in enhancing my ability to ‘bracket’ my presuppositions. I attempted to maintain an open and curious stance and pay attention to interesting points or nuances brought up in the men’s accounts. In hindsight, I wonder how my own anxiety and preconceived ideas may have hindered my exploration of interesting details during the first few interviews when I kept more to the structure and prompts I had to hand. During the interviews, I picked up on nuances and chose to explore these further in the later stages of the interviews, which could be said to be my own bias. Accordingly, I understood that my own bias can both obstruct and enrich my interpretations of the men’s lived experience (Shaw, 2010). This research inevitably has my biases entwined and as such offers richness to this phenomenological enquiry. By undergoing reflective practice, e.g. reviewing the interview schedule in supervision and with peers, I became aware of my own blind spots and anxieties which I was able to bracket without silencing the participant’s voice (Finlay & Gough 2003). I believe that during the mid-to-end process of carrying out interviews, I had gained momentum and confidence in conducting them in a way where I was more open and focused more on exploratory aspects of their experience.

CHAPTER THREE: Analysis

Overview

The analysis of the transcripts yielded data that covered a range of the men’s experiences, from the moment of learning they had vitiligo to the present time. Given the extensive nature of the data, it was important to prioritise the narratives that related to the research questions. Doing this offered insights into previously neglected areas in the literature, and helped identify novel and unanticipated aspects of the men’s experience. It is recognised that these themes cover one account of the experience of vitiligo. They do not cover all aspects of the participants’ experience, and were selected due to their relevance to the research questions. It is acknowledged that the interpretation is subjective and that other researchers may have focused on different aspects of the accounts. This section aims to present and discuss the emergent themes under three broad organising categories or superordinate themes: processing the vitiligo diagnosis, focus on self, and focus on relationships. These superordinate themes and corresponding sub-themes are presented in Table 2 below.

Table 2: Summary of superordinate themes and sub-themes arising from the participants’ accounts

Superordinate themes	Sub-themes
1: Processing the vitiligo diagnosis	Acknowledging the reality of vitiligo
	Feeling unseen during the medical interface
	Feeling helpless; ‘just live with it’
2: Focus on self	Living with an unwanted self
	Managing distress and shame; ‘dirty little secret’
	Perception of self
	Patterns of behaviour

3: Managing relationships	'Fear of being ridiculed, rejected'
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This section will focus on an interpretative analysis of the data. A theoretical discussion of the relevant literature will follow. Each superordinate theme, together with its sub-themes, is explored below. Verbatim excerpts from the original transcripts will illustrate these. All participants have been given pseudonyms. In the following section, it is recognised that some of the data is retrospective and may not accurately capture the full nature of past experience. Some events and feelings associated with these past experiences may be forgotten over time and thus the information provided may not fully reflect the participants' past experience of living with vitiligo.

Superordinate theme one: Processing the vitiligo diagnosis

The first superordinate theme presents an account of the time when the men first learnt about their vitiligo. The vitiligo appeared unexpectedly, and initially the men's accounts showed a level of unawareness of the change in their skin colour. Other family members tended to notice the difference first, and were the first to suggest seeking medical attention. A transition from unawareness to the acknowledgement of vitiligo occurred. The men also described the feelings associated with vitiligo and the medical professionals' response to them and their new diagnosis. Facing the reality of limited treatments on offer, they experienced disappointment and helplessness, while gradually adjusting to their diagnosis.

Acknowledging the reality of vitiligo

This theme illustrates the men's experience of learning they had vitiligo. All but one of the participants developed the condition in childhood. When the white patches first appeared, there was little concern due to the normal variation of skin appearance. This is well illustrated in Ben's account:

Well, I think it was my parents first noticed some white flecks on the back of my legs and I seem to remember they took me to the doctor initially about that but at that age it doesn't mean anything to you and you kind of just want

to be a normal kid and not have to be worried about going to see the doctor about something that doesn't hurt you or anything like that.

Ben (2: 34-39)

Ben's memory of his vitiligo is of his parents first noticing the demarcation on the back of legs. He did not notice the change, maybe because it appeared at a place that was not easily visible to him. His remark "it doesn't hurt" indicates he may associate having a medical condition with physical pain, and that he did not feel it was necessary to see a doctor. Since vitiligo did not result from a traumatic event, cause any pain or impair his health, it is possible to interpret that it was hard for Ben to process and acknowledge this medical condition. Also, he stated that he wanted to be a "normal kid." It seems that Ben might have resisted this change since he was unable to see the visible difference; it was his parents who drew attention to his vitiligo. Ben goes on to explain how he wanted to be normal, and to not have medical appointments. Being told of this change in skin appearance may have been stigmatising, making him feel different, 'not normal.'

Mark's vitiligo was also first noticed by a parent. He, however, reveals indifference to the diagnosis of the condition:

I think it might have been my mother but I think she pointed it out then...I can't recall to be honest. It was a long time ago. I might have, I might have noticed it but probably not given it a lot of notice.

Mark (1: 10-12)

Mark describes the vitiligo being "pointed out", which has connotations of being exposed and focused upon. These words can be interpreted as something being distinguished on the skin which could elicit feelings of being stared at, with all its associations of shame. It could indicate that, initially, it was more noticeable for the parent than for Mark himself. Other participants talk of it being noticeable to others rather than themselves, and as such it is possible that participants did not acknowledge their vitiligo until the patches began spreading and became noticeable and something to be concerned about. Sean, who ignored the patches of depigmentation in the first instance, describes similar sentiments:

(...)and it developed to start off with on my hand, my, I think it was my left hand, there was a very small white milky patch which in fact I ignored...because I just, I didn't know what it was and it really, didn't really bother me a great deal but then it started to develop, not rapidly but, you know, it was progressive in its nature.

Sean (1: 4-8)

Sean is precise, recalling the patch was lighter, on his left hand. He hesitated, as he was unsure of what this “milky patch” phenomenon was, and he did not allow himself to be concerned. It began spreading, “not rapidly”, a slow change. However, Sean’s use of the word ‘develop’ and ‘progressive’ might suggest an anticipation that the vitiligo would get worse. His quote may reveal an interplay between the ‘new’ skin brought by vitiligo and the ‘old’ skin which is lost. In a parallel fashion Sean’s own identity is altered; while still remaining himself, he nonetheless feels the other inside i.e. the vitiligo. In this way, he has taken on a new and seemingly different persona or identity with the vitiligo. When the men were first diagnosed, they appeared to be torn between knowing and not knowing about their dermatological condition. Vitiligo can be seen as a growing marker, white in colour, potentially different to them and exposing their very body. Vitiligo seems to stamp itself on these men, as if marking its own territory.

Many of the participants interviewed spoke of traumatic experiences prior to the development of the vitiligo. Sean describes being in a car accident:

I had a car accident and I had plaster on my leg from the top of my leg down to my ankle and when the plaster came off I had one patch of vitiligo just under my knee and a patch of psoriasis and that's where it started, um and it's gradually spread....

Sean (1: 3-7)

Similar to Sean, Tom also disclosed a similar trigger caused by trauma to the body when he broke his arm at the gym:

Right, well it, I was 14 so many, many years ago. I, um, [pause] broke my arm in the, um, in the gym at school, when the plaster came off and there was

a little, very small white patch.

Tom (1: 3-5)

Feeling unseen at the medical interface

Concern and anxiety grew as the patches progressively spread across the participants' skin. It was at this point that they sought professional advice from their general practitioner (GP). There was a diverse response, both cognitive and behavioural, following the diagnosis. Participants felt disappointed with their GPs' reaction and with the choice of treatment options. They also felt unacknowledged. As Sean illustrates in his account:

Then it started...it started to develop on my face, I think just below my lower lip again on the left hand side and I think it was at that point that I kind of started to worry, you know, what was it? I went and saw [clears throat] my general practitioner who said that I had vitiligo and, erm, sitting right behind that, came the observation that there was no cure and you just have to live with it. So that was pretty distressing.

Sean (1: 8-13)

Sean begins to explain the development of the patches spreading with trepidation, "then it started...it started to develop." He was able to pinpoint the start of the patches' progression, but it appears that he was unable to make sense of this development. The 'not knowing' led him to see his GP. One interpretation is that the uncertainty and discomfort is experienced internally while talking about the diagnosis, as evidenced by his throat clearing and hesitation, almost as if the vitiligo has infiltrated his body. The use of "sitting right behind that" is interesting as it is suggestive of him receiving two blows; two pieces of distressing news one after the other. It may also suggest the idea of the unknown sitting behind his skin, which the participant is unable to see because it is invisible to him. It is possible that the diagnosis came as a shock, which came right after the initial shock of noticing the vitiligo spreading on his face. The 'expert's opinion' that there is no cure and that the patient will "just have to live with it", shows the medical professional's reductionist approach to vitiligo, and that they are unable to see what the client is going through

or trying to express. All of this, together with the sense of a potential threat to his skin, understandably leads the participant to feel distressed, perhaps invisible as the GP dismisses his concern.

Similarly, Tom describes feeling discouraged by his medical professional as he states:

There was no pain and I think I went and said what can you do about this? I think the doctor said nothing, it's incurable you just have to put up with it. [pause] I thought okay great. So from that point on I didn't do anything about it. I've never had any treatment.

Tom (3: 77-80)

Tom reported experiencing no pain but only alteration of skin colour to his doctor. It is interesting how he recalls his doctor not saying anything to him. One interpretation of the vitiligo is that it has the weight and power to mute the medical professional and the sufferer. Tom explains there is no cure, he just has to “put up with it”. He then pauses. This pause is significant as it reiterates feelings of discouragement as he too momentarily becomes mute. A parallel can be drawn with the condition of vitiligo, a silent and unheard of skin condition that neither causes pain to the skin nor offers indications of growth, and is also unacknowledged and unseen. Tom appears to surrender to his vitiligo. The GP too seems to feel helpless, leading to a dismissive and defensive reaction which is then experienced by the patients, as the next section, in which the typical responses of GPs are illustrated, shows. Tom asks his GP what can be done “what can *you* do about this”: it is possible he has faith in the medical system and in the GP’s ability to cure him. For Tom the condition has been medicalised, in that he considers his vitiligo as a ‘sickness’ to cure and treat. Furthermore, from the somewhat flat and ironic way Tom speaks having been told it is incurable, when he pauses and thinks “okay great”, it can be interpreted that the feelings of being told this news may be too overwhelming and that it is easier to rationalise than to feel disappointment or sadness.

A dismissive approach from the medical professional was a common theme, which left participants frustrated, helpless and unable to understand what vitiligo

entailed. It appeared to cause annoyance with a healthcare system which neither showed support on an emotional level nor offered treatment options:

I was quite curious as to what it was and wondered it was a bit of an odd thing to find. I then went to the doctor, who was very dismissive about the whole thing which didn't really help and made me [pause] quite, well initially I think I made myself stew on that a lot and think about it rather than do something about it and that made me quite annoyed really.

John (1: 7-11)

Unlike Tom, who felt passive in the medical consultation, John expressed annoyance. He was curious to understand the colour change in his skin. John describes how the GP assessed his dermatological condition as unworthy of consideration. One interpretation of John's pause is that it signifies the depth of his frustration and anger at the incident. The reaction to this anger is suppression. There seems to be an interesting parallel process at work: the GP cannot face the client's distress, and so is dismissive and angry. His evocative use of the word "stewed" describes a process of many different feelings and thoughts in a boiling pot, one that holds a mixture of feelings, not reducible to one. Furthermore, it can be interpreted that the word stewed indicates he is somehow trying to control feelings or keep a lid on them; the feelings are perhaps "bubbling up". This is similar to the idea of the vitiligo taking over their bodies via their biggest organ, their skin. This melting pot incorporates the notion of change: from the original ingredients, it forms a new recipe, one that the participant is uncertain of, fearful and potentially angry about.

Feeling helpless; 'just live with it'

Many participants were told to 'just live with it' by their GPs, which can be a common response when there is no clear-cut explanation or treatment option. Again, this may reveal the GP's own feelings of helplessness or uselessness in not knowing a cure or how to help. As vitiligo is not a terminal illness, participants need not concern themselves about it.

Peter commented on his experience:

It was very much the doctors, the hospital were very, were okay about it but, erm, I have had the comments, well it's not cancer so you know... you know you're not going to die from it so just live with it, that was very much the attitude.

Peter (4: 108-112)

Cancer is often associated with death, and the medical professionals who made this downward comparison may have believed it was helpful (“vitiligo is not so bad when compared to other conditions”). However, this approach of “just live with it” created a helpless and isolated position for the afflicted. Peter does not fault the hospital per se, but the doctors whom he saw, and who considered his vitiligo to be a mere shadow next to a disease like cancer. It is possible that these men are made to feel their vitiligo is not significant since it is not cancer, but really it is an immense concern for them. One interpretation could be that the GPs are trying to normalise vitiligo, but in retrospect it appears to have the opposite effect in that these men do not feel heard or potentially not respected. It brings up an image of a child practically being told off for complaining as there are more important things to worry about in life, like cancer. This shadow, or this smaller-scale health condition, is what the men live with day-to-day. The participants will later refer to the condition as an intruder or spectre, which comes out to attack the skin.

Having received so little information, participants described how they sought information online. All participants commented on how they found the Vitiligo Society to be a useful and supportive resource. It gave them a greater understanding of their dermatological condition. Disappointment with NHS services was apparent in the participants’ accounts. One participant described how he felt that vitiligo was not seen as a concern and was even regarded as insignificant since it was not life threatening, but considered a cosmetic condition. Their experiences were not satisfactory, and they felt their feelings and adjustment to their diagnosis of vitiligo had been dismissed.

Ben echoes these experiences in his account:

I mean I guess now there's a lot more information on the website. It's difficult because you don't know ... your GP probably doesn't know much about it so you do a lot of the research yourself and a lot of stuff out there might not be particularly kosher or work and so maybe there are people that are being taken for a ride in terms of what's available. But when you have vitiligo all you hear is that there isn't a cure, there isn't a cure. It's not life-threatening so people, you know, the NHS won't commit to funding more research so it's kind of almost like a no hope spiral kind of thing in terms of nobody is that bothered about it and if it's not going to kill you then...

