Exploration of the Experience of Living with a Skin Condition with a Focus on Stigma

A thesis submitted in partial fulfilment of the requirements for the Doctorate in Clinical Psychology

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Declaration

This thesis has not been submitted to any other institution, or for the purpose of obtaining any other qualifications

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Lay Summary

Previous research has shown that psychological effects of living with a skin condition, such as psoriasis, are common. Survey data has limitations in how much it can understand this lived experience. Part one of this thesis comprises of a systematic review and synthesis of qualitative research (research that collects rich information about experience via methods such as interviews and focus groups). The focus was on research in to the experience of living with psoriasis. Twenty-two studies were included and their data were analysed using a method called thematic synthesis. Themes identified in the data described experiences of psoriasis as an uncontrollable force, and the impact of psoriasis on people's emotional expression and sense of self. Further themes detailed the experiences of stigmatisation in people with psoriasis and how this led people to have a reduced social life. Coping was identified as a major theme in the data, with some coping strategies having a negative impact on quality of life. Activities of daily living were identified as limited in people with psoriasis. Finally, themes were identified that acknowledged the challenge of coping with burdensome treatment and varying experience of healthcare systems.

The second part of this thesis outlines a research project conducted to explore further the effects of stigmatisation in people with a range of skin conditions. It aimed to investigate the relationship between stigma and wellbeing in people with skin conditions and to identify whether being more psychologically flexible interacted with any relationship between stigma and wellbeing. Psychological flexibility is a concept from Acceptance and Commitment Therapy that encompasses the ability to separate from ones' thoughts and be in the present moment to engage in activities in line with your values. A survey study was conducted with 105 people with skin conditions who attended outpatient services. Measures of anxiety and depression symptoms, self-rated health, feelings of stigmatisation, and psychological flexibility were completed. Relationships between these concepts were analysed using the statistical techniques of regression, moderation, and mediation analysis. Increased feelings of stigmatisation were found to relate to increased anxiety and depression, and lower levels of self-rated health. Mediation analysis indicated that feelings of stigma were related to poorer outcomes on these wellbeing measures, at least in part, due to a relationship between stigma and psychological flexibility. Increasing psychological flexibility, for example via an Acceptance and Commitment Therapy intervention, could therefore be beneficial to people living with skin conditions experiencing the negative effects of stigma.

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Section 1

Literature Review

The Experience of Living with Psoriasis: a Meta-Synthesis

Abstract

Objectives

Quantitative research has identified significant areas of difficulty for people living with psoriasis and indicated that psychological variables are important in understanding this experience. This meta-synthesis aimed to identify, evaluate, and synthesise qualitative studies to gain a richer understanding of the experience of living with psoriasis.

Design and Methods

Three databases were systematically searched for qualitative studies that explored the experience of living with psoriasis. Twenty-two studies met criteria for inclusion and were critically appraised. Data were extracted and analysed according to thematic synthesis.

Results

Analysis resulted in seven superordinate themes and twelve subthemes: psoriasis as an uncontrollable force; impact on the self and self-image (altered mood and identity and a need to hide); the social effects of stigmatisation (experienced or expected negative reactions and a reduced social life); finding ways to cope; impact on daily activities (physical burden and limited activities); experiencing the healthcare system (dissatisfaction, relationships with staff, and a wish for knowledge); coping with the burden of treatment (treatment as burdensome, varying opinions of treatment, and taking control of treatment).

Conclusions

The meta-synthesis found psoriasis to be a biopsychosocial experience with wide-ranging effects on quality of life. Findings are discussed in the context of theory on illness representations, coping, and adjustment. The visible nature of psoriasis and subsequent feelings of stigma are highlighted as central to the experience of living with psoriasis, and provide indications for future research.

Limitations

- One researcher completed the data analysis
- A second rater reviewed the quality appraisal of only approximately 25% of papers
- Papers not in English language and "grey" literature were not included

Practitioner Points

- People with psoriasis experience biopsychosocial effects on their lives; the importance of psychosocial difficulties should not be overlooked.
- People with psoriasis share dissatisfaction with health services; consultation with patients when planning services could improve satisfaction.
- Further exploration into stigmatisation and its links to psychological wellbeing could provide insights in to how to better support people with psoriasis.

Keywords

Psoriasis, Skin, Dermatology, Meta-synthesis, Qualitative Research

Introduction

Psoriasis varies in its presentation and severity, however, it is a condition characterised by red or pink “plaques” on the skin, covered by white “scales”; it can present acutely or chronically (Griffiths & Barker, 2007; Langley, Krueger, & Griffiths, 2005). The primary physical symptoms of psoriasis are pruritus and a burning sensation (Langley et al., 2005). Psoriasis presents in populations worldwide and its prevalence ranges from 0.2% to 4.8% (Gudjonsson & Elder, 2007). A proportion of people with psoriasis will develop psoriatic arthritis, which can lead to functional difficulties and requires further treatment. Psoriasis is most likely to appear during teenage and early adult years (Gudjonsson & Elder, 2007), and thus has the potential to impact upon identity and intimate relationship building (Erikson, 1994). For most people, psoriasis becomes a chronic condition which follows a lifelong “waxing and waning” disease course (Gudjonsson & Elder, 2007). In the United Kingdom, The National Institute for Health and Care Excellence (NICE) recommends that topical therapies are used as first-line treatment for psoriasis (NICE, 2017). Topical treatment involves the frequent application of creams, oils and/or gels. Secondary to this, practitioners can offer phototherapy or systemic therapy (medication given orally or via injection; NICE, 2017).

Psychological Impact

Survey studies have found psoriasis to effect quality of life in numerous areas; this includes physical discomfort and pain, emotional difficulties, poor body image, limited activities, and interference with work commitments (e.g. Armstrong, Schupp, Wu, & Bebo, 2012; Darjani et al., 2014; de Korte, Mombert, Bos, & Sprangers, 2004). In a survey study involving 17,488 patient members of the National Psoriasis Foundation, 79% of respondents reported psoriasis had a negative impact on their lives (Krueger et al., 2001). This study concluded that psoriasis affected people’s emotional, social, and physical quality of life. People with psoriasis have been found to report a reduction in physical and mental functioning comparable to the effects of long-term conditions such as cancer, heart disease, diabetes, and depression (Rapp, Feldman, Exum, Fleischer, & Reboussin, 1999). Rapp et al. conclude that although psoriasis is not threatening to life itself, it is debilitating both physically and emotionally, and can threaten the quality of life.