Ben (24: 766-777)

Ben remarks on the amount of information that can be accessed from the UK Vitiligo Society website. He then addresses the lack of expertise shown by his GP, which led him to seek information on his own. In a sense this is echoed in Ben's journey of living with vitiligo, which he describes as an isolating process of trying to put together and make sense of pieces in a puzzle. Ben's use of the word "kosher" is interesting in this extract. Whilst Ben is perhaps highlighting the information and treatments claiming to "cure" vitiligo, it could also be interpreted as the hygiene element associated with having a dermatological condition. By saying "kosher" he is perhaps grappling with not knowing who or what he can trust. His anger appears to be externalised and directed to wider systems such as the health care system and existing research. This anger and blaming can perhaps be viewed as a defence mechanism. The hopelessness expressed in the extract may be understood as frustration with his treatment and at having to live with, and fight, vitiligo. Again, the same theme of helplessness is highlighted as he describes how medics had been unconcerned and dismissive.

In summary, the first superordinate theme, 'processing the vitiligo journey' illustrates the complexity of men's reactions to the vitiligo diagnosis and their initial feelings towards the condition. It also uncovers the participants' appraisal of their medical consultation as well as the health professionals' view of vitiligo, with their recommendations. The extracts reveal how these men felt invisible and unheard in consultations, which led them to manage the condition in different ways. Some

sought no further treatment while others sought information on vitiligo from other sources. The next section highlights the internal struggles these men went through while searching for meaning and masculinity.

Superordinate theme two: Focus on self

This section describes the impact of vitiligo on the participants' internal world. The men described a range of feelings and intrusive cognitions as a response to the change in skin pigmentation and appearance. Many experienced undesirable negative emotions, particularly anxiety, as they feared their vitiligo would spread to other body parts. Their anxiety was at times difficult to deal with due to the unpredictable nature of vitiligo. The feeling of shame often made the men feel self-conscious tending to be unduly aware of themselves through continuous self-scrutiny. This had implications for their interactions in social relationships. The men worried about others noticing the change in their appearance as they felt they looked different from their peers. Their perception of themselves had changed. Accordingly, this began a process of living with an unwanted self as they viewed the vitiligo as a separate entity.

Living with an unwanted self

Interestingly, men described their vitiligo as something that was not part of them. They described it as being its own entity and having its own form. It was often related to as another ‘thing’ living on their skin. Vitiligo had its own control or surveillance so the sufferer would have to scrutinise their skin constantly. One participant described it as an inspector standing constantly behind him. This caused him to be in a constant state of alertness and hypervigilance. He would check his patches of vitiligo continuously see if they had spread or not. Sean describes:

It does, there's no doubt that this condition erodes, erodes my confidence, not all the time but because of its progressive nature it's almost like something hanging over your shoulder, you know, it's like spectre there in the background.

Sean (9: 268-271)

Sean reiterates how it impacts on his confidence and how vitiligo appears to be lurking in the background. His use of the words “spectre there in the background” alludes to a threatening shadow that is constantly behind him. This gives the impression that he is highly aware of his vitiligo at all times as it may continue to spread on his skin. The description sounds ghost or phantom like, which is interesting as these are often associated with the colour white. He also uses the word ‘erode’, which can be understood as the vitiligo eating away his skin, like a dead body which, it could be argued, then becomes a ghost. Sean may understand his vitiligo as destroying his body. He personifies the vitiligo as something scary, sinister like an evil ghost out to harm him. Arguably, the extract reveals how the participant does not have a sense of mastery over the vitiligo, as Tom also describes, using a different metaphor:

And if that's out of your control because of this [pause] you know, this nasty little disease that's sort of eating away at your skin then that's just awful.

Tom (10: 315-317)

Tom reveals the extent of his discomfort with his vitiligo. He describes how he feels his vitiligo is out of his control: it is not a condition that can be tamed. The pause

may represent not only an overwhelming sense of having no autonomy or power, but even something “nasty”, horrid and offensive attacking him. He describes vitiligo rather like a poisonous leech that is “eating away” at his skin with him at its mercy. Therefore, the vitiligo takes on a persona of being uncontrollable, which men struggle to live with and want to escape from.

Living with an unwanted part of themselves tended to leave participants struggling with their self-identity. The participants appeared to struggle to accept this condition as a part of them. Vitiligo was split off from their known selves, and integrating it seemed to cause fear. Some even described vitiligo as controlling them, rather than them taking control of their vitiligo:

I suppose there is a sort of powerlessness of, of watching this, er, er, er, thing happen to myself, yeah watching my pigment disappear and not really being sure [pause] well I suppose there is nothing you can do about it so that is a frustration in itself.

John (3: 75-78)

John experiences his vitiligo with a sense of powerlessness. He stumbles, perhaps due to how overwhelming the change in his pigment is. His uncertainty, marked with a pause, appears significant as he feels helpless in being able to take control of his body: again, this reflects how he sees vitiligo as an unwanted part of himself. In this extract John uses the word “disappear” which may reveal an eroding or disappearing of the self. In general, men described vitiligo as an external body part, which appeared to have a voice of its own, i.e. critical, haunting and spectating. From the narratives it appeared vitiligo developed into a separate entity which governed the participants, forcing them to engage in certain cognitive and behavioural tasks, such as avoiding the sunshine.

Managing shame and distress; ‘dirty little secret’

Most participants described emotional distress such as anxiety or feelings of helplessness. One participant, Jo, described vitiligo as a condition he was battling with:

I do think you know for me the link between [clear throat] my ability to spend a lot of time fighting myself mentally, if that's the right word and the parallel with what vitiligo does with your body is quite strong and I know there's kind of, you know there is some evidence of stress relation in terms of vitiligo and its appearance.

Jo (8-9: 205-209)

Jo shows insight into his difficulties in living with vitiligo: a considerable amount of time is spent combating his negative thoughts. He describes spending a lot of time in his thoughts, struggling with his vitiligo. He uses an interesting word, “fight”, to describe the parallel situation that indicates his battle with his own body and the vitiligo. This further suggests that his self loses the battle to vitiligo as it is perceived as ‘quite strong,’ powerful and undefeated.

Most participants also spoke of shame surrounding their vitiligo. It became apparent in men's accounts that there was a sense of internal shame and this was related to their self-identity perceived by them as flawed or inferior. Ben, in particular, described his vitiligo as a “dirty little secret” a couple of times in his account which touches on his feelings of unattractiveness and his acceptability for himself and others. As he described:

It's kind of almost like having a dirty little secret, it's just yours and you don't particularly want to share it with anyone.

Ben (24: 748-750)

Ben describes his vitiligo as a secret that he wants to remain unrevealed. It can be interpreted as a condition similar to leprosy, which has been stigmatised for countless generations. Vitiligo was felt to be so shameful that Ben does not want others to become aware of what he has.

In addition to the participants struggling with their difference, identity crises and many undesirable feelings were also there with their vitiligo. Sean describes some of his feelings and how they affected his work:

My skin started to, it started to break down quite quickly on my forehead and the job that I was doing then was as a frontline, it was called an Independent Reviewing Officer, again where I was the face of the organisation and it

really played on my mind. God this is going to sound terrible but I was always looking in the mirror, always checking to see whether I could see my vitiligo, trying to cover it up, you know, combing my hair a different way and I became almost obsessed with it really, erm, and that was very distressing

Sean (7: 203-210)

This extract reveals how Sean placed great significance on his facial appearance. He used the word “frontline” which suggests a position where he is exposed; he can be criticised or attacked. This reveals interesting insights into how vulnerable he feels regarding his appearance and the consequences of vitiligo on his work. The word frontline is often associated with war, as soldiers fight out on the frontline. Perhaps vitiligo can be understood in a similar fashion, in that having vitiligo makes Sean feel as if he is under potential attack or threat. The worry and how it “really played on my mind” is one of the consequences of his anxiety. This perhaps led to compulsive checking behaviour in front of the mirror. He was overly concerned that someone would notice his patches, and the checking caused further anxiety and disquiet. Moreover, Sean described himself as the “face” of the organisation in this extract. The word that he uses is very captivating. Not only does it indicate the extent that he represents the children and young people’s organisation, but also the symbolic meaning of what his face portrays to the public. His face is important in representing the organisation to the outside world and others; as such his performance is vital for the organisation to project and maintain a good image. It is this image that perhaps elicits immense shame due to what he feels has changed. Many of the participants spoke of experiencing embarrassment, shame and stress due to their vitiligo. Peter earlier described feelings associated with shame when reapplying his make-up in the men’s toilet. Furthermore, the undesirable feelings that were held by the men would impact them in different ways. As John describes, he experienced psychosomatic symptoms:

(.....) just about sort of internalising stress and emotions and, er, er, other things like irritable bowel that are all, I guess...I think it is psychosomatic or whatever but you know me fighting myself internally and I guess I saw vitiligo as a kind of consequence of some of that.

John (2: 32-35)

John reveals how he tends to keep his emotions bottled up and then stutters “er, er,” as he goes on to disclose his suffering of irritable bowel syndrome as a result. One interpretation would be that his body and mind are caught in a battle where he is fighting himself “internally.” It appears that feelings of stress and other difficult emotions make it hard to be at peace. These inner bodily tensions cause an array of physical health problems such as irritable bowel syndrome, and this can exacerbate the condition of vitiligo, i.e. make the patches spread. Again, the significant themes of fighting and battling come up in the participants accounts. It is perhaps possible that they do not want to acknowledge their condition, since they find it hard to accept. It is possible that they believe charging at it will make a difference, which keeps them in a vicious circle which inevitably causes distress. It also appears that John believes his vitiligo developed from internalising his stress or having irritable bowel syndrome as he says “consequence of some of that” which possibly suggests an understanding of the origin of his vitiligo.

In addition, all but one participant described feeling different since having vitiligo, as Tom describes:

So bit by bit all these things, one thing after the other, make you a little bit more different to the guy over there. So in the end, it's not just one thing it's just a multitude of different things, whichever reason you want to pick but you feel different and that's what I don't like. I don't like being different. So anything I can do to make that, make me look straighter or wider or tanned or whatever and if you can't fix it you just hideaway or cover yourself up or put on this mask.

Tom (16: 644-650)

Tom reveals how living with vitiligo added to the list of others physical complaints that he also experienced and made him feel different from the average man. He uncovers a feeling of genuine dislike of being different and repeats this twice in his account. Tom might feel rather apart, disconnected and alienated, in that he had a deep felt sense of not being the same as others. Vitiligo made him unlike “the guy over there” in the nature, form, or quality of his skin. It seems difficult for Tom to adjust to this difference, which is why he continues to conceal or hide his vitiligo

from others. He used the words “anything I can do” which suggests a possible sense of desperation to make himself normal and fit in. This idea of vitiligo being a problem that needed to be “fixed” when there was nothing to cure it meant he would use all attempts to conceal his vitiligo. This indicates a struggle in acceptance of the vitiligo, and covering it up and hiding it away suggests that he cannot tolerate his altered skin. It is possible that he has difficulties in integrating this change in his self-identity, as the consequence of this acceptance and altered appearance would be a change in the way not only he saw himself, but how others viewed him.

Perception of self

This theme addresses changes in how the men appraise themselves. They describe themselves in a negative light, indicating low self-esteem, as they perceive themselves to be different. They also appear to feel demasculinised as they feel imperfect and not the image of what a man should look like. Although men express differing views of their understandings of themselves, they share feelings of dissimilarity and appear to struggle with the acceptance of vitiligo:

it ebbs and it flows this confidence thing, I don't know whether that makes any sense to you but that's how I experience it. Sometimes I feel perfectly ok about myself, being mindful that I've had some really bad depressive episodes, I think when that happens I feel worse about my vitiligo, you know, the way you see the world is very dark and so the way you see yourself is equal, or equally in my experience can be very dark.

Sean (8: 235-241)

There is a real sense of the volatile nature that vitiligo presents for Sean. When he describes his self-assurance using the words “ebbs and flows,” it reflects his confidence highs and lows. One interpretation is that his view of himself is unstable, as his confidence, like the tides, rises and falls. The second part of the extract affirms the volatile effect of the condition, particularly when Sean describes his vitiligo as dark, like depression. This connotes being unable to see, struggling in the darkness. His use of the words “very dark” twice in the extract suggests that something deeply embedded, and embodied as a highly sinister shadow, casts a shade on the man

inside, obscuring his reflection. It is also possible that the contrast of vitiligo's 'white' patches with the vitiligo being 'dark' is interesting, as how can something so white be so dark? This contrast might suggest how difficult it is for men to understand and accept their vitiligo and also themselves.

Many participants spoke of seeing themselves differently to the 'norm,' as Tom explains in his account:

People most likely accepted you were just different and well you were different. But were you different because you liked dressing like in the winter or were you different because you, there was something wrong with you?

Tom (9: 299-301)

Tom speaks of how others accepted him with his differences. Although recognising that he is different, he then questions whether his clothing differentiated him, or whether perhaps there was something more profoundly noticeable about him. This quote suggests that Tom contemplates the possibility that there is a profound difference in him, which goes further than his choice of clothing. It is interesting to note that he questions why he is different, and wonders whether there is something inherently wrong with him because of his vitiligo. This raises the question: if others view Tom as being different, has he then accepted himself as being different? Also does vitiligo set him apart from others, reinforcing that that he is different.

Similarly, Peter also describes how his skin colour changes and how he yearns to be normal:

I mean it all goes very red and things like that and then you're all different colours again you know, so um, yes, so you just like to look as, it sounds awful but the word normal, as normal as you can you know. And again I don't know if I have, I have many hours of thinking of this and I think why am I like that and I think if people... in some ways if people could turn round and say 'oh he's got vitiligo' that's it, but they've not seen it, they've not heard of it a lot.

Peter (9: 257-263)

In this extract Peter explains how his skin turns red in the sun. This metamorphosis of colour he perhaps views as an abnormality as he reiterates twice that he would like to look “normal”. One interpretation of this is that he feels anything but normal. It appears that this desire for normality makes him ruminate on his vitiligo and on fitting in. He seems to want people to label him as having vitiligo, if people knew his condition. Thus, they could say “oh, he’s got vitiligo” which would normalise it. Some men also held resentment towards their vitiligo. In their accounts they spoke of what their skin colour could have been like as opposed to how it is now:

So I, I, I, you know I still partly resent being pale and interesting because I am used to having fairly good skin colour but in terms of being able to tan and so on, so I think I do still resent the fact that I don’t have that, if I’m honest about it.

John (4-5: 113-116)

John stutters as he describes feeling indignant at being “pale.” He recalls being used to having good skin colour. This brings about connotations that being pale is somehow bad; he considers being darker to be “good”. There is a sense of bereavement in his account: the loss of pigmentation also means the loss of what he once had. Ben was highly critical of his image. He did not feel he fit the category of being “tall, dark and handsome”, as he reveals:

There’s a big thing about pale, there seem to be a lot of quite negative connotations of being pale and, as a man, you should be tall, dark and handsome.

Ben (9: 264-266)

To Ben, it seems, being a lighter skin tone is unsatisfactory. One interpretation is that aesthetic preferences operate to visually emphasise gender differences and enhance social status. What vitiligo does, in essence, is take away the pigment, the colour. It raises the issue of whether in taking away the pigment it can take away their masculinity, in terms of the ideals of complexion and attractiveness which can dictate lightness and darkness based on gender. Thus, turning light rather than dark can appear to do the opposite of what Ben strives for as part of his masculine identity:

vitiligo may even emasculate him. Therefore, there seems to be a social or cultural pressure of what a man 'should' look like, which the vitiligo undermines by making a man less of a man. This was echoed in Peter's account, when he talks of cover-up products. He felt his self-esteem had been eroded and feared how he would appear to others. He spoke of how he had to be on guard when checking or re-applying his make-up in men's toilets. Peter would always ask his wife to carry his make-up and a mirror as he explained that men's toilets would not necessarily have mirrors. Peter explained the safety-behaviours he would employ if someone did enter the toilets:

you sort of tend to do a little bit and if somebody does come in you just pretend you're wiping your face or something or um... you know or just readjusting your hair or something you know but again it's just so embarrassing you know the thought of being caught putting make up on.

Peter (20: 678-681)

Peter appears to worry about being "caught in the act" as he re-applies his make-up. This extract shows how difficult the practice is for Peter as before vitiligo this routine was not part of his identity for his skin. Peter reveals a deep sense of embarrassment of other men seeing him putting on make-up, which is perhaps seen as stereotypically feminine behaviour, destabilising his masculinity. If a man did "catch" him and made a value judgement, it would bring about immense embarrassment and shame. The word 'pretend' is interesting, as possibly Peter is pretending not to have vitiligo by trying to conceal it. In this way, he is unable to live with it, but rather hides it due to the stigma this dermatological condition brings. This facade then takes away his real sense of self which perhaps he avoids, is shameful about and rejects.

In summary, 'focus on self,' explored and understood how men made sense of their vitiligo in their internal world. This theme revealed their undesirable feelings: anxiety, embarrassment, being different and shame. Vitiligo also shaped the way they perceived themselves: low self-esteem and difficulties with their masculine identity. Finally, the men described vitiligo as a separate entity on their skin which stayed with them like a dark shadow.

Superordinate theme three: Managing relationships

The third and final superordinate theme presents an account of how men manage and cope with social interactions and relationships. The previous sections have described the emotional and cognitive effects of vitiligo on the participant. As is the case with most physical health conditions, it emerged in the accounts that vitiligo also had an impact on the participants' relationships. This section relates to social contexts in which the individual experiences difficulties regarding their vitiligo.

'Fear of being ridiculed, rejected'

While adjusting to having vitiligo, how others viewed them became a preoccupation with the men, affecting their self-image. Some participants described situations where they had abrupt exchanges with a stranger. Such experiences increased the participants' feelings of self-consciousness as they feared being perceived as different, and consequently dreaded being rejected and ridiculed. These worries dominated the men's day-to-day lives. The need to fit in, although generally always there, was especially pronounced during the school and college years:

My pattern it starts with the hands and up the arms and [pause] and then your genitals go and you think oh my God that's, you know, because it started off sort of much darker and then goes to complete...that's when it's worst because you're still at school. You're still going in the showers and things. So all of a sudden you're really from being...I think the thing is when you're outgoing to start with like I was what it does is it makes you more introvert.

Tom (1: 17-23)

Tom was in his adolescence when his vitiligo began spreading. His response of "oh my God" may perhaps show his shock of the unexpected change in colour around his genitalia, which went from a dark colour to pigment-less. This was a difficult period for Tom: whilst at school his body was exposed, for instance in the showers, and he describes a process of going from being an extrovert to an introvert. One interpretation of this is how powerful vitiligo is in terms of muting the individual's

voice so that less attention is paid to him, and by extension to his appearance. It seems to be very significant for him that it spread on his genitals, which is possibly linked to his sense of manhood and confidence. Therefore the vitiligo's transformation of colour there transformed his sense of masculinity, and perhaps his sense of self. Unlike Tom, Jo recalled a few moments during school when he was ridiculed:

(...) sort of negative comments or mickey taking about it. I did have a few but, um, not, not extensive from memory.

Jo (2: 46-47)

Other participants worried so much about their patches that they concealed them:

(...) that I didn't let anyone see it enough to comment on it. And as I said, I never...it got my arms.

Tom (9: 277-279)

Even in the present day, men spoke of a preoccupation with how others would react. It transpired to be a type of social anxiety, as Sean explains:

I know that we all go out there and we interact with the world every single day and that generally involves other people. So I am frightened of ridicule, sorry I'm frightened by the possibility of ridicule, I'm frightened of the possibility of people laughing at me or not wanting to be associated with me

Sean (2: 382-388)

Sean describes feeling frightened of ridicule in common, everyday interactions. Sean goes on to apologise for feeling frightened. This indicates how he regrets feeling this way and in a sense may be self-deprecating. One interpretation of someone apologising is that they are passive in nature, when they are being harmed or threatened. As such this perhaps consolidates feelings of being under the watchful eye of the intruder, bowing down to it taking over his skin. The extent of fear in Sean is immense as he mentioned the word frightened three times in the extract. The stigma and shame of having his vitiligo seen by others terrifies him. A real sense of rejection is felt in the last statement, where he fears his vitiligo will lead others to see him as a 'fool', or as obscure.

Patterns of behaviour

Participants in the study used a variety of coping strategies, mostly behavioural, of avoidance and concealment. These were used in order to reduce the chances of being discredited by others and to maintain impression management. Often participants would avoid social contexts where their vitiligo would be visible, such as going for lunch in the sunshine or playing sports. Some participants described how the social interactions at work led them to isolate themselves. As Tom describes, he now works from home as this keeps him from the pressures of socialising at work:

With the job I do I can get away with it because you know the fact that I now work from home on my own I love that. I don't have to go you know in the past when I used to work with a load of other people in an open plan office ... you know are you coming out to lunch? Go down the park, sit in the park and have your lunch. No I'm alright, going to stay in its okay. [Pause] That sort of thing, the pressure is on you to do, you know going down the pub at lunchtime, and we'll sit outside.

Tom: (10, 338-343)

Tom reveals in this extract that he is “getting away with” working from home. One interpretation of this is he understands his vitiligo to be somehow bad, and that getting away with it means he is succeeding in avoiding punishment or criticism. Consequently, he loves working from home. Tom goes on to describe working in an open plan office where perhaps he felt exposed to criticism due to his vitiligo. He evokes a sense of vulnerability in this scene, which makes the fact he is comfortable working on his own understandable. There is no risk of attack. When invited out for lunch, he makes excuses to stay in. The pause in the extract possibly signifies the heaviness of peer pressure, necessitating him to behave as everyone else does. Avoiding sunlight on skin affected by vitiligo is a common theme with all participants. As Jo also describes, he would limit the amount of time spent in sunlight:

When I used to sort of go away on holiday with friends say early teens, 20's, um, you know I would avoid the sun but I'd say to them I can't really go on

the beach for more than a half hour and they were, they were cool with that. You know they understood what the problem was.

Jo (8: 222-226)

Jo describes going out in the sun for a short time and his friends were aware of his vitiligo. Interestingly, he views his vitiligo as a “problem” which perhaps indicates how he feels vitiligo is an unwelcome condition of his body. Tom extends his avoidance to family holidays in hot countries altogether as he states:

So I, um, we just bypassed it, so we just don't have holidays in the sun anymore. And so yeah you can say I missed out or the family's missed out

Tom (2: 41-42)

In addition, participants spoke of how their vitiligo would make them feel self-conscious in social settings such as going to the restaurant or for a drink as Peter explains:

I feel daft saying some of these things because actually it's like when you go out with friends in a restaurant I'm always conscious where the light is because I think that might emphasise where it's not properly done you know. And you think these are things I shouldn't worry about. You go out for a drink with your mates and you go to the bar and there's always the lights coming down there and I'm trying to be in the dark.

Peter (16: 552-560)

Peter reveals feeling foolish when he describes a situation in the restaurant with his friends where he worries that his vitiligo has not been effectively concealed. It perhaps can be related to the act of putting make-up on and being highly self-conscious that others will notice. He goes onto describes another scenario where he goes for drinks with his friends and takes certain precautions of sitting in the dark. This reflects how much Peter wants to fit in and be normal. One interpretation of the two scenarios is how he feels extremely exposed and fears being caught with something pointed out as wrong or different. Furthermore, the term “trying to be in the dark” might also imply that he is trying to keep his friends in the dark about his vitiligo, just as men wanted their partners to be, as some participants spoke of how they would avoid lights during sexual acts. As Ben explains:

Obviously sort of like, you know, intimately in terms of sexual relationships and stuff like that, that wasn't something that you particularly wanted to be doing in bright lights.

Ben (9-10: 287-290)

Ben struggles to say that in sexual relationships, he does not feel comfortable with bright lights, possibly for the same reasons of being exposed and worrying about being caught. The words “obviously sort of like, you know....and stuff like that” indicate how difficult it is for Ben to talk about his vitiligo. In a similar way, it may reflect his difficulties in his sexual relationship with his wife. Peter also spoke of seeking reassurance during these times:

You've got it all around your genitals and that, I mean that could be you know... I mean I was lucky in that sense and I just get reassured by my wife who says it doesn't matter, you can have the light off it doesn't matter, don't worry. I said yeah I know but it's still... and I know it doesn't matter but I still feel it, I don't feel complete I suppose in a sense you know.

Peter (18: 606-613)

Peter describes his vitiligo on his genitalia. He repeats the words, “but I still...and I know it doesn't matter but I still feel it.” This can be interpreted as his vitiligo seemingly scarring him in that he feels threatened by the fact that he has vitiligo on his genitalia. Perhaps shying away from light accentuates his feeling that he is less of a man in his intimate life. The words “I don't feel complete” indicate a potential loss of manhood. He uses the word “feel” repeatedly which shows the depth of the impact that vitiligo has had on his masculinity. It is interesting that in such intimate situations these men do not want to reveal their true self which has vitiligo. There is a sense of keeping their real self in the dark, not opening up to others and revealing their ‘real skin.’ Intimate settings were not the only situation where men would engage in safety tactics. Ben describes a range of hobbies and activities in which he would swiftly get out of what he perceived to be a threatening situation:

Ben: And I guess it's similar to going swimming or going to the gym or something in a changing room. Even though there wasn't any kind of ... you

know, you weren't in a relationship with anybody there, it's still that not wanting to take your clothes off in front of people in case they're thinking, "What's that?"

Researcher: So how would you manage those different situations? You mentioned dimming the lights...

Ben: Yes, dimming the lights. Darkness, you know, at night. And I guess in changing rooms, just very hunched up in the corner and just really quick. Keeping a towel around you, in and out very quickly. You know, not using any of the showers or anything like that.

Ben (10: 294-308)

Interestingly, Ben explains that he, too, hides his vitiligo as much as possible from unfamiliar people other than his partner in settings outside of his home. He shows indications of severe anxiety in his actions by being "very hunched up in the corner." One interpretation could be that of a child backed into a corner due to sheer feelings of fear of something terrible about to happen, hiding in shame. Ben's grave concern for what other people think of him and how they view him is prolific. He exits such situations as swiftly as possible, trying his best not to extend his time in a vulnerable position. In contrast, other participants would feel resentment at having to routinely cover-up and put sunscreen on when exposed to the sun:

I kind of have to resent having to put sunscreen on for short trips in sunshine and what have you.

Jo (5:102-121)

Besides the behavioural coping strategies, John tried cognitive coping strategies such as rationalising his negative thoughts, as he explains:

I'm much more self-aware of doing this and I, I do think I can stop myself [laugh] doing all that sort of rationalisation and arguing in my head, much more than I did when I was younger

John (6: 168-170)

Another coping strategy that men used involved carrying out a comparison of their vitiligo with other individuals who also have vitiligo. All men revealed that they felt lucky to be light-skinned, considering the demarcation was considerably stronger in someone who had dark skin. They found it difficult to conceptualise what it would be like for darker skinned people. As Sean explains:

Look online and see other people's vitiligo and see how they're managing and I look at some people with black skin, darker skin and I'm thankful for being white skinned because I can't imagine how devastating that must be.

Sean (15: 463-468)

Sean is grateful that his skin tone is not any darker, as is Ben:

I don't think people realise sometimes what it takes away from you and I realise that I'm lucky because I'm pale skinned, pale hair, so for me it's not like a massive ... not like people who maybe are darker skinned and, you know, Asian people. That sort of thing which must be much more difficult. Especially as a man because that would be the worst... because there's nothing to hide behind.