Gupta, Schork, and Gupta (1993) reported an increased likelihood of anxiety and depression disorders, and suicidal ideation in people with psoriasis. There are also reports of psychosocial difficulties, such as avoidance of social situations and concerns of evaluation by others based on skin appearance (Griffiths & Richards, 2001).

It is essential to use a biopsychosocial model to fully understanding the impact of health conditions such as psoriasis (Wade & Halligan, 2017). Health psychology literature has developed models that aim to capture the experience of living with an illness or chronic condition. These models consider mental processes as intertwined with the physical aspects of illness (Walker, 1999). One model that has been applied to psoriasis is Leventhal’s Common Sense Model of illness representation (e.g. Scharloo et al., 1998). This model proposes that people’s perceptions of their illness directly influences their style of coping and, in turn, their health outcomes (e.g. Diefenbach & Leventhal, 1996). Research has identified that people cognitively represent illness dependent on five areas: identity (description of symptoms), timeline (how long the illness will last), consequences of the illness, amount of control over the illness, and beliefs about cause of the illness (Broadbent, Petrie, Main, & Weinman, 2006). More recently, Broadbent et al. (2006) added further components to the model that consider emotional responses to illness and how well someone understands their condition. In psoriasis, research by Scharloo et al. (1998; 2002) has found that illness representations of psoriasis that include a strong identity, long duration, and strong consequences were associated with worse day-to-day functioning and mental health outcomes. In support of this, Fortune, Richards, Griffiths, & Main (2002) found that increased stress, distress and disability related to beliefs that psoriasis has strong consequences and a stronger illness identity. Fortune et al. also found that a belief in an emotional cause of psoriasis related to poorer emotional and physical outcomes. Fortune, Richards, Main, & Griffiths (2000) found an association between pathological worry and illness perceptions in psoriasis patients, particularly beliefs that used self-blame as an explanation for the cause of psoriasis. The quantitative research therefore suggests links between representation of illness and psychological and physical outcomes.

Psychological theory has attempted to define types of coping with distressing experiences, for example, Lazarus and Folkman (1984) distinguished between emotion- and problem-focused coping strategies. Studies exploring coping in psoriasis have found that use of avoidance and other emotion-focussed coping strategies predicts higher anxiety, more disability, and worse health-related quality of life (Fortune, Richards, Main, & Griffiths, 2002; Miniszewska, Juczyski, Ograczyk, & Zalewska, 2013). Conversely, less use of coping through problem-focussed coping strategies (e.g. reappraisal) was associated with higher depression scores. Scharloo et al. (2002) found that people with psoriasis who coped by seeking social support and using distraction had better physical and mental health one year later. Coping is therefore indicated as influencing wellbeing outcomes in psoriasis; however, the mechanisms of these relationships have not been fully identified by quantitative studies.

Survey-based studies have begun to demonstrate the importance of psychological variables in conceptualising the experience of living with psoriasis, however, quantitative research does not allow for a rich exploration of the experience of people with psoriasis. It can also be constrained by research designs that only measure concepts selected by the researcher. In this regard, exploratory qualitative research can provide a valuable contribution to the field.

Aims of the Review

The aim of this review is to identify, evaluate, and synthesise qualitative studies that have investigated the experience of living with psoriasis. Increased understanding of the experience of living with psoriasis has the potential to highlight barriers to accessing treatment, and increase empathy amongst healthcare providers (Kreueger et al. 2001). More research in to psychological interventions for people with dermatological conditions is required (Lavda, Webb, & Thompson, 2012). Therefore, this meta-synthesis also aims to inform areas of concern that could be targets for psychological interventions.

The reported meta-synthesis uses thematic synthesis. Thematic synthesis is founded in the epistemological stance of critical realism. Critical realism states that our perceptions and beliefs mediate knowledge of reality (Barnett-Page & Thomas, 2009). The choice of thematic synthesis facilitates flexibility in interpretation and prevents a pre-selected theory/framework masking novel themes or interpretations. This approach enables detailed themes to be built from the data. The aim is that by creating such themes, thematic synthesis creates a “'whole', which is more than the sum of its parts” (Barnett-Page & Thomas, 2009).

Method

The protocol for this review was registered on PROSPERO, an international prospective register of systematic reviews (reference: CRD42019128237).

Search Strategy

The electronic databases SCOPUS, MEDLINE and PsycINFO were searched on 17th December 2018 using the search terms outlined in Table 1. There was no date boundary applied.

Table 1
Search Terms

All databases	“psoriasis” AND “perception*” OR “experience*” OR “view*” AND “qualitative” OR “findings” OR “interview*”
MEDLINE additional subject heading	“qualitative research”
PsycINFO additional subjects	“world view”, “qualitative research”

Inclusion and Exclusion Criteria

Articles were deemed to meet inclusion criteria if participants were adults living with psoriasis (over 18) and if the article included original qualitative findings. Articles were excluded if the experiences explored were solely about a specific medical treatment or service, could not be accessed in English, or were reviews or meta-syntheses.

Screening Method

The lead reviewer screened titles and abstracts for eligibility after the removal of duplications. They reviewed full-text articles and conservatively removed those not meeting criteria. Ancestry and citation searches were performed on remaining studies. A second researcher co-reviewed remaining full-text studies and came to consensus with the author about inclusion. Twenty-two studies were accepted for the meta-synthesis. Figure 1 shows a PRISMA diagram summarising the searching and screening process. From initial screening of papers, it was not deemed necessary to contact experts or search individual journals for any further papers; however, this could be seen as a limitation of the search strategy.