Ben (16-17: 510-516)

Ben reveals how being pale skinned and having pale hair means his vitiligo may not be as big a problem as it would be for someone who has darker pigment. Interestingly, he picks up on a gender issue of make-up. It can be perhaps interpreted that men's skin is more transparent or exposed, as putting make-up or cover-up on is taboo. It is also possible that these men are trying to feel better about their vitiligo, by trying to diminish the impact it has on their lives. Could it be one possible step to acceptance? Also, Ben's statement "I don't think people realise sometimes what it takes away from you" firstly implies that others do not really understand or appreciate the impact of vitiligo, and secondly implies that it literally "takes away" his colour and, possibly as with all the men in this study their confidence, masculinity and even their sense of being normal.

The last superordinate theme, 'managing relationships', described a range of coping patterns in how men tended to manage intimate and social interactions with others in light of their vitiligo. It also explored their fears of evaluation from other people in managing day to day situations.

Concluding remarks

In summary, this analysis has sought to present the three superordinate themes, "processing the vitiligo diagnosis", "focus on self", and "managing relationships". Within these superordinate themes a diverse range of areas have been introduced. The process of lived experience of vitiligo is a fragile one where there is considerable disappointment with the healthcare system in terms of interaction with professionals and the interventions on offer. Furthermore, the men experience a sense of being invisible, since any feelings or concerns they expressed were dismissed by the medical professionals. The reality of vitiligo sets in and personal feelings of helplessness are highlighted. Furthermore, this section portrayed the influence of their initial feelings and understanding of their skin condition on the world of a man's experience, and their early interpersonal encounters which shaped their current experiences.

The second superordinate theme illustrated how vitiligo impacted on their self-identity, in terms of how they constructed and accepted meaning of their vitiligo in their internal world. Men largely experienced a variety of emotions including anxiety, shame and embarrassment. The way they viewed themselves indicated low self-esteem, and described a feminine quality of having their vitiligo, bringing up difficulties with their masculine identity. They also described vitiligo as a separate entity and struggled with accepting it as part of themselves. Vitiligo was seen as a separate figure of threat, alienating yet all-consuming, which brought with it a considerable turmoil of emotions.

The final theme was the influence of vitiligo on managing relationships, which often gave rise to poor interpersonal interactions and behaviours of avoidance and concealment. These adaptive coping strategies were set in place to reduce the chance of being discredited by others and were way to manage self-image, which behaviour often stemmed from a fear of being ridiculed. A positive theme that was uncovered was that all the male participants were from a white ethnic origin and that in itself made the men feel lucky to be light, in comparison to those who had darker skin tones and as such had a more striking contrast in their skin colour and their vitiligo.

CHAPTER FOUR: DISCUSSION

Overview

The aim of this study was to gain an in-depth understanding of the experiences of men living with vitiligo. This was achieved by using IPA and analysing data through semi-structured interviews. No studies have explored men's experiences of skin conditions like vitiligo. For this reason it is anticipated that this study will add to existing literature, especially from a qualitative approach. As outlined in the methodology and procedures chapter, IPA was deemed suitable, given that men's phenomenology is under-researched, and the question of how to understand their experiences was open for exploration. In addition, IPA was considered consistent with the underpinnings of Counselling Psychology (Strawbridge & Woolfe, 2003) as uncovering the individual's meaningful and lived experiences are fundamental to this branch of psychology (Smith & Osborn, 2008).

Three main themes emerged from the analysis. In this chapter, the findings will be reviewed and explored in light of previous research, highlighting the novel elements and insights revealed by the current study, as well as overlaps with previous studies. It will also attempt to identify the potential influence of the participant's experiences of their vitiligo and the clinical implications of the research findings, both for Counselling Psychologists and health care professionals. Following this, a critical evaluation of the research study will be presented, and the section will conclude with an exploration of methodological and personal reflexivity.

How do men experience their vitiligo?

In this section, the findings will be considered in light of the research question as well as in relation to the existing literature outlined in chapter one. Where unexpected or novel findings have arisen from the analysis, some additional research has been drawn upon which has not previously been reviewed.

Processing the vitiligo diagnosis

Consistent with recent qualitative literature is the first superordinate theme, “processing the vitiligo diagnosis”, which explores how the men adjusted to their dermatological condition (Borimnejad, 2006; Thompson et al., 2003). All the men in this study spoke of how they initially ignored the depigmented patches which had appeared on their skin. Other family members tended to notice and point out the difference in their skin colour. As vitiligo spread across their skin, the participants’ anxiety amplified. It was at this point that a difference in appearance was acknowledged and medical attention was sought. Previous studies support this common process of unawareness to acknowledging vitiligo, with all the related negative feelings (Thompson et al., 2003; Thompson et al. 2010). This present study reveals similar findings.

For the study, participants were asked to recall their childhood diagnosis and experience of their vitiligo. The implications of this in terms of collecting relevant data may have been biased. Recall or memory bias can often allow an individual to recall negative feelings or cognitions more than positive ones. Childhood diagnosis affected some of the men when they were young. Therefore, it is important to be cognisant of this during the evaluation process. Within the accounts captured for this study, participants recalled feeling different during particular age spans. During these respective times participants felt self-conscious due to their visible difference. These feelings of being marked out by the depigmenting condition may indicate the development of mental health problems in adulthood. This supports Kent and Thompson’s (2002) model explaining shame-proneness in individuals distressed by disfigurement. Accordingly, they have argued that experiences of stigmatisation, particularly if this occurs in a repeated fashion in childhood, when there is an early onset of skin conditions, can lead to the development of body shame and social anxiety.

It is recognised that participants were recalling their childhood diagnosis and the implications of this in terms of validity of data. Recall or memory bias can often allow an individual to recall negative feelings or cognitions more than positive ones (Blaney, 1986). Therefore, it is important to be critical when evaluating participants’ experience of childhood memories. Within the accounts from this study, participants

recalled feeling anxious and different during what can be viewed as a vulnerable age, i.e. being marked out by this depigmenting condition. On reflection, future research could be extended by interviewing parents or siblings accounts to validate the recollections, or furthermore carrying out research with children and adolescents at the point of diagnosis

Distressing emotional responses to vitiligo are not recent findings in the literature. Porter introduced the psychosocial effects of vitiligo to the field of dermatology in the late 1970s using questionnaires (Porter, Beuf, Nordlund & Lerner, 1978; Porter, Beuf, Nordlund & Lerner, 1979). The initial feelings of fear, anxiety and embarrassment that men experienced in this study are congruent with recent qualitative studies in which women were interviewed. Participants repeatedly emphasised the way in which they felt disregarded during the medical interface, and their feelings of helplessness. These two feelings appear to be specifically important to the male participants, as “helplessness” or feeling unseen were not the key findings reported in the Thompson et al. study (2003). This might be an interesting gender difference, enforced by society and culture, which may cause men to feel vulnerable. Few participants sought treatment or alternative therapies such as homeopathy. Brown (2010) researched the differences between men and women in terms of feelings of vulnerability and concluded that shame was underpinned by vulnerability for both genders. A key take-home message of “just live with it” was given by their general practitioners, with little information offered. This finding of participants receiving limited support and accessibility, is also supported by the recent study by Thompson, Clarke, Newell & Gawkrödger (2010). It is also supported by a quantitative study carried out in Saudi Arabia, which found that vitiligo participants did not understand their dermatological condition, and believed little could be done to improve it (AlGhamdi, 2010). The men in the current study expressed their struggles i.e. feeling invisible and dismissed by the health professionals while accessing treatment. Men highlighted lack of knowledge, understanding and information on behalf of the GP; a finding supported by Thompson et al. (2003). This study reveals how, when these men discussed their skin appearance with medical health professionals, they often felt dismissed, that their concerns were minimised and that little information was imparted.

When participants attended medical consultations there was a sense of disappointment for various reasons, namely the absence of empathy, information on vitiligo and treatment options. Other sources, such as The UK Vitiligo Society, empowered participants, giving both practical and emotional support via their helpline and support days. The findings suggest a sense of helplessness due to the lack of information and the attitude of “just live with it” given at the first point of contact with medical services. Since the participants initially failed to acknowledge the vitiligo on their skin, which had to be pointed out to them, it can be assumed that it was difficult for the individuals to seek support. The GPs then appeared to do the opposite of the family members who had alerted them to the changes in skin colour, by dismissing the condition and often giving the message that it is incurable and they should just live with it. By withholding and minimising their concerns for the dermatological condition in this way, the medical professions seemingly made the men feel isolated in their search, and that they were making a mountain out of a molehill. They were not viewed as needing treatment. Papadopoulos et al.’s study (2001) examined the cognitive representations which individuals with vitiligo developed using the Illness Perception Questionnaire (IPQ; Weinman et al., 1996). They suggested that individuals are more likely to understand and comply with treatment if they understand and agree with the reasons that their medical professional gives for their illness. Findings in this study re-iterate other research recommendations that eliciting individuals’ beliefs about vitiligo can be helpful in terms of their response to their condition (Borimnejad, et al. 2006; Thompson et al., 2003; Papadopoulos et al., 1999). Consultations and the IPQ measure can be ways of giving a reliable assessment of the understanding and illness representation of vitiligo clients, which could facilitate a closer union between them and medical professionals.

Focus on self

Following the men’s experience of being diagnosed and then being seen and thought of in a different light by medical professionals, novel conceptualisations of how they saw their vitiligo were described. The second superordinate theme that

emerged from the data was the way in which their sense of self altered internally while their skin changed externally, giving rise to the complex set of feelings they experienced while adjusting to this chronic condition.

The findings reveal an understanding of the complex set of relations between the participant's internal world and their pigment loss. In a very real sense, men described how their vitiligo made them feel as if they were living with an unwanted other. This separate entity appeared to impose itself upon the individual regardless of behaviours to deter it, such as receiving interventions e.g. light therapy. These findings show a novel concept of vitiligo as an intruder on the skin. This is a powerful description; this metaphor causes continual anxiety as men experience it persistently in the background. Furthermore, some men described this intruder as a phenomenon that 'attacked' their skin, over which they had no control, reiterating their feelings of helplessness. This doubling up of another 'being' resulted in turmoil of emotions which the men had to live with on a daily basis. This appears to be a unique issue in men with vitiligo, which is not evident in previous studies of vitiligo.

Although experienced as intrusive, vitiligo is also entwined with a part of the individual, as it occupies much of the men's attention on their appearance and their feelings of self-esteem. Their vitiligo is inevitably woven into their sense of identity, which is continually revising and moulding the expression of self. This can be understood in terms of the social identity theory. Tajfel (1979) proposed that groups (e.g. family or a football team) offer individuals a sense of belonging that can be a source of pride and self-esteem. It can be said that groups give us a sense of social identity: a sense of belonging to the social world. However, through a process of social categorisation individuals are separated, with some placed in the in-group and others in the out-group. Social identity theory states that the in-group will discriminate against the out-group to enhance their self-image. So when vitiligo is apparent on their skin, it can perhaps lead men to feel different and therefore not part of the in-group. The out-group then reinforces the perception that they are different. It would be interesting to explore what assumptions these men have about these notions. The process of forming a social identity is at the heart of self-identity. The findings of this study suggest that men grapple with their self-identity, experiencing tensions in their social life and struggling to perceive themselves in a masculine and

“macho” light when their confidence and self-esteem are low. The men in this study tried to conceal their difference (and stay belonging to the in-group) rather than identify themselves with the out-group and reinforce the perception of themselves as different.

The men in this study also reported a range of distressing feelings related to health and social situations. Vitiligo provokes difficult emotions such as shame or embarrassment, and anger (Jowett & Ryan, 1985). These emotional responses are common when living with vitiligo (Thompson et al., 2010; Borimnejad, et al., 2006; Thompson et al., 2003; Porter, et al., 1979). Since vitiligo is an episodic condition with an uncertain aetiology, men described a range of intrusive cognitions and feelings that revolved around the implications of the disease on their sense of self. Men reported feeling distressed, embarrassed and ashamed. They also appeared poignantly aware of being different to others, separated from them by what felt like “white markers” on their skin. This difference made them feel they were deficient both as individuals and as men. The men explicitly disliked the feeling of being different and attempted to be invisible as a way of hiding their difference. This became one of the most pressing concerns in their daily lives. While there was a level of acknowledgement of appearing unlike others, tolerating these feelings was difficult. Previous research supports the way in which individuals’ feel different when living with vitiligo and other dermatological conditions (Rumsey, 1998; Papadopoulous & Bor, 1999; Thompson & Kent, 2001; Rumsey & Harcourt, 2012). It also supports Cash’s (2011) integrative cognitive-behavioural framework of body image; how men’s past early experiences predispose how men now come to think, feel and behave in relation to their body. It is interesting how cultural socialisation in particular played a part in men’s low self-esteem and identity, for example the idiom of being “tall, dark and handsome”. This further supports the work of Mishkind, Rodin, Silberstein, and Striegel-Moore (1986) who argued that men were under increasing pressure to conform to this cultural ideal of the lean, well-toned, muscular build, paralleled by an increasing preoccupation among men with weight and body image. Understandably, feeling different in these men’s accounts led them to conceal their condition and use avoidance behaviours in an attempt to maintain normality. Also, the role of early experiences and cultural stereotypes such as internalising

negative reactions towards their skin by other children can develop unhelpful beliefs about their appearance and role of appearance. This is true of body image difficulties in other dermatological conditions such as alopecia or acne as it is a visible condition which can have a disfiguring effect on appearance. This in turn impacts the perception that the individual has with living with their condition and how others perceive the visible difference. Thus, it can be said that appearance and body image did matter to men. A wealth of literature supports this notion (Skeggs, 1999, 2001; Palmer, 2004; Taylor 2007; Rumsey & Harcourt, 2012). The accounts revealed how their appearance impacted them in both intra- and interpersonal construction of subjectivity, and also in the rearticulating of social divisions and processes of inclusion and exclusion (Skeggs, 2001; Taylor, 2007). Appearance conveys information about status and psychological character, and is central to the process of classification of value and worth, of ourselves and others. This study revealed that appearance and perceived thoughts of others on their appearance are central to men, and that it often led them to feel unworthy, causing a lack of self-esteem. Furthermore, the findings suggest that men viewed their own appearance as unattractive and un-masculine, and that they wished for a perfect self-image: “Tall, dark and handsome.” As such they became engrossed with their vitiligo, with some focussing on the visible areas of their skin e.g. hands or face, while others' grew preoccupied with the appearance of their face and hair. These feeling reflected a preoccupation with their appearance, which could be viewed as dominating their sense of identity.