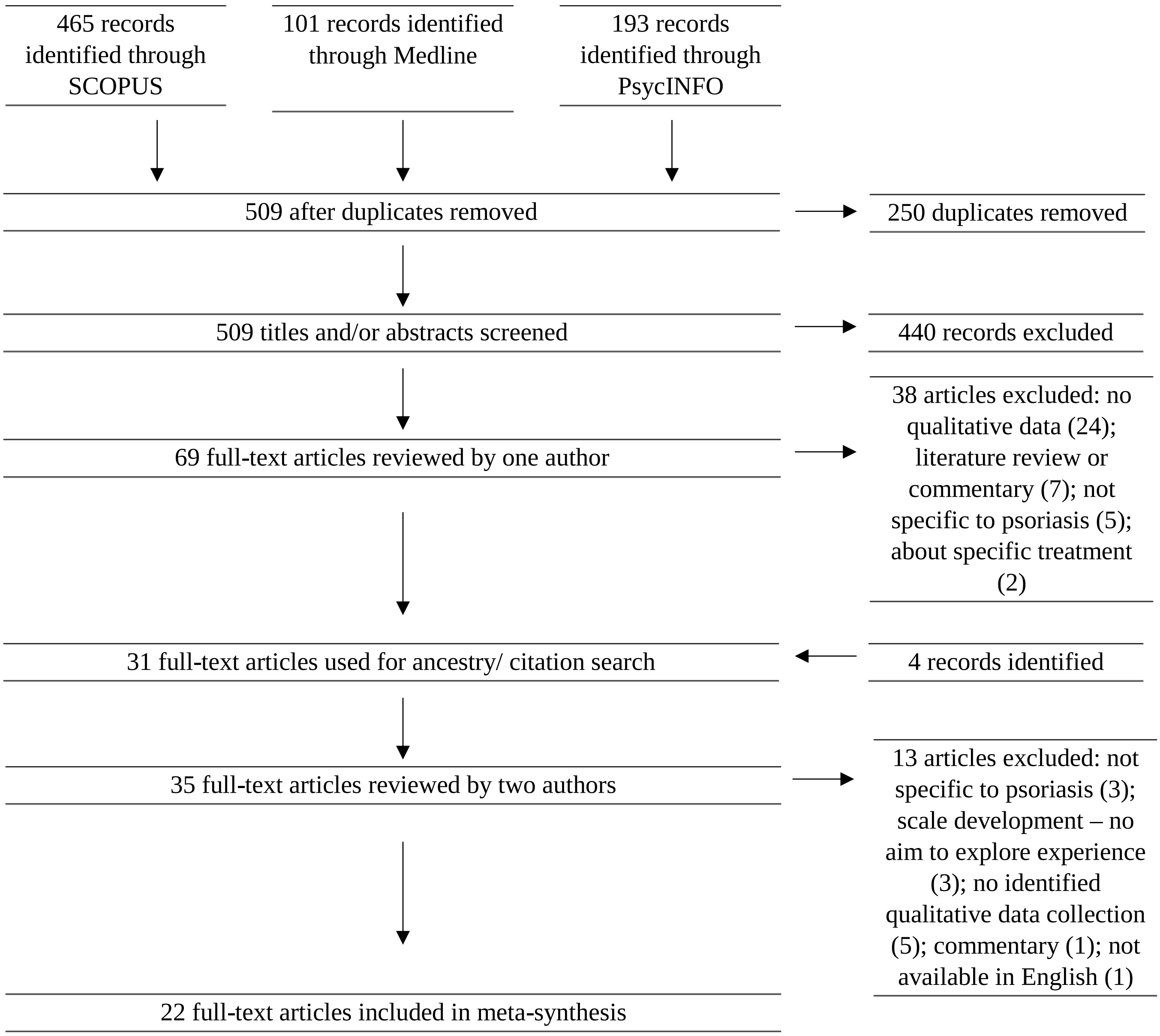


Figure 1: PRISMA diagram (adapted from Moher, Liberati, Tetzlaff, & Altman, 2009)

Table 2

Critical Appraisal Skills Programme (CASP) Criteria for Qualitative Studies

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been take into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Quality Appraisal Method

The Critical Appraisal Skills Programme (CASP) criteria for qualitative studies were used to assess quality (CASP, 2017; see Table 2). CASP tools provide a framework for appraising the quality of published studies. CASP authors do not recommend applying a numerical scoring system to the tool (CASP, 2017). Each study included in the meta-synthesis was given a rating of “poor”, “moderate”, or “high” quality on each criterion. Studies were also given an overall rating, determined by the rater, who considered the relative “weight” of the strengths and weaknesses highlighted by use of the CASP tool. An independent rater reviewed approximately 25% of the included studies, and discussed disagreements with the lead reviewer to support consideration of accuracy and objectivity of appraisal.

Synthesis Method

Synthesis was in the form of an aggregative thematic synthesis. Based upon the method outlined by Thomas and Harden (2008), contextualised qualitative data was systematically extracted and organised under tentative initial codes generated inductively. Codes were grouped in to themes and sub-themes. As themes were identified these were checked against raw data to ensure they were firmly grounded. Researchers can unintentionally influence their findings due to their personal and professional characteristics and background, particularly in qualitative research (Mruck & Breuer, 2003). A reflective log was therefore kept during the research process to support consideration of reflexivity.

Table 3

Overview of Included Studies

Author and Aims	Year	Country	Population	N	Age Range	Qualitative Methodology	Data Collection Method	Main Findings/ Themes
Campbell, Warburton, Amos, & Roland To describe the impact of psoriasis on patients' lives and patients' perceptions of the role of the general practitioner	1996	UK	Patients with psoriasis from GP practise list	24	-	Content analysis	Interviews	Psoriasis has a psychological impact. Loss of self-esteem. Coping often by avoidance. Treatment a burden. Doctors not supportive.
Wahl, Berit, & Hanestad To understand the experience of living with psoriasis	2002	Norway	Hospitalised patients with severe psoriasis in acute phase	22	20-80	Grounded theory	Interviews	Bodily suffering a core theme. Subthemes: the visible body, social vulnerability, staying on an even keel, and an all-consuming disease
Uttjek, Nygren, Stenberg, & Dufaker Find out how psoriasis can affect the individual's everyday life, and if there are any variations between gender	2007	Sweden	Unspecified (living with psoriasis)	18	37-54	Content analysis; Grounded theory	Semi-structured interviews	Most difficult aspect of psoriasis is visibility. Common coping strategies were routinisation, adjustment, and acceptance. Most experienced a good quality of life
Watson & de Bruin To describe the lived experience of men and women who suffer from psoriasis and the impact of psoriasis on their concept of self	2007	South Africa	Diagnosed with psoriasis	7	29-65	Existential phenomenology	-	Self-concept key to living with psoriasis; doctors' attitudes impact wellbeing, trait self-esteem relates to psychological recovery

Author and Aims	Year	Country	Population	N	Age Range	Qualitative Methodology	Data Collection Method	Main Findings/ Themes
Amatya & Nordlind Assess patients’ perspectives of pruritis in psoriasis vulgaris of plaque type	2008	Sweden	Chronic plaque psoriasis	20	30-55	-	Focus groups	Identified worsening and relieving factors for pruritis. For some, pruritis affected quality of life e.g. reduced social activities.
Globe, Bayliss, & Harrison Better understand the impact of psoriasis	2009	USA	Patients with mild-severe psoriasis from GP lists	39	20-74	-	Focus groups	Itch frequently reported as most important and problematic symptom of psoriasis; negatively impacted daily activities and emotions.
Magin, Adams, Heading, Pond, & Smith Examine the psychological effects of psoriasis in a broader range of subjects across differing stages of disease severity	2009	Australia	Patients of dermatology clinics and GPs	19	25-73	Modified grounded theory	Semi-structured interviews	Psoriasis related to low mood, anxiety, shame, low self-esteem, stigmatisation, avoidance, and altered sexuality. Psoriasis seen as incurable and this related to pessimism regarding treatment. Some reported personality change.
Ersser, Cowdell, Latter, & Healy To explore how adults with mild-moderate psoriasis manage their condition and identify strategies that can support people to self-manage effectively	2010	UK	Mild-moderate long term psoriasis	22	35-79	-	Focus groups	Participants found self-management difficult had low expectations of health care. Participants wanted more education, individualised treatment, and to have their expertise valued.

Author and Aims	Year	Country	Population	N	Age Range	Qualitative Methodology	Data Collection Method	Main Findings/ Themes
Uhlenhake, Kurkowski, & Feldman To determine whether physicians perspectives on communication with psoriasis patients match patients perceptions of that communication and their perceived needs and goals	2010	USA	Self-reported moderate to severe psoriasis	25	-	Thematic analysis	Focus groups	Patients want more information, fast treatments, clear expectations, and recognition of the emotional burden of psoriasis
Nelson, Chew-Graham, Griffiths, & Cordingley Explore perspectives of people living with psoriasis, including coping, self-care and how consultations with health care professionals experienced	2012	UK	Unspecified (living with psoriasis)	29	20-84	Framework analysis	Semi-structured interviews	Desire for the reality of living with psoriasis to be understood (stress, distress, stigma, and lack of control); desire for professional engagement with the effects of psoriasis; coping with psoriasis by disengaging with health care
Nelson, Barker, Griffiths, Cordingley, & Chew Graham To compare and contrast perspectives of people with psoriasis and GPs on the challenges of managing psoriasis in primary care	2013	UK	People with psoriasis in the community	29	20-84	Framework analysis	Semi-structured interviews	GPs seen as lacking in confidence and knowledge in treating psoriasis, patients dissatisfied, patients wished for shared management of condition

Author and Aims	Year	Country	Population	N	Age Range	Qualitative Methodology	Data Collection Method	Main Findings/ Themes
Bewley, Burrage, Ersser, Hansen, & Ward Identify issues faced by patients, as well as their current practices and beliefs relating to their psoriasis	2014	Canada, France, Germany, Italy, Spain, UK and US	Database of people with psoriasis	56	20-67	Ethnographic	Observation; semi-structured interviews	Disappointment with treatment and confusion/ lack of direction concerning psoriasis
Bundy et al. To understand patients' personal models of psoriasis	2014	UK	Members of psoriasis association, people in waiting rooms of outpatient clinics	92	-	Modified grounded theory, constant comparison, and thematic analysis	Asked to write a letter to psoriasis	Identity and relationships, battleground, control, emotional consequences, hypervigilance, coping, and treatment burden
Khoury, Danielsen, & Skiveren Explore the influence of psoriasis on patient body image using the Body Image Model	2014	Denmark	Attendants at outpatient department	8	21-59	Template analysis	Semi-structured interviews	Body coverage, sexual inhibitions, the influence of social support, reduced exercise and a negative self-image
Martin et al. To understand the relevance and consistency of experiences of pain and redness in psoriasis and evaluate content validity of Psoriasis Symptom Inventory items	2015	UK & Canada	Moderate to severe psoriasis	30	-	-	Concept elicitation and cognitive interviews	Pain and redness frequently reported in psoriasis

Author and Aims	Year	Country	Population	N	Age Range	Qualitative Methodology	Data Collection Method	Main Findings/ Themes
Ghorbanibirgani, Fallahi-Khoshknab, Zarea, & Abedi Describe and explain the social stigma and rejection experienced by patients with psoriasis	2016	Iran	Psoriasis patients referred to clinic and ward	15	18-58	Hermeneutic phenomenological approach, thematic analysis	Semi-structured interviews	Lack of social support, unrealistic and inappropriate labelling, rejection and isolation, feelings of absurdity and futility. These themes related to social stigma and rejection.
Pariser et al. Focus on reports of symptoms, experience with psoriasis treatments and impact of psoriasis and psoriatic arthritis on patients' lives and functioning	2016	USA	Moderate to severe plaque psoriasis	101	-	-	Semi-structured narrative interviews	Patients frequently reported flaking and itching; there was wide ranging social and emotional impact.
Cather et al. Identify key genital psoriasis symptoms and their impact on health related quality of life from the patients perspective	2017	USA	Dermatologist-confirmed genital psoriasis (moderate to severe)	20	21-68	Content analysis	Semi-structured interviews	Most bothersome symptoms itching and stinging. There was an impact on many areas of sexual health and experiences. Further impact on mood, daily activities, and relationships.
Khoury, Skov, & Moller Explore unmet needs and health perceptions of people with psoriasis, particularly experience of interactions with clinicians and hospital consultations	2017	Denmark	Moderate or severe psoriasis in outpatient clinic	16	18-69	Template analysis	Semi-structured interviews	Patients have strong need to be treated as individuals; the impact of psoriasis goes beyond skin; patients dream of a cure; they want more education