The participants' identity as men took on a fluid quality that was subject to the progress of their vitiligo. A 'fluid identity' fittingly describes how the men's outlook and behaviour was dependent on how visible and unattractive they experienced their vitiligo to be. As such, both their identity and skin condition were in a constant state of flux, indicating that the men's self-image was damaged and their self-esteem was threatened. As a consequence, they tended to view themselves in a negative light. Porter et al. (1979) also found that individuals with vitiligo, especially those who were single and male, had low self-esteem and as a result considered their appearance important. A more recent study by the researchers concluded that the development of overall self-esteem may be helpful, particularly in

men who are more at risk of experiencing sexual problems (Porter, Beuf, Lerner & Nordlund, 1990). The men in this research study did report sexual encounters to be difficult in their adolescence, early adulthood and in the present. This also has a profound impact on how men feel about themselves having lived with vitiligo for many years since their initial diagnosis. Some men still reported feeling unattractive in their sexual relationships with their current partners. Here, it is evident how their sense of self is intimately bound up with what is viewed through other's eyes. Al Robaee (2007) observed that women are more embarrassed and self-conscious about skin conditions than men, as it impairs social life, personal relationships, sexual activities, and choice of clothing. When examining this study within the context of Saudi society, where vitiligo is seen as infectious and as a genetic disease which affects women in regards to marriage, it is not surprising that women feel more distressed than men. Thus, these findings, when conceptualised under the cultural and religious umbrella of values, make sense. However, the present study highlights that men are equally distressed by vitiligo. These feelings are influenced by societal pressures: in a British-Western culture particular emphasis is placed on appearing manly and flawless. These pressures are somewhat different to those of Saudi Arabia (Edwards, 1997; Nixon, 1996). That said, this study's findings of men's negative perception of themselves are commonly found in previous studies and are therefore not so novel. Here, however, participants told of overcompensation behaviours, such as buying designer gifts or working hard in order to feel good about themselves, and to make up for not being 'good enough' husbands, for example. The findings again indicate how difficult it was for the men to accept themselves in light of how the outside world perceives them.

The sub-theme "perception of self" relates how their identity is tied to the ways in which others perceive them, and their internalisation of this. While previous research had already established this, participants described an erosion of self-confidence and self-esteem, and feeling different (Thompson et al., 2010; Ongena, van Geel, De Schepper & Naeyaert, 2005; Parsad, Dogra & Kanwar, 2003; Thompson et al., 2003; Kent & Al'Abadie, 1996). Furthermore, there was a shift in the way they viewed their identity, as if they had become 'feminine', which had not been found in previous published research. It was not only the whiter pigment, but

also the act of covering up and potentially applying make-up, that destabilised their previous masculine identity. Participants with vitiligo struggled to accept this change and feared discrimination by others. Thus, certain coping behaviours to appear “normal” to others in society were adopted by most men in order to remain part of a larger social identity and maintain the self-image they had had prior to the patches on their skin. This will be discussed in the context of relationships in the next section.

Managing relationships

Aside from discomfort in themselves and perceiving themselves to be different, men also felt unease in their relationships, both personal and social. Participants recounted how existing social relationships had been damaged as their level of social interaction diminished. Men's attempts to fit in followed three main types of coping strategies. The two behavioural strategies were 'avoidance' and 'concealment' and the cognitive strategy consisted of 'making social comparisons'.

Participants often described their current experiences in juxtaposition to previous early experiences, as well as drawing comparisons to other people. This would allow men to reflect on their vitiligo in terms of equality and self-worth. Potential stigmas may be readily apparent to others. The data revealed that men avoid places and situations where loss of skin pigment might be noticeable, and experience stigmatisation and fear of intrusive reactions such as staring. This is common, and has been reported by quantitative studies (Porter & Beuf, 1988, 1991; Porter, Beuf, Lerner, & Nordlund, 1990). These findings can be related to Goffman's (1963) research on stigma, where personal attributes can be deeply discrediting. Goffman argues there is a need for this to be managed during social interactions between individuals who are being stigmatised and those who remain unaffected. Participants in the present study found their vitiligo was highly visible to others. It could be understood as "being marked," like a stigma on the skin. Interestingly some participants avoided using the terms vitiligo or disfigurement in their interview. This suggests a parallel process of avoiding what was so very visible to them in their day-to-day life. In the absence of self-protecting identity beliefs of their own, the stigmatised individual tends to hold the same beliefs about their identity as the wider society, and as such, may see himself as 'falling short'. Such a response makes the experience of shame in men possible. Brown (2010) suggests that behind shame lies vulnerability and that those who are more accepting of their vulnerabilities hold greater and stronger social relationships. Hence, the idea of connection occurs when an individual, man or woman, can truly be seen with vitiligo. Stigmas such as facial vitiligo can cause difficulties in social interaction with 'normal' individuals, which have lasting and damaging effects on the self-identity of men affected by the condition (Murray & Rhodes, 2005). Furthermore, this can be understood under social constructionism, which often deconstructs the very idea of coherent selfhood

(Sampson, 1989). This approach considers the ways in which an individual is identified, talked about, and treated which all contribute to creating a particular identity. In light of this framework, the men's experiences of feeling different and invisible in the face of medical professionals, of feeling dismissed, and of feeling unattractive during sexual encounters, are just some of a multitude of experiences which shape these men's identities. These are further negotiated and defined within specific interpersonal relationships and cultural contexts. Furthermore, the way in which men spoke about themselves, i.e. their language, also determines the nature of their experiences. Therefore, it is apparent that their identity is tied to how they see themselves and how others treat them. Already discussed in this section is the idea of stigmatisation, which has been reflected in the history of vitiligo although confused with leprosy, both have been problematised and stigmatised conditions throughout the ages. It is interesting to note that Foucault (1961) describes how leprosy was replaced by madness, i.e. mental health issues. In light of the social constructionism, which accepts that there is not an objective reality, this study gives some insight into how this particular group of men constructed their knowledge of vitiligo and understood this dermatological condition. The way in which the men described their everyday interactions with others, and the language they used to construct their reality, gave rich insight into their experiences. Viewed more closely in this way, vitiligo still leads to negative self-appraisal, struggles with identity and stigmatisation, in accordance with local, provisional and contextual factors. Subsequently, the way in which vitiligo has been thought of in the past as a contagious disease similar to leprosy, and the way in which the medical model continues to take a reductionist approach, impact individuals with vitiligo. In light of this, perhaps there is a need for men to reclaim their identity, come to acceptance of this chronic condition and promote education in communities to potentially help alleviate stigmatisation of this condition.

Data revealed maladaptive strategies included avoiding family, friends and colleagues during social occasions, such as avoiding going out for work-lunches or attending barbeques. Men would also avoid situations where their vitiligo would be most noticeable such as avoiding sports e.g. swimming as well as taking vacation in hot countries. Participants described how they feared they would be rejected or

ridiculed because of this social withdrawal. This led to a sense of social isolation, a feeling of inferiority, and consequent stigmatization. Participants displayed various concealment behaviours to minimise the impact of their vitiligo on their day-to-day life, such as growing their hair longer to hide vitiligo patches around the neck and scalp regions. Other strategies entailed using camouflage or tanning products to conceal their lighter-pigmented skin. In the summer months especially, men would remain covered up, and avoid wearing shorts or sleeveless tops, thus covering their legs and arms in particular. All participants were married and the data revealed that many would dim the lights in social and intimate settings with their partners. These findings of managing difference through these behavioural coping strategies are supported by other research (Moos & Schaefer, 1984; Thompson et al., 2003, Thompson et al., 2010). Interestingly, one of the behavioural strategies found with women in the Thompson et al. study, namely addressing their condition with others, was not found in this research. Men did not talk openly, confront or explain their vitiligo to others, who were curious or made comments, in an adaptive manner. This could be related to the unease that men spoke of in their interviews, which is discussed later in the reflective section. Moreover, it can be suggested that women are more expressive of their emotional feelings than men. Developmental psychologists have suggested that males learn to conceal their feelings relatively early in life, whereas females develop the expression of their emotions more freely (Brody & Hall, 2000; Fischer & Manstead, 2000). Possibly women define or gain their sense of self by “belonging” and therefore take actions to bridge gaps to others, while men define themselves more through what they can or cannot do, thus a sense of control and being capable is more important and therefore it seems more important to conceal what they may perceive as a flaw, leading to social isolation. Furthermore, research based on survey data from community and national samples of adults, consistently indicates that women report more symptoms than men of generalised anxiety, distress and depression (Meyers et al. 1984; Mirowsky & Ross, 1995). Because feelings of fear and sadness are key components of anxiety and depression, subscales and epidemiological research strongly suggests that women experience negative emotions more often than men and, by extension, that men experience positive feelings more often than women (Bradburn & Caplovitz, 1965; Campbell, Converse, & Rodgers, 1976; Mirowsky & Ross, 1995). In this way, the findings of

this study can suggest that men struggle to be upfront regarding their dermatological condition. Furthermore, men struggle to come to terms with their condition in terms of accepting and integrating their dermatological condition as part of them. Their appraisal of their vitiligo was that of a separate entity from their own skin. The way they viewed their skin condition was a phenomenon that was 'being done to them' by their own body. In this way, the process elicited inner turmoil resulting in anxiety. Data revealed that they would try to minimise their vitiligo at all costs and manage their perceived difference day-to-day. It was proposed that due to their light skin colour, there was less of a stark difference in their skin's colour to be seen. Given this assumption, men may not want to draw more attention to their appearance by acknowledging it to others, due to how anxious they feel regarding their dermatological condition.

The key cognitive coping strategy that men employed in this study was one of expressing gratitude at being light skinned. All participants originated from White British backgrounds. All the men in the study expressed social comparisons between themselves and others with vitiligo, who had darker skin than themselves. This process was a beneficial one in allowing them to view their dermatological condition from a different perspective. Comparisons were made with those perceived to be in worse situations, serving to reduce the importance of the disease's impact in their lives. This research supports the work carried out by Thompson and his colleagues in 2003.

In summary, these behavioural and cognitive strategies were employed mainly as efforts to control impression management (Leary & Kowalski, 1995). Moreover, it appears that men employed these as a protective strategy to reduce the likelihood of being discredited by others (Goffman, 1963). The novel finding from this study is the positive thinking the men draw on when comparing their vitiligo condition with individuals from a non-white background. The cognitive coping strategy of upward comparison served as a helpful technique in placing perspective on their appearance. The avoidance and concealment strategies are common findings in previous research on both social anxiety and disfigurement to manage the impression they made on other people (Leary & Kowalski, 1995). The overriding theme apparent in the group of men interviewed was fear of rejection and ridicule i.e.

social exclusion (Goffman, 1963). Furthermore, understanding the last theme of managing relationships in light of the cognitive adaptation model (Taylor, 1983) in relation to vitiligo, these men appear to be stuck in the first process of adjustment, the stage where men possibly search for meaning in the experience of living with vitiligo. In this way, the men in this study have not surpassed the stage of avoidance and concealment and have not described coping strategies of acceptance or confrontation or seeking other's inclusion actively. The findings of these results reveal a struggle to attempt to gain a sense of mastery and acceptance over their dermatological condition. This relates to the way they see vitiligo as a separate entity. The process of adjustment and integration is a salient one which can lead to a restoration of self-esteem.

Clinical implication and applicability to CoP practice

The present study has identified potential recommendations for clinical interactions including assessment and treatment of men with vitiligo, as suggested by participants. Papadopoulos et al., (1999) stated the importance to listen to and acknowledge clients' needs and recommendations in order to improve treatment provision in health care services. This is further echoed in CoP values of "listening to our clients to determine the best way forwards" (p.8). The recommendations in the following sections will explore the applicability in clinical practice and inform health care professionals when working with this client group. The present research has a clear relevance to clinical practice and research in psychodermatology. This section will consider the implications of present research for the field of Counselling Psychology and link the role of counselling psychology within psychodermatology. In addition, methodological issues and directions for future research are discussed.

The role of a Counselling Psychologist and clinical recommendations

Considerable value is given to counselling psychology's focus on facilitating growth. In applying this value to research, it is hoped this research will make a positive contribution to the lives of those who access it for knowledge. Counselling psychology research should ideally have a potential for direct application to the work

of Counselling Psychologists (as detailed below). This research seeks to fulfil this aim by investigating a topic which is often seen as merely cosmetic within the medical field. Research has shown that psychological factors have an impact and can be useful predictors for managing this chronic dermatological condition (Papadopoulos & Bor, 1999). Fully understanding the psychological adjustment during the onset and long-term management of vitiligo requires careful consideration of many factors that may affect the psychological well-being of an individual. There may be specific gender role related difficulties that the Counselling Psychologist needs to be sensitive to. For example, a client may be more comfortable with a clinician of the opposite gender. Therefore, a general campaign on dermatological conditions that can cause difference in appearance needs to be carried out regularly across communities, both nationally and internationally. A good example of this in the UK comes from a charity, Changing Faces, which has begun this education. Furthermore, health care professionals who work in primary care with men must be educated about the nature, prevalence, aetiology and treatment options of vitiligo. The psychological aspect of empathy is key in helping clients with initial concerns, anxiety and loss. This in turn will enable practitioners to identify concerns around adjustment to diagnosis and whether patches are spreading. A referral pathway for stepped care to a psychologist for the appropriate prevention or intervention efforts needs to be in place.