Author and Aims	Year	Country	Population	N	Age Range	Qualitative Methodology	Data Collection Method	Main Findings/ Themes
Simpson et al. To identify key factors influencing the health-seeking choices and map the health seeking pathway of patients with psoriasis	2017	UK	Referred to dermatology department	16	26-81	Thematic framework analysis	Semi-structured interviews	Triggers for health seeking: onset of psoriasis, knowledge of treatment options, influence from partners and friends, seeking help for other conditions, and presenting in extremis. Barriers: family experience, treatment dissatisfaction, lack of review, difficulty getting referral to secondary care, beliefs of tolerance, incurability, and that psoriasis not worthy of help
Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley To explore individuals' perspectives of their psoriasis, medications and its management	2017	UK	Diagnosis of psoriasis	20	21-71	Framework analysis	Cognitive interviews	Depletion of personal coping resources; conflict with the management of other illness tasks; adherence to medication; relationships with healthcare professionals as an additional stressor
Kouwenhoven, vender Loeg, & van de Kerkof To explore treatment goals in patients with psoriasis	2018	Netherlands	Attendants at outpatient clinic	15	18-71	Template analysis	Semi-structured interviews	Total skin clearance s common treatment goal. Barriers to goals were chronicity of psoriasis, lack of effective treatments and side effects of treatment

Results

Study Demographics

For a summary of demographic data extracted from the 22 included studies, see Table 3. Included research originated from 14 countries; data included in the review originates mostly from westernised, English-speaking countries, although there is some varietyThe severity of psoriasis varied between studies. Severity was not specified in 14 included studies. One study reported on mild-to-moderate psoriasis, five on moderate-to-severe psoriasis, one on severe psoriasis, and one paper included a range from mild-severe psoriasis. There was variety as to whether diagnosis and severity of psoriasis was based on self-report or confirmed by a physician.

Included studies recruited participants from outpatient dermatology departments (6), the community (4), GP surgeries (2), and an inpatient ward (1). Recruitment involved a mix of sources in five studies and four studies did not report recruitment source. Four studies also reported on physicians' experiences; this data was excluded from analysis (Globe, Nayliss, & Harrison, 2009; Nelson, Barker, Griffiths, Cordingley, & Chew Graham, 2013; Nelson, Chew Graham, Griffiths, & Cordingley, 2012; Uhlenhake, Kurkowski, & Feldman, 2010). Data collection comprised of interviews in 16 studies; four studies utilised focus groups. One study did not specify the data collection method (Watson & de Bruin, 2007). Bewley et al. (2014) utilised observation as well as interviews. Bundy et al. (2014) utilised a novel method in which participants wrote a postcard to psoriasis. Studies used a variety of data analysis methods (see Table 3). Five studies did not specify analysis method. Methodologies represented varying epistemological standpoints, which adds some complexity to synthesising findings (e.g. Atkins et al., 2008). Zimmer (2006), however, outlines that synthesising across methodologies can be appropriate and useful if researchers bring interpretative skill to the analysis. The current synthesis synthesises across methodologies, with the aim to benefit from the breadth of interpretative styles.

Aims of the included studies varied (see Table 3); all included an aim to explore experiences of living with psoriasis. Further to this aim, eight studies included a specific aim to investigate experiences of healthcare or treatment (Campbell, Warburton, Amos, & Roland, 1996; Khoury, Skov, & Moller, 2017; Nelson, Barker, Griffiths, Cordingley, & Chew Graham, 2013; Nelson, Chew-Graham, Griffiths, & Cordingley, 2012; Pariser et al., 2016; Simpson et al., 2017; Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017; Uhlenhake, Kurkowski, & Feldman, 2010). Two studies aimed to explore how patients manage psoriasis (Bewley, Burrage, Ersser, Hansen, & Ward, 2014; Ersser, Cowdell, Latter, & Healy, 2010). Other additional aims focused on the impact on concept of self (Watson & de Bruin, 2007), psychological effects of psoriasis (Magin, Adams, Heading, Pond, & Smith, 2009), body image (Khoury, Danielsen, & Skiveren, 2014), pain and redness (Martin et al., 2015), social stigma and rejection (Ghorbanibirgani, Fallahi-Khoshknab, Zarea, & Abedi, 2016), and health seeking (Simpson et al., 2017).

Quality Appraisal

Table 4 shows results from the quality appraisal. The tables colours indicate how well each CASP criteria was adhered to, and the overall quality rating (red = poor, amber = moderate, green = good). The majority of studies were categorised as “moderate” quality, three studies as “high” quality, and three as “low” quality. A second rater quality assessed a random selection of five studies (23%). Of the 50 criteria considered, there was disagreement on three. The second rater’s overall quality ratings of studies were identical to the first reviewer’s ratings, indicating no significant concern regarding accuracy of the quality appraisal.

Problems frequently raised in quality appraisal included sparse detail about research design, such as not specifying the analysis method, or not justifying the choice of method. Only two studies commented on reflexivity or the relationship between researcher and participants (Nelson, Chew-Graham, Griffiths, & Cordingley, 2012; Magin, Adams, Heading, Pond, & Smith, 2009). Included studies frequently had sparse discussion about the implications of the findings e.g. no recommendations for future research or clinical practice. Studies in the review generally showed good quality regarding clear aims, appropriateness of qualitative methodology, recruitment strategy, ethical consideration, and clear statements of findings.

Table 4

Results from Quality Appraisal Using the CASP Tool

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Campbell et al. (1996)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟧	🟩	🟧	🟧
Wahl et al. (2002)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟧	🟧
Uttjek et al. (2007)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟧
Watson & de Bruin (2007)	🟩	🟩	🟩	🟩	🟥	🟥	🟩	🟧	🟩	🟩	🟧
Amatya & Nordlind (2008)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟧	🟩	🟧	🟧
Globe et al. (2009)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟧	🟩	🟧
Magin et al. (2009)	🟩	🟩	🟧	🟩	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Ersser et al. (2010)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟩
Uhlenhake et al. (2010)	🟩	🟩	🟧	🟩	🟧	🟥	🟧	🟥	🟩	🟧	🟥
Nelson et al. (2012)	🟩	🟩	🟧	🟩	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Nelson et al (2013)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟩	🟩	🟧	🟧
Bewley et al. (2014)	🟩	🟩	🟩	🟩	🟧	🟥	🟥	🟧	🟩	🟩	🟥
Bundy et al. (2014)	🟩	🟩	🟧	🟩	🟩	🟥	🟥	🟩	🟩	🟩	🟧
Khoury et al. (2014)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟩	🟩	🟧	🟧
Martin et al. (2015)	🟩	🟧	🟧	🟧	🟧	🟥	🟥	🟧	🟩	🟧	🟥
Ghorbanibirgani et al. (2016)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟧
Pariser et al. (2016)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟩	🟩	🟧	🟧
Cather et al. (2017)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟧
Khoury et al. (2017)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟧	🟧
Simpson et al. (2017)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟧
Thorneloe et al. (2017)	🟩	🟩	🟧	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟧
Kouwenhoven et al. (2018)	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟧	🟧

* red = poor, amber = moderate, green = good

Reflexivity

As the lead reviewer of this study, I have a professional background in psychology and therefore a particular interest in psychosocial effects of living with a skin condition, I was concurrently involved in research in the area of stigma. These factors require that I consider potential attentional bias towards these areas in the processes of literature searching, data extraction, and interpretation, and/or quality rating. The reflexive log demonstrates awareness of these potential biases when extracting data and coding studies (see Appendix A). This awareness helped me to make efforts to code and included data in a range of areas. To minimise the chance of a biasing effect at literature searching, I consulted an academic librarian regarding the choice of search terms. I also consulted with a non-psychologist expert in qualitative research regarding methodology, coding, and the generation of themes. The second-rater for the quality assessment was unaware of my research interest in stigma, minimising the chance that this potential bias influenced their ratings.

Synthesis

Analysis of the data identified seven superordinate themes and twelve subthemes (see Table 5). Appendix B provides a table illustrating which studies contributed data to each subtheme. Appendix C shows a worked example of a superordinate theme and the codes that contributed to it, alongside example extracts from the data.

Table 5
Themes derived from the data

Superordinate themes	**Subthemes**	**Supporting quotation**
Psoriasis as an uncontrollable force	-	*"It can happen to anybody, at any time, you have got to live with it, there is no treatment" (Simpson et al., 2017, p.746)*
Impact on the self and self-image	Altered mood and identity	*"I think [psoriasis] is just your self-image. You think ''I can't be attractive because I look like this thing, like this leopard''" (Magin et al., 2009, p. 155)*
	A need to hide	*"I even hide the rash from my husband. Especially when I have lots of lesions." (Wahl et al., 2002, p. 255)*
The social effects of stigmatisation	Experienced or expected negative reactions	*"One of my friends told me: people say you're infected, for this reason people do not talk to you" (Ghorbanibirgani et al., 2016, p. 5)*
	A reduced social life	*"I want to be a positive person and talk to other people. But the psoriasis stops me from seeking the contact I want with others. I'm afraid of rejection" (Wahl et al., 2002, p. 255)*
Finding ways to cope	-	*'I suppose people with psoriasis just cope with it and get on with it because I think it's not life threatening and it is...it's just your skin looks yuck'(Simpson et al., 2017, p. 748)*
Effects on daily activities	Physical burden of psoriasis	*''You want to rip your skin off because it's just so irritated'' (Pariser et al., 2016, p. 22)*
	Limited activities of daily living	*"I am thinking of things I used to do every day, and that I might not be able to do them anymore and that can be very hard" (Uttjek et al., 2007, p. 367)*
Experiencing the healthcare system	Dissatisfaction with the healthcare system	*"There's never any offer of regular consultation. You go once, they look you up and down and say ''you've got psoriasis – have some cream''"(Nelson et al., 2013, p. 358)*
	Relationships with healthcare staff	*"Acknowledging that it can affect your confidence and some reassurance [from specialist nurse] was really helpful" (Nelson et al., 2013, p. 357)*

Superordinate themes	**Subthemes**	**Supporting quotation**
	A wish for knowledge	*“we are the best people to deal with our own* psoriasis *but we will only be the best people if we have knowledge – but we are living in ignorance” (Ersser et al., 2010, p. 1046)*
Coping with the burden of treatment	Treatment as burdensome	*“You just can’t do it [follow the topical therapy regimen]. Especially working and things like that, you just can’t do it.”* (Thorneloe et al., 2016, p. 671)
	Varying opinions of treatment	*“I should have gone to my GP about [psoriasis], but...I was just under the general impression that there was very little they could do” (Nelson et al., 2013, p. 164)*
	Taking control of treatment	*“Often I alter the dose if I’m feeling that my psoriasis is particularly bad at the time or if I need to get my psoriasis to a manageable level ... Leave it on for longer, that kind of thing.” (Thorneloe et al., 2016, p. 673)*

Psoriasis as an Uncontrollable Force

The first theme derived from the data indicates that people experience psoriasis as an unpleasant externalised force over which they have little control (e.g. Bundy et al., 2014, p. 828):

"'No matter what I do, if you decided you will flare up you will'"

Participants described psoriasis as a chronic, life-long, incurable condition (e.g. Ersser, Cowdell, Latter & Healy, 2010; Uttjek, Nygren, Stenburg, & Dufaker, 2007). It was described as unwanted, disliked, and "evil" (Bundy et al., 2014; Khoury, Danielsen, & Skiveren, 2014). Some participants described psoriasis as an unpredictable entity; separate from them but with a large influence on their lives (e.g. Magin et al., 2009; Nelson, Chew-Graham, Griffiths, & Cordingley, 2012). Psoriasis was also characterised as an invasive other who violated participants' bodies against their consent (Bundy et al., 2014; Watson & de Bruin, 2007). Participants related psoriasis' unpredictability to a lack of control over the disease; this was exacerbated by failed treatments (e.g. Simpson et al., 2017; Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017).

As opposed to an uncontrollable force, Uhlenhake, Kurkowski, & Feldman (2010) reported that some people with psoriasis saw their disease as self-inflicted. Some reported that their family or friends also held this belief (Ghorbanibirgani, Fallahi-Khoshknab, Zarea, & Abedi, 2016).

Beliefs about psoriasis were a major contributor to the diseases' emotional impact (Uttjek, Nygren, Stenburg, & Dufaker, 2007; Magin, Adams, Heading, Pond, & Smith, 2009). Study findings related a lack of control to difficulties adjusting to psoriasis, feelings of helplessness or despondence, and increased likelihood of "psychological morbidity" (e.g. Magin et al., 2009; Watson & de Bruin, 2007). Two studies described the chronicity of psoriasis being associated with a sense of resignation ("just having to live with it": Kouwenhoven, vender Loeg, & van de Kerkof, 2018; Simpson et al., 2017). The links between thoughts about the control and timeline of psoriasis and people's emotional response to it fits within the Common Sense Model of illness representations (Diefenbach & Leventhal, 1996).