Counselling Psychologists not only produce research, but also work therapeutically where they relate their theoretical knowledge to the world of psychological therapy. Therefore, an area of consideration when thinking of men's experience of vitiligo is how a Counselling Psychologist might approach men with dermatological conditions different from other fields of therapy. The types of therapeutic approaches espoused by counselling psychology in the U.K. are diverse in nature. Most training courses offer training in one or two approaches such as CBT and psychodynamic methods, others are based on existential or person-centred philosophies. Therefore, Counselling Psychologists use a broad repertoire of approaches i.e. integrative to their therapeutic work. A current zeitgeist which seems to fit counselling psychology's essence of engaging with diversity is the epistemological position of pluralism. Pluralism expresses the idea that "any

substantial question admits of a variety of plausible but mutually conflicting responses” (Rescher, 1993, p.79). Accordingly, Counselling Psychologists should be mindful that different clients may want different things from a clinician at different times and, in order to progress, we should ask the client on what - and how - they wish to work. This in itself, ties in with the values which distinguish the counselling psychology profession from others. The profession encompasses acknowledgement of inherent subjectivity, intersubjectivity and a humanistic focus on facilitating growth (Division of Counselling Psychology, 2006; Kasket, 2012).

As a Counselling Psychologist, it is important to recognise the philosophical underpinnings of the profession on the research process. A humanist approach provides the researcher the stance to view the individual holistically, rather than just as a medical diagnosis per se. In this way, Counselling Psychology highlights the strengths and the values that each participant brings. This contrasts with a medical model approach, which has a tendency to pathologise individuals. This research has given these men a voice to express the views that their previous medical experience had neglected. This way of working reflects the BPS (2005) practice guidelines “to recognise social contexts and discrimination and to work always in ways that empower rather than control” (p.2).

Access to a Counselling Psychologist appears to be of great importance during the period when a young child, adolescent or adult man is diagnosed with vitiligo. Counselling Psychologist’s attention to the individual’s sense of how the vitiligo is affecting them may help alleviate the longer-term psychological distresses which are possibly a result of difficulties in accepting this chronic dermatological condition as part of their new identity. The findings of this research imply that the role of a Counselling Psychologist is of major importance through the particular stages of their condition, e.g. diagnosis and the start of treatment at their dermatology clinic. This was evident in the theme of ‘focus on self’ which highlighted the undesirable feelings about oneself and their low self-esteem. It can be suggested that a Counselling Psychologist needs to be trained about the specific psychological issues that may arise and it is very important for a Counselling Psychologist to collaborate with the GP, dermatologist, support groups and nurses. In some cases the role of a Counselling Psychologist will involve engaging family members in order

for them to help clients cope with their psychological difficulties (Papadopoulos & Bor, 1999).

Figure two includes some guidelines for the role of a Counselling Psychologist in dermatology specific to vitiligo. The first circle proposes that Counselling Psychologists can train multi-disciplinary professionals around the psychological impact of appearance and the common beliefs, feelings and behaviours that individual's experience. For example, it is can be a common belief that men do feel unattractive as they do not fit the social stereotype of male beauty. The second circle focuses on how Counselling Psychologists can conduct assessments of psychological difficulties such as shame, which can then prompts a referral pathway for therapy (third circle). The fourth and fifth circle requires Counselling Psychologists to embrace a curious and exploratory stance in searching for meanings it holds for the individual on the appearance, adjustment process and exploring issues around their masculinity. The sixth circle highlights the importance of stigma and shame that individuals may feel when attending sessions that Counselling Psychologist hold in mind and where possible to normalise these experiences. The seventh circle highlights the importance of Counselling Psychologists working systemically by engaging with the individual's family and or partner to help in understanding the nature of their dermatological conditions and address their concerns. Furthermore, collaborative working is also advocated within other multidisciplinary teams in order to ensure a holistic care plan.

Figure 1. The role of a Counselling Psychologist in dermatology



A bridge between Counselling Psychology and Dermatology

There is growing literature on, and acknowledgement of, the importance of understanding the client's experience of having a dermatological condition, from both a psychological and a medical field. A recent Cochrane review (Whitton et al., 2010) of interventions for vitiligo indicated that while there was some consensus amongst researchers as to the causes of vitiligo, there are still various on-going trials which examine a wide range of interventions. Therefore, as current research stands, there is not a cure for vitiligo or an effective method of limiting the spread of the condition. A better understanding of the pathogenesis of vitiligo may lead to improved treatments. Almost all treatments have been borrowed from therapies whose prime target is another disease (Gawkrodger et al., 2010). Therefore management is crucial in living with this dermatological condition. Vitiligo is known to cause profound psychological effects, and therefore psychological approaches need to be assessed to see if they help clients. Papadopoulos, Bor and Legg (1999) suggest that quality of life and coping mechanisms may improve over time. Cognitive behavioural therapy strategies rather than avoidance or concealment may be associated with better coping (Thompson et al, 2003). This study suggests that to improve the phenomenological experience, it is necessary to improve the relationship the dermatologist or medical professional has with the client. This study's findings suggest that this relationship has the potential to be more intimate and profound, it has shown lasting meaning. Dermatologists are in a unique position to recognise psychological suffering from symptoms of anxiety and/or depression and mood disorders and should be prepared with referral strategies to mental health professionals. The dermatologist society have created an interest group in psychodermatology and are beginning to acknowledge and promote the emotional well-being of dermatology clients and have begun to create posts for Clinical and Counselling Psychologists, although funding resources are limited.

To bring this finding a step forward it can be suggested that it would be useful for Counselling Psychologists to educate other mental health professionals in primary care, and dermatologists and nurses who may meet with clients who have vitiligo. Understanding the issues of identity, acceptance, feeling different and stigmatisation and screening for psychological morbidity could be fruitful.

Presenting information to clients on available resources such as psychotherapeutic services and to facilitate referral for them could be beneficial as well as signposting to organisations like the Vitiligo Society. A strong recommendation is made for the continuous presence of a mental-health professional as part of a dermatology clinic, which may be an asset both in providing support to the clients and in training staff to reduce the potential stresses which provoke anxiety in men living with vitiligo.

To date, there has been a paucity of psychological intervention studies for vitiligo, despite this being an apparently obvious area. There is a clear need to implement psychological approaches to psychological difficulties at the point of diagnosis and then the psychological management of this condition. This could potentially alleviate the struggles of identity, adjustment, acceptance and anxiety in living with vitiligo.

Methodological and personal reflexivity

There were many processes that I felt went on during the interview process with all six participants. To begin with, my initial reflections after the pilot study were related to my gender. Many of the men that were interviewed had not spoken about their vitiligo to their partners. It became apparent that I was the first woman they had confided in and, at times, the interviews felt like therapy. One participant remarked during the interview that “you’re more like a counsellor than anything actually, I say that because a lot of the things are kept inside,” (page 18, line 601). This process made me reflect on the literature of gender norms for men and how they are taught at an early age to be “tough”, meaning hiding distress and appearing independent (Mahalik et al., 2005). In addition, conducting the interviews brought up personal experiences I went through early on in my life such as avoiding activities and sunlight. However, I was able to make use of supervision to bracket these. Furthermore there is the gender norm of refraining from help seeking behaviour to avoid indicating subordination, and in this way I understand that men do not seek help for mental health difficulties in general. Research indicates this behaviour in relation to their vitiligo (O’Loughlin et al., 2011).

The men appeared to reflect on the meaning of vitiligo in their day-to-day lives in relation to their family, to others, and in a work context. For example, they were aware of their fear being ridiculed or rejected. This was apparent in their narrative when they spoke about how vitiligo affected them, their relationship with others, and more widely, their own sub-culture. On reflection, I'm aware that this reaffirmed my epistemological stance for this research study. As the men spoke about their experiences, I picked up on their sense of identity, which was changing, as one that they struggled to accept. This process itself made me question my position and my personal experiences of living with vitiligo and how they related to the shared construction of meaning we made during the interview process such as feelings of being disconnected from the other and not having control over the vitiligo. This was especially the case when I experienced a parental bereavement and soon after patches of vitiligo occurred on my body.

Conducting this research has been a difficult learning journey: personal feelings around vitiligo were challenging, as was carrying out this study itself. Etherington (2004) describes this as a process of becoming and transforming. On reflection, conducting this research has made me realise how important it was to allow these men to be heard; for them to have a forum to talk about the impact of their vitiligo. It has been cathartic for me, the researcher to work with the Vitiligo Society, to set up psychological support groups and signpost support for the struggles of identity, stigma and acceptance. The study reveals that vitiligo is more than "skin deep". In a world in which significance is placed on physical appearance, it is increasingly likely that both men and women will suffer from psychological and social consequences from this stigmatising condition. For practising Counselling Psychologists it is imperative and a duty of care to understand the illness; to allow individuals to be heard and understood, and in this way to explore novel ways of adjusting and coping adaptively for the well-being of individuals.

Limitations and suggestions for future research

The present study explored six men's experiences and understandings of living with vitiligo. According to IPA's (Smith et al., 2009) idiographic feature this study does not attempt to simplify or take a reductionist approach regarding every

man's experience of having vitiligo, but rather it reveals a significant contribution to the limited literature of men living with vitiligo. Furthermore, this study emphasises unique findings resulting from the researcher's interpretations and attempts to understand how men made sense of their condition, which adheres to IPA's hermeneutic feature (Smith et al., 2009). As such, it needs to be acknowledged that other researchers might have developed a different set of themes from the data in this study.

An attempt was made to avoid methodological shortcomings. However certain limitations need to be taken into account when considering the results. A possible limitation is that the study only recruited men from a Caucasian background. The study did receive interest from men from non-white backgrounds, however due to circumstances they could not be interviewed (e.g. two clients expressed interest but were then abroad for 2-3 months). It would be interesting to understand the experiences of men from different ethnic backgrounds as well as different skin colours as there has been a wealth of research carried out in India which has shown psychiatric morbidity in clients with vitiligo (Ongena, Beelaert, van Geel & Naeyaert, 2006). Furthermore, this study can act as a sound starting point for future research, in the same way that Thompson's 2003 study led to the investigation of the experiences of women in South Asia. There is also scope to further investigate the experiences of various ethnic and minority groups.

Another possible limitation lies in the participants' struggles to talk about vitiligo with a female researcher. This may have brought about issues around disclosure, such as their perceived manliness, their expectations of not being understood, and the question of shame. They may have experienced considerable difficulties in talking about their feelings about their masculinity, for fear of being judged. However, all men were aware that the researcher, too, has vitiligo. Furthermore, post interview, all participants commented on how it was the first time they had spoken in depth about their feelings regarding their vitiligo and had not even spoken to their partners in this detail. From this, it could be argued that men find it easier to speak to a woman researcher than to speak to their partner or that they find it easier to speak to someone who also has the same condition. It is possible speaking to another man, particularly to someone who does not experience from

vitiligo, may increase their sense of shame and male role expectations. It appeared that talking about health problems and emotions may not be part of the family discourse. It is possible that their experience of the interview process itself was one of catharsis. It would be interesting to repeat this study with a male researcher and examine whether there could be possible differences.

The sample was purposive and it was small in size and homogenous. These factors suggest that it is therefore unlikely to be a good representation of the population of men in general, thus limiting the generalisability of the research. It would be interesting, to examine these issues in other groups of men of different social, ethnic, economic and educational backgrounds and of different age ranges in order to investigate differences and commonalities in their experience. From this identification of significant and central themes it may be possible to move from the particular to the universal (Eatough & Smith, 2008; Smith, 2004). Furthermore, there is the possibility that selection bias might account for results. The sample consisted of individuals that were willing to accept and participate in the study; therefore making it difficult to generalise findings to a) less motivated or unwilling clients, b) clients who fail to read the 'Dispatches' magazine. It might also mean that only participants who feel they are reasonably successful at concealing or avoiding their condition, or individuals who feel their vitiligo is not very visible or noticeable, have agreed to this study, accounting for the results of not having any other coping strategies. This is often an issue with research of this nature.

The present research addressed the experience of vitiligo in men. It is acknowledged as a first step and much more additional work needs to be done to unravel whether these interpretations and understandings manifest in men from different backgrounds and even other skin conditions. This study has highlighted the issue of masculinity in men with vitiligo, i.e. their sense of attractiveness and their complexion ideals. Further qualitative studies could be beneficial in exploring and understanding this issue in greater detail and depth. It would be necessary to explore the cultural impact on men's experiences of living with vitiligo as most studies have been carried out with western participants from a white ethnic background. Ascertaining rich information from these clients could further inform clinical

practice. Such findings could propose recommendations that would be invaluable to Counselling Psychologists when working with a culturally diverse population.

Most men's vitiligo started in childhood years, which could possibly have an impact on men's experiences and understanding of vitiligo. A suggestion for future research is to recruit men with a similar onset age, in order to explore or uncover common factors in the childhood onset of the condition. It would be interesting to understand more about when they are newly diagnosed in order to help manage their trajectory with this dermatological condition. Given the limited literature base on men with vitiligo, there are a number of suggestions for future research. It would be advisable to employ qualitative designs where factors such as age, gender, cultural and ethnic backgrounds could be explored as variations in the process of adjustments to vitiligo. The present study is the first study exploring men's experiences and understanding of vitiligo. Repeating this study could be beneficial in consolidating the findings and further contributing to this under-researched area. All future research could be salient in informing not only Counselling Psychologists, but other health professionals with a view to tackling the challenges of isolation, difference, struggles with masculine identity and the stigma that men face, all of which may be helpful to service provision and clinical practice.