Impact on the Self and Self Image

Participants frequently reported a change to their emotional self and identity due to psoriasis. This included hiding aspects of themselves (e.g. Pariser et al., 2016, p. 25):

> *''It made me self-conscious about myself. And I became shy and withdrawn. I really didn't want to be around people. I was embarrassed because of those symptoms.''*

Altered mood and identity. The emotional impact of psoriasis was pervasive in participants' and authors' reflections (e.g. Khoury, Skov, & Moller, 2017; Watson & de Bruin, 2007). This was associated to changed appearance, uncomfortable physical symptoms, lack of control, and reduced activity (e.g. Khoury et al., 2014; Uttjek et al., 2017). People with psoriasis reported low mood; this was described on a continuum from sadness (e.g. Kouwenhoven, vender Loeg, & van de Kerkof, 2018) to depression or despair (e.g. Magin, Adams, Heading, Pond, & Smith, 2009). In some cases, participants used depression as a descriptive term, whereas in others they reported a diagnosed condition that received psychological or medical treatment (e.g. Amatya & Nordlind, 2008; Watson & de Bruin, 2007). In two studies, participants disclosed experiencing suicidal thoughts linked to their condition (Ghorbanibirgani, Fallahi-Khoshknab, Zarea, & Abedi, 2016; Magin et al., 2009). Several studies referred to feelings of hopelessness or helplessness (e.g. Bundy et al., 2014; Pariser et al., 2016). Reasons for these feelings included reactions to ineffective treatment or perceiving psoriasis as incurable (e.g. Magin et al., 2009; Wahl, Berit, & Hanestad, 2002).

Some people with psoriasis expressed a difficulty understanding why they had developed psoriasis, wondering “why me?” or what they had done to deserve the illness (e.g. Bundy et al., 2014; Khoury, Danielsen, & Skiveren, 2014). Here again, representations of psoriasis are linked to emotional responses.

The included studies also discussed anxiety (e.g. Bewley, Burrage, Ersser, Hansen, & Ward, 2014; Cather et al., 2017). Magin et al. (2009) described people with psoriasis showing social phobia or panic symptoms in relation to being seen. They also outline “obsessive-compulsive” symptoms relating to skin care or checking appearance. Uttjek et al. (2007) report that anxiety was commonly due to a fear of the consequences of psoriasis. Fewer studies reported angry emotions, including being angry at having the disease and being more irritable (e.g. Ghorbanibirgani et al., 2016; Wahl et al., 2002).

Participants frequently reported that psoriasis effected how they thought of themselves. This included reports of feeling like a different person or low in confidence or self-esteem (e.g. Khoury, Skov, & Moller, 2014; Uttjek, Nygren, Stenburg, & Dufaker, 2007). For some, this marked a change from their pre-disease personality, which had been less introverted (Magin et al., 2009; Pariser et al., 2016). In some instances, participants felt psoriasis became their whole self, or that their self-image had become defined by it entirely (Magin et al., 2009; Watson & de Bruin, 2007). Participants described psoriasis contributing to them disliking themselves, particularly their appearance; they compared themselves to “healthy” others or perfect images in the media and spoke about feeling inadequate (e.g. Campbell, Warburton, Amos, & Roland 1996; Wahl et al., 2002). Participants reported feeling disgusted by their own body or skin (e.g. Khoury et al., 2014; Wahl, Berit, & Hanestad, 2002). They related the appearance of psoriasis to feelings of embarrassment or shame (e.g. Khoury et al., 2017; Pariser et al., 2016).

Although less common, participants volunteered examples of psoriasis changing their personalities in a positive way, for example, gaining maturity and an understanding of others' suffering (Uttjek et al., 2007; Watson & de Bruin, 2007). Watson and de Bruin (2007) report that study participants became stronger and more resilient through their suffering and gained an appreciation of what was important in life. Bundy et al. (2014) include examples of participants describing psoriasis as a companion and missing it when it has cleared.

A need to hide. People with psoriasis commonly described its visible nature as one of the most difficult aspects of living with the disease (e.g. Kouwenhoven, vender Loeg, & van de Kerkof, 2018; Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017). Studies described visibility as a constant reminder of illness and a root of psychological distress (e.g. Magin, Adams, Heading, Pond, & Smith, 2009; Wahl, Berit, & Hanestad, 2002). These difficulties had the behavioural consequence of hiding, for example, covering the body with clothes, cosmetics, and hairstyles (e.g. Uttjek, Nygren, Stenburg, & Dufaker, 2007; Wahl et al., 2002). People with psoriasis avoided activities that show the body (e.g. public showers) and learnt to hold their body in a way that hid psoriasis (Cather et al., 2017; Khoury et al., 2014). A wish to hide psoriasis caused some participants to avoid going out entirely (Pariser et al., 2016; Wahl et al., 2002). Psoriasis was also hidden by cleaning the home to remove scales, choosing light coloured clothes to prevent visible shedding, and trying not to itch in front of others (e.g. Globe, Bayliss, & Harrison, 2009; Uttjek et al., 2007). Two studies reported that as participants grew older, they were more comfortable showing signs of psoriasis (Nelson, Barker, Griffiths, Cordingley, & Chew Graham, 2013; Uttjek et al., 2007).

The Social Effects of Stigmatisation

The third theme identified in the data relates to stigmatisation. Participants reported both enacted and perceived stigmatisation. These experiences reduced participants' social lives and put limits on new or intimate relationships (e.g. Wahl, Berit, & Hanestad, 2002, p. 255):

"I want to be a positive person and talk to other people. But the psoriasis stops me from seeking the contact I want with others. I'm afraid of rejection."