Concluding remarks

Attention has increasingly been given to the psychosocial impact of dermatological conditions. The observed importance of psychological factors represents a move toward the recognition that coping with a disfiguring, chronic skin disorder represents a complex, multidimensional and ongoing bio-psychosocial process. Indeed, present research provides support for the existence of psychological problems experienced by clients with vitiligo. Findings demonstrate that the process of diagnosis and management of vitiligo is a complex one in men, where adjusting to difference and the implications for sense of self are unlikely to be explained solely by physical symptomatology. Thus, they suggest that the conceptualisation of vitiligo, or any dermatological condition, goes beyond mere medical diagnosis (Main, et al, 2000).

This study also demonstrates how the men experienced a fundamental sense of shame and stigma, which made them feel vulnerable in social interactions. These findings are similar to those of Northoff (1992), who stated that the skin can easily become a predominating figure among individuals with skin conditions. Those with other dermatological problems such as psoriasis and eczema also frequently consider themselves unattractive, unlovable, and different, and these perceptions bring with them feelings of anxiety, shame, loss and despair (Papadopoulos & Bor, 1999). Vitiligo is not to be considered in isolation, but rather within the context of a body-conscious culture in which stereotypes of beauty, attractiveness and health are prevalent, and in which there are certain gender role expectations for men and women, which affect how they may or may not be perceived. Lemma, a psychoanalyst, (2010) proposed that the experience of the mind and body is a challenging task in itself; it is one which fluctuates in people at varying degrees. The cultural emphasis on the body is hugely significant as our body connects us to our primary caregivers, and is inescapable not only for us, but for the others who see us, and it can often be the site of pain and be where conflicts are enacted, all of which can trigger a distressing lack of control. This study also shows the evidence for the benefits that Counselling Psychology can bring for example as shown by the men's feedback if the researcher received positive feedback.

The skin is the largest organ of communication and social interaction, and a vital one. Dermatological conditions at any point in life can be associated with disruptive or damaging experiences for the self, and with serious psychiatric morbidity and impact on quality of life (Gupta 2005; Picard et al, 2000). By understanding the impact and phenomenology of vitiligo in men, i.e. knowledge of the changes in their sense of self, the way they view their condition, the distress they experience and how they relate to others, health professionals would improve the assessment and management of skin disorders. In this way, knowledge of underlying mechanisms affecting not only adjustment, but possibly the severity of the dermatological condition itself could result in better client care.

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LIST OF APPENDICES

APPENDIX A: Recruitment Poster

APPENDIX B: Participant information sheet

APPENDIX C: Consent form

APPENDIX D: Interview schedule

APPENDIX E: Debriefing sheet

APPENDIX F: Distress protocol

APPENDIX G: List of useful services

APPENDIX H: Extract from a transcript

APPENDIX I: Master themes

DO YOU HAVE VITILIGO?



- **ARE YOU MALE?**
- **18 YEARS OF AGE AND OVER?**
- **WERE YOU DIAGNOSED WITH VITILIGO OVER 3 YEARS AGO?**

IF YES TO ALL OF THE ABOVE, THEN PLEASE READ ON.....

My name is Sarah Jane Khalid and I am currently studying towards a Professional Doctorate in Counselling Psychology at the London Metropolitan University.

My research focuses on how vitiligo affects men. Your participation in the study would involve sharing your experience with me through an interview lasting approximately one hour.

University Ethical Approval has been gained for this study.

If you are interested in participating or would like to know more about the study please contact me on: [REDACTED]

Email: [REDACTED]

Or my supervisor: Dr Anna Butcher

Email: [REDACTED]

Telephone number: [REDACTED]

THANK YOU FOR TAKING TIME TO READ THIS POSTER

PARTICIPANT INFORMATION SHEET

Study Title: An exploration of men's subjective experiences of vitiligo: A qualitative study

You are invited to participate in a research study. I am looking for men who are aged between 18 and 30 years and who have had a diagnosis of vitiligo for more than three years and less than eight. Before you decide whether you would like to take part or not, it is important that you understand why the research is being carried out and what it will involve. Please take time to read the following information carefully. I would be happy to discuss any aspects of the study with you. If you have any questions or require more details, you are welcome to contact either myself, or my Research Supervisor (contact details are provided below). Please take your time in deciding whether you would like to take part or not.

Purpose of the study

This research is being carried out as part of a Professional Doctorate Course in Counselling Psychology. The intention of the study is to explore men's experiences of vitiligo and to investigate how men deal with this skin condition in everyday life. You will be able to share your experiences of vitiligo and how you cope with the vitiligo through an interview with me. You will also be asked about any forms of support that you currently access, as well as your views/feelings about professional health services.

I am interested in understanding participants' experiences and seeing whether any common themes or issues arise. It is hoped that the results of the study will help develop a better understanding of the ways in which UK health services may help men living with vitiligo.

Am I obliged to take part in the study?

Participation in this research is voluntary. If you choose to participate, you will be asked to sign a consent form. However, you have the right to withdraw from the study at any time. If you decide to do so from the study following the interview, you will have up to two weeks to do it. This means that any information that you provide will be destroyed.

What happens I decide to take part in the study?

If you are interested in taking part in this study then you can get in touch by phone or email using the details on the next page. I will contact you to further explain the purpose of the study and to arrange a suitable time to meet where consent for the

participation will be gained. There will also be an opportunity for you to ask any questions you may have. The interview will be conducted by me and will last approximately 45-60 minutes. I will ask you a series of general questions about your experience of vitiligo.

What about confidentiality?

With your permission, the conversation will be voice-recorded and transcribed. The transcripts will be anonymised and returned to the participants to ensure they are satisfied with the details included. Anonymised extracts may be incorporated in a report of the results and may be used if this research is published in a journal. These extracts will also be accessible to other individuals, such as the Research Supervisor and other tutors who will be formally assessing the report. However, you will remain completely anonymous i.e. your name and identity will not at any point be made available and will be kept separate from the findings of the interview. No one will have access to this information except myself.

All the information that you provide will be secured in a locked computer file and any hard copies will be stored in a locked cabinet. The tapes used during the conversation will be destroyed following transcription once the study has been assessed and marked. Transcripts of the conversation will be kept for a maximum period of 5 years in case the study is published and will then be destroyed.

Costs

The study will take place within the premises of London Metropolitan University in Calcutta House. You will be fully reimbursed for your travel expenses and will be given a £10 gift voucher for your participation.

Risks

While it is anticipated that there is no serious risk involved in participating, given the personal nature of the issues you will be discussing in the interview, it is possible that you may experience difficult thoughts and feelings. If you wish, you may take small breaks during this period to help you feel more relaxed. In order to ensure that your well-being is safeguarded at all times, both you and I will have the right to end the interview if you become unduly distressed whilst talking about your experiences.

Information will be provided to you regarding appropriate forms of help that you can access if upsetting feelings are evoked during the process. Help will include local counselling/therapy and general support services.

Making a complaint

If you wish to make a complaint about any aspect of the study, please contact my Research Supervisor:

Supervisor's name: Dr Anna Butcher

Email: [REDACTED]

Telephone number: [REDACTED]

What about the findings of the study?

If you wish to obtain a copy of a summary of the findings, please provide your contact details. These details will be held separately from our transcribed conversation. The results of the study may be published in a journal. However, no information identifying you as a participant will be included.

Your contribution to the study

Your contribution will be invaluable, as it will offer information to different health professionals who work within health services that are essential for developing and providing appropriate support services to those who have vitiligo. Dermatology is currently being restructured within the NHS, but it is still unclear how the new dermatology services will be shaped. The NHS is under pressure to make economies and it is more likely that “soft” areas, such as dermatology, will be targeted. The Vitiligo Society has been playing an active role in the Dermatology Council for England and supports a manifesto, which has been submitted to the government as part of the white paper consultation process. Within their key manifesto defining requirements in skin care they demand that *all* dermatology services should provide holistic support, treatment and care. Moreover, in order to achieve gold standard status, all services must offer access to psycho-social support, including specialist nurses, camouflage services and where appropriate, counselling and psychotherapy. I sincerely hope that by carrying out this piece of research I can add research evidence to this argument and provide psychological care that is much needed for this skin condition.

I am happy to respond to any further questions or queries that you may have.

Many thanks,

Sarah Jane Khalid

Counselling Psychology Trainee and CBT Psychotherapist

My mobile phone number: [REDACTED]

Email: [REDACTED]

Supervisor’s details are: Dr Anna Butcher

Email: [REDACTED]

Telephone number: [REDACTED]

APPENDIX C: Consent form

An exploration of mens' subjective experiences of vitiligo: A qualitative study

Researcher: Sarah Jane Khalid

CONSENT FORM

This consent form is to ensure that you are happy with the information you have received about the study. It is also important to check that you are aware of your rights as a participant and to confirm that you wish to take part in the study.

To be completed by the participant:

Please circle Yes or No

- Have you read and fully understood the information sheet?

Yes/No

- Have you had the opportunity to discuss further questions related to the study?

Yes/No

- Are you satisfied with the answers to your questions?

Yes/No

- Have you received enough information about the study to decide whether you want to take part?

Yes/No

- Have you understood that all information you reveal will be kept confidential?

Yes/No

- Have you understood that confidentiality will have to be broken if the information disclosed describes illegal activity (such as illegal drugs or involvement in terrorism) or likeliness to cause harm to self or to others?

Yes/No

- Do you understand that you are free to refuse to answer any questions?

Yes/No

- Are you clear that you have the right to withdraw from the study up to two weeks following your interview?

Yes/No

- Are you clear that both the researcher and the participant have the right to terminate the interview if undue distress is evident?

Yes/No

- Do you give consent for the researcher to audiotape the conversation and also for her to use verbatim quotations from your statements in the writing-up or publication of the study?

Yes/No

- Do you understand that you will have the opportunity to review transcripts from the interview yourself to ensure anonymity?

Yes/No

- If the results are published, do you understand that you will not be identified in anyway?

Yes/No

- Do you agree to your taped conversation and transcript being kept for up to a period of five years in case the study is published?

Yes/No

I agree to take part in the above study.

Name of Participant _____
Date _____
Signature

Researcher _____
Date _____
Signature

INTERVIEW SCHEDULE

PROMPTS

- **Switch on tape recorder**
- **Give overview of study & answer questions**
- **Indicate duration of the interview and what it will consist of. Explain to the participant that I am interested in their personal journey of having vitiligo.**
- **Ask to sign consent form**

1) I would like to start by asking you when you first learnt that you had vitiligo?

Use prompts if necessary:

- Who noticed your vitiligo?
- What kind of contact did you have with services? (GP/dermatology services)
- What if any alternative treatment did you seek?

2) Could you please tell me what it was like (i.e. your initial thoughts and feelings about) having this skin condition?

Use prompts if necessary:

- How did you feel when you were diagnosed with vitiligo?
- What were your concerns?
- How did people react to your vitiligo (e.g. family members/ work colleagues/ your partner/ your friends)?
 - How did they feel about your vitiligo?
 - What kinds of beliefs did they have, if any?
- How have strangers reacted to your vitiligo?
- What other things made you feel the way you did about your vitiligo? (e.g. do you know of other people who may have shaped how you feel)

3) Could you tell me how you see (appraise) / view your vitiligo today?

Use prompts if necessary:

- What do you make of it? (own understanding/beliefs why depigmentation has occurred)
- How do you see yourself in light of this condition?

- What sources of support do you have? (friends, vitiligo society etc)
- What influences your feelings about your vitiligo today?

4) Can you tell me how you manage with these problems?

Use prompts if necessary:

- What sorts of ways are you coping – physically: medical interventions/camouflage
- What ways are you coping? Avoidance /concealment/other safety behaviours
- What are your sources of support (e.g. self/partner/family member/religion/vitiligo society/other)
- Can you tell me your reasons for accessing/not accessing - medical/psychological support?

5) Can you tell me what, if any, the effect/impact your vitiligo has on your everyday routine?

Use prompts if necessary:

- Internally – how do you feel/think/ about your vitiligo
- Where do you feel this in your body?
- Others – how do people react around you? E.g. comments/ remarks/ views

6) Could you tell me if you have had any treatment for your vitiligo?

Use prompts if necessary:

- How successful has it been?
- How has the treatment affected your vitiligo?
- How has the treatment affected your view of your skin condition?
- (If treatment is skin bleaching) How do you see your cultural identity now?

7) Can you tell me if you've had any experience of accessing dermatological services?

Use prompts if necessary:

- What was it like?
- What was helpful?
- What was unhelpful?
- What were your expectations?
- Were there any difficulties that you faced?

8) Is there anything else that you feel I have failed to ask in this interview that you feel is important and would like to share?

WRITTEN DEBRIEFING SHEET

Title: An exploration of men's subjective experiences of vitiligo: A qualitative study.

Thank you for your participation in this study. This debriefing gives you the opportunity to learn more about this research study, how your participation in it has helped and why it is important.

There is growing evidence to suggest that psychological and social factors are linked with those who have skin conditions. There have been many studies in other skin conditions such as psoriasis and acne, but relatively few have been carried out on vitiligo. The research carried out so far looking at men and women who have vitiligo appears to be inconsistent and suggests the experiences are complex. Recent studies have used only female participants highlighting themes around difference, acceptance, coping styles and social support. As there has been no study in this area in understanding the male experience of living with vitiligo, my study is the first of its kind. Understanding your experiences and views of this condition is essential to my work as it can help develop psychological services in dermatology and raise awareness with health professionals in primary care (GPs, other doctors, counsellors, therapists).

I understand that it may be difficult at times to answer the questions that inform this research, and your generosity and willingness to participate in this study are greatly appreciated. I do however request that you do not discuss the nature of the study with others who may later participate in it, as this could affect the validity of the research conclusions.

Occasionally, people find the subject matter of these interviews difficult. If answering any of these questions has caused you any distress, anxiety or concern and you would like to speak to someone about your thoughts or worries, I am enclosing a list of counselling and support services that you may find useful.

As stated previously, the information that you provide will be held securely and will be accessed only by myself, my supervisors and those formally assessing the research. There will be no information that will identify you, as pseudonyms will be used. It may be possible that the results of this study are presented at academic conferences or published as an article in a journal. If you would like to receive a summary of the findings of this study or have any additional questions, you may contact either myself or my supervisor.