Experienced or expected negative reactions. People with psoriasis displayed a tendency to worry about negative reactions from others (e.g. Ghorbanibirgani, Fallahi-Khoshknab, Zarea, & Abedi, 2016; Khoury, Skov, & Moller, 2014). This included fears that others would be disgusted or judge them by their appearance (e.g. Campbell, Warburton, Amos, & Roland 1996; Magin, Adams, Heading, Pond, & Smith, 2009). Participants reported fearing that others' thought they were contagious or unhygienic (e.g. Pariser et al., 2016; Wahl, Berit, & Hanestad, 2002). People with genital psoriasis expressed fears that sexual partners would think they had a sexually transmitted disease (Cather et al., 2017). Some single participants expressed a belief that they would never find a romantic partner (e.g. Uttjek et al., 2007; Watson & de Bruin, 2007). Some authors interpreted that participants had an expectation of rejection due to projecting their own opinions of themselves on to others (Cather et al., 2017; Wahl et al., 2002). Five included studies labelled this "perceived stigmatisation" (e.g. Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017; Watson & de Bruin, 2007).

Further to fear of others' reactions, participants gave examples of experiencing negative reactions (enacted stigma). Participants had experienced bullying and insensitive comments across the lifespan; this included comments that they were contagious or infectious (e.g. Magin et al., 2009; Khoury, Skov, & Moller, 2017). There were examples of others acting with disgust or staring and pointing (e.g. Khoury et al., 2014; Watson & de Bruin, 2007). Participants also reported members of the public and acquaintances avoiding touching them or backing away (e.g. Ghorbanibirgani et al., 2016; Pariser et al., 2016). Uhlenhake, Kurkowski, and Feldman (2010) report that people with psoriasis had experienced exclusion from beauty treatments due to staff refusing to treat them.

A reduced social life. People with psoriasis often reported having reduced social contact, becoming withdrawn and even isolated (e.g. Bundy et al., 2014; Kouwenhoven, vender Loeg, & van de Kerkof, 2018). Frequently, reduced social contact was a choice driven by concerns about others' reactions, or a wish to hide (e.g. Khoury, Skov, & Moller, 2017; Pariser et al., 2016). Participants also perceived that they had a reduced social life due to treatment and appointments occupying their time, others distancing themselves, or unbearable symptoms making socialising difficult (e.g. Amatya & Nordlind, 2008; Ghorbanibirgani, Fallahi-Khoshknab, Zarea, & Abedi, 2016). Low mood was another reason given for reduced socialising e.g. participants spoke about being too preoccupied with worries (Nelson, Barker, Griffiths, Cordingley, & Chew Graham, 2013; Wahl, Berit, & Hanestad, 2002).

For some participants, psoriasis led to an avoidance of sexual intimacy (e.g. Kouwenhoven et al., 2018; Pariser et al., 2016). For some, this was due to a change in how they felt about their own sexuality; others reported that it was a consequence of reduced desire or confidence (e.g. Khoury et al., 2014; Magin, Adams, Heading, Pond, & Smith, 2009). Physical symptoms of psoriasis were another contributor to reduced sexual intimacy (e.g. Khoury, Danielsen, & Skiveren, 2014; Uttjek, Nygren, Stenburg, & Dufaker, 2007).

Participants reported other difficulties in relationships, further to reduced intimacy. Participants described that psoriasis had an emotional impact on family members due to the burden of supporting them; this included tolerating increased irritation caused by psoriasis symptoms and psoriasis care taking up potential quality time (e.g. Bundy et al., 2014; Pariser et al., 2016). Participants' descriptions of stigmatisation showed cultural difference. In

Ghorbanibirgani et al.’s (2016) study with participants from Iran, examples of rejection were particularly frequent and severe. They reported divorce and separation, participants whose family no longer visited them, and people who were completely ignored in the community. It is likely that the effects of stigmatisation depend on the environment and culture in which the person with psoriasis lives.

Finding Ways to Cope

Coping was frequently discussed in the literature. This theme includes exploration of “unhelpful” ways of coping, as well as descriptions of coming to terms with having psoriasis and ways of managing its effects day-to-day (e.g. Uttjek, Nygren, Stenburg, & Dufaker, 2007, p.368):

“But this has turned into a routine, like washing yourself every day and getting ready in the morning. You just take that private moment. It has become a part of yourself; you learn to live with it.”

Participants gave examples of feeling able to cope with psoriasis and come to a level of acceptance of it (e.g. Campbell, Warburton, Amos, & Roland, 1996; Simpson et al., 2017). Time and age reportedly helped with developing this sense of acceptance (e.g. Uttjek, Nygren, Stenburg, & Dufaker, 2007; Watson & de Bruin, 2007). Magin, Adams, Heading, Pond, and Smith (2009) state that coming to a place of acceptance is helpful in reducing the psychological impact of psoriasis. Study authors reflected that participants appeared to alter their relationship with psoriasis by comparing themselves to others who they saw as “worse off”, such as people with life-limiting illnesses (Simpson et al., 2017; Uttjek et al., 2007).

Other ways of coping with psoriasis included adjusting lifestyles and finding new ways of doing activities (e.g. Cather et al., 2017; Khoury, Danielsen, & Skiveren, 2014). Uttjek, Nygren, Stenburg, and Dufaker (2007) report that this adjustment was important for maintaining a good quality of life. Participants in some studies spoke about "routinisation" of their health behaviours as a means of coping (Cather et al., 2017; Uttjek et al., 2007). Some participants also used dark humour to cope (Bundy et al., 2014; Uttjek et al., 2007).

"Unhealthy" coping strategies described by participants included comfort eating, drinking alcohol, or escapism through parties and sex (e.g. Magin et al., 2009; Watson & de Bruin, 2007). Coping theory literature would define these strategies as emotion-focused coping, as they attempt to supress or minimise the negative emotions associated with a difficult situation (Lazarus & Folkman, 1984). Another emotion-focused strategy mentioned in almost half of the studies was avoidance. This included avoiding situations where psoriasis would be visible, such as exercise (e.g. Campbell et al., 1996; Kouwenhoven, vender Loeg, & van de Kerkof, 2018). Participants also avoided social situations, often reporting this was due to feeling stigmatised or embarrassed (e.g. Cather et al., 2017; Pariser et al., 2016). Khoury, Skov, and Moller (2017) give examples of people with psoriasis avoiding seeing their own reflection.

Effects on Daily Activities

Participants frequently discussed the physical impact of psoriasis; this linked to discussion about day-to-day functioning. Psoriasis had an impact in many areas of daily life such as movement, leisure, and work (e.g. Khoury, Danielsen, & Skiveren, 2014, p.5):

> *"When my psoriasis flares up, I don't exercise