My contact details are: Sarah Jane Khalid

My mobile phone number: [REDACTED]

Email: [REDACTED]

Research Supervisor: Dr Anna Butcher
Email: anna.butcher@londonmet.ac.uk
Telephone number: 020 7320 1077

APPENDIX F: Distress protocol

Distress Protocol

This protocol has been devised to deal with the possibility that some participants may become distressed and/or agitated during their participation in my study. I expect that the interview may cause emotional discomfort because previous research has highlighted that this subject matter can evoke distressing feelings. This protocol outlines a three-step approach detailing the different levels of distress to which the researcher will be attentive and the action plan to put into place at each stage. I will monitor and manage situations where distress and any risk occur. It is hoped that extreme distress will not occur, and that the relevant action will not become necessary. However, it is included in the protocol and in case of emergencies where immediate support is unavailable.

Mild distress:

Potential signs:

- 1) Tearfulness
- 2) Voice becomes choked with emotion/difficulty speaking
- 3) Participant becomes distracted/restless

Action plan:

- 1) Ask participant if they are ok to continue
- 2) Offer them time to have a break so that they can compose themselves
- 3) Remind him gently that he can stop at any time he wishes if he becomes too distressed

Severe distress:

Potential signs:

- 1) Uncontrolled crying/wailing
- 2) Panic attack - e.g. hyperventilation, shaking, sweating, fear of impending heart attack
- 3) Inability to talk coherently

Action plan:

- 1) The researcher will intervene to terminate the interview
- 2) The debrief will begin immediately
- 3) Relaxation techniques will be suggested to regulate breathing/ reduce agitation
- 4) The researcher will recognise participant's distress, and reassure him that his reactions to such a disfiguring skin condition are natural. This is to ensure that his well-being is safeguarded at all times.

- 5) If any unresolved issues arise during the interview, accept and validate his distress, but suggest that he consults with mental health professionals as the interview is not designed for therapeutic purposes
- 6) Details of counselling/therapeutic services available will be offered to participants.

Extreme distress:

Potential signs:

- 1) Severe agitation/restlessness
- 2) Verbal or physical aggression

Action Plan:

- 1) Maintain safety of participant and researcher
- 2) If the researcher has concerns for the participant's or others' safety, she will inform them that she has a duty to inform any existing contacts they have e.g. with mental health services, such as a duty officer at a community mental health team or their local GP.
- 3) If the researcher believes that either the participant or another person is in immediate danger, then she will suggest that they present themselves to the local A&E Department and request for the attendance of a member of the on-call psychiatric liaison team.
- 4) If the participant is unwilling to seek immediate help and becomes violent, then the Police will be called and asked to carry out the Mental Health Act assessment. If suitable then the outcome would be to detain the participant and take them to a place of safety. (Please note that this action would be used in an extreme emergency).

APPENDIX G: List of useful services

LIST OF USEFUL SERVICES

IF YOU REQUIRE COUNSELLING OR SUPPORT FOR ANY ISSUE YOU MAY CONTACT ANY OF THE FOLLOWING ORGANISATIONS:

MENTAL HEALTH SUPPORT/GUIDANCE

The Vitiligo Society

125 Kennington Road, London SE11 6SF

Freephone: 0800 018 2631

They help people to deal positively with their vitiligo by offering information on all aspects of vitiligo via a free information helpline, an interactive website, regular newsletters and events for their members. Their aim is to help people cope better with the psychological, social and physical impacts of the condition.

Changing Faces

Changing Faces, The Squire Centre,

33-37 University Street,

London, WC1E 6JN.

Tel: 0845 4500 275

Fax: 0845 4500 276

Changing Faces is a UK charity that supports and represents people who have disfigurements of the face or body from any cause.

Mind

15 – 19 Broadway

London E15 4BQ

Tel: 020 8519 2122

Email: contact@mind.org.uk

Website: www.mind.org.uk

Has a confidential helping line. Local Mind Associations provide services such as counselling, advocacy, befriending and support on a wide range of mental health issues.

Samaritans

Offers a 24 hour counselling help-line service.

Tel: 08457 90 9090

Email: jo@samaritans.org.uk

COUNSELLING/PSYCHOTHERAPY

British Psychological Society

St Andrews House

48 Princess Road East

Leicester LE1 7DR

Tel: +44 (0)116 254 9568

Fax: +44 (0)116 227 1314

Website: <http://www.bps.org.uk>

Provides details regarding qualified psychologists trained in a variety of methods/approaches in UK.

The British Association of Behavioural and Cognitive Psychotherapies (BABCP)

Cognitive Behavioural Therapy (CBT)

Globe Centre, PO Box 9

Accrington, BB5 2GD

Tel: 01254875277

Website: www.babcp.co.uk

Provides details regarding qualified Cognitive Behavioural Therapists in UK.

British Association for Counselling and Psychotherapy (BACP)

BACP House,

35 – 37 Albert St,

Rugby, Warwickshire

CV21 2SG.

Tel: 0870 443 5252

Website: www.bacp.co.uk

Offers CBT, counselling, group therapy and psychotherapy

UK Council for Psychotherapy (UKCP)

167 – 169 Great Portland Street

London W1W 5PF

Tel: 0207 326 3002

Website: www.psychotherapy.org.uk

Offers CBT, couples, family, group therapy and psychotherapy

Dermatology

British Association of Dermatologists

Willan House
4 Fitzroy Square
London
W1T 5HQ
Tel: +44 (0)207 383 0266
Fax: +44 (0)207 388 5263
Email: admin@bad.org.uk

YOU MAY ALSO CONTACT YOUR GP IN ORDER TO ACCESS FREE
COUNSELLING AND PSYCHOLOGICAL SUPPORT.

This list has been compiled by referring to a variety of sources taken from the internet.

APPENDIX H: Extract from a transcript

	65	I: How did you...how was your family? How did your family react to it?	
Covered up to family with clothes	66 67 68 69 70	R: Well they never really...they never said anything and I think the transition between me actually stopping going in the sun, if you like, and it happening they never really...because I always kept pretty much covered up. I've never been one for t-shirts and that sort of thing. So I also had, you know, kept long sleeves so that the change was a bit blotchy.	Family did not ever say anything. He kept out of the sun and did not expose his skin to the family or to the sun. Always kept covered up where he was blotchy.
	71	I: Yeah.	
Vitiligo silences family	72 73 74	R: And then it just sort of went. And then, ah, but they were, nobody on the family side, they'd say oh well, you know, that ...they'd never say urgh what's wrong with you or anything like that. They just didn't really comment about it.	No-one in the family would not say anything to him. Family did not make a big deal about it.
	75 76	I: What was...when you noticed the patches could you tell me about whether you sought any medical advice at that time?	
Just have to live with it. Sought no treatment. Phantasies of reading about a cure Tanned-others expectation	77 78 79 80 81 82 83 84 85 86 87 88 89 90	R: Yeah well then I went to the doctor a bit later, not at the time because there was no pain and I think I went and said what can you do about this? I think the doctor said nothing, it's incurable you just have to put up with it. [pause] I thought okay great. So from that point on I didn't do anything about it. I've never had any treatment. I've never been to any of these...I mean you read the Vitiligo news and they've got this that and the other going on but as far as I was concerned I was past that. Even today I don't know if anything would be any good for me as far as I'm concerned. Reading that's my only link to vitiligo now is what I read. You know you'll open up the ... and hope oh they've got a miracle cure overnight. But it's never there. So you, um, you just accept that you are what you are. I mean you would love to just be able to go and have an instant tan, you know, because it's what people expect you to have. They expect you to look healthy and, ah, [laughs] whatever.	Sought medical treatment later as there was no pain. When he did see a medic they could not help and said he just has to live with it. Listened to what the doctor said and just got on with it- did not explore other options. Never had any treatment. Shut down to any possibility of treatment. Is unsure whether there would be any benefit to his vitiligo to reduce. Phantasies of opening up the vitiligo magazine and wanting to read about a cure. There is never a cure though. So he accepts how he is. He would love to go and get an instant tan. Other's expect you to have a tan. Tan is associated with a good health.
	91	I: Where do you think those messages are coming from?	
Beautiful and tanned – look the package	92 93 94 95 96 97 98 99 100 101 102 103 104	R: Oh the media and everything. It's just such a...the celebrity world we live in now, I mean years ago when I used to watch Top of the Pops for instance, you used to have these ugly people on there. You know loads of ugly people doing some stupid joke song that people would buy and that was fine. Then you wouldn't get that anymore because everyone has to look like they come out of a beautiful tanned, um, you know package. So you're slim, you're tanned, you've got lovely teeth, you've got lovely hair and you dance and you can sing, well you don't have to sing but you can...and that's what people look at. And that's what they perceive to be nice. And it's the same, you know, women have it, men and women have it and it's the same. I mean you can get away more with it probably as a man not being quite so gorgeous. But even so, people still expect you to look, you know, The Only Way is Essex look you know. That's what it's expected to be. And I think because I'm now 52 and I'm married and I've got a family and I don't	Messages are coming from the media. A celebrity pressures. When he was younger he would watch music programmes where there were ugly people on there. Times have changed, people need to look the package. Tanned and beautiful. Slim, tanned, lovely teeth, hair and dance and

Age- not so many pressures	105 106 107 108 109	really have to worry so much about that. But I always think for my kids, you know, you know if they were in my position now how much pressure they would be under to be, you know, the normal look or the perceived to be pretty look because that's what people expect now and I think it's even worse now for anyone to have a disfigurement or something different. You either get pointed at or laughed at. People will feel sorry for you but they will still stare at you and I think everyone will do anything they can just to get that normality back because everyone tries to make themselves look nice.	can sing. Other perceives it as nice. Same for both genders, maybe a little less for men. In that they can get away with a little less, men are less gorgeous than women.
These times are hard – pressure to be normal and pretty	110 111 112 113 114 115 116 117	Whether you make yourself up or do your hair, everyone tries, most people anyway, to make an effort leaving the house, it's just personal pride. [pause] But then lump into that the fact that you've got this other problem as well, you know. I mean I've got, um, osteoporosis as well. You know, whether that's from not going out in the sun I don't know but it's just one of those things. But all the things, I've had many ailments over the years, you know, autoimmune things, I've collected them up and I've got - started with vitiligo [and colitis] as well as rheumatoid arthritis now, you know, Crone's Disease, I've had them all. So they're all as far as I'm concerned my body just tries to attack it all the time. And that was the first thing that came up, and it's just unfortunate but coming back to the whole psychological thing, you know, it was I think lucky I got it when I was old enough [phone rings] it wouldn't be so bad if I'd have had it when I was, ah, 20 something you know and it would have just gradually got...but because I was just at that sort of puberty time as well – probably that's got something to do with it as well I don't know. But, um, no I think for me because I was able to sort of not have it and not show up because I'm not you know from the coloured, you know my skin is not generally coloured and I really feel sorry for those people who can't...really don't have an option, you know, you are...so I was, in a way you had a bad time, oh no the summer's coming up. But when I think about people who've got it all year round then I think actually I'm quite lucky.	Other's expectations of looking the perfect tanned and beautiful man. However, due to his age, these pressures do not apply so much, as he is married and has a family. But puts himself in the children's position and thinks about the amount of pressure that they are under to look "normal" or "pretty" – these times are even harder especially if there is disfigurement/ difference. People will try hard to reduce the stares and look normal. Others feel sorry for disfigurement. Personal pride to look good. On top of physical health conditions, namely autoimmune problems. He got his vitiligo when he was in puberty which felt difficult. There wasn't a stark contrast due to his light skin. He feels sorry for those that are darker who have it all year round rather than just in the summer time. When he reflects on that then he feels quite lucky.
Try to "look normal" and fit in.	118 119 120 121 122		
Worse for darker skinned people.	123 124 125 126 127		
Hard during summer	128 129 130		
	131	I: Yeah.	
	132	R: So [laughs] it's a bizarre way of looking at it but there you are.	Feels like it is a strange way to look at it. Glad he is not darker.
	133 134 135	I: So how was, could you tell me a bit more about as you then got in your late teens to early adulthood, how, um, how you found managing vitiligo back then?	
Genitalia different – remark made. Cope by laughing-disgust	136 137 138 139 140 141	R:It was more, as I said, when your, your genitals have gone different colours and then you're trying to be Mr. Cool with the ladies and it's very difficult because you end up with...I remember being with someone and saying oh it's, I've got a 2 toned [laugh] making some sort of light of it but deep down you're thinking I don't really want to actually go as far as to show these people because it's going to put them off. So that'swhere ...	Genitals have gone a different colour is very difficult as a woman did remark that it was 2 different colours. Tried to cope by laughing it off – however he was

			fearful that they will be put off by it.
	142	I: Yeah.	
Limits sexual relations	143 144 145 146 147 148 149	R: And it's, um, that straightaway limits how much you're prepared to go in a, you know, sexual sort of thing. So already you're backed up, you know, I don't, I don't actually want to sort of have as many girlfriends or go as far as I would with it because then I'm not prepared to show this. And again that cleared to all the same and you're back, you're happy again then because you're all the same colour. And so your skin was at its worst at probably about 15 no 16, 17 and it was very blotchy.	Limits the physical relationships. Vitiligo backs you up against a corner. Doesn't want to show his genitalia to lots of girls. All the skin on his penis lost its colour. The worst time of it being different was 15-17 years old.

APPENDIX I: Master themes

Superordinate Themes	Sub-themes
1: Processing the vitiligo <i>diagnosis</i>	Acknowledging the reality of vitiligo
	Feeling unseen during the medical interface
	Feeling helpless; ‘just live with it’
2: Focus on self	Living with an unwanted self
	Managing distress and shame; ‘dirty little secret’
	Perception of self
3: Managing relationships	Patterns of behaviour
	‘Fear of being ridiculed, rejected’
	‘Lucky to be light’; comparing with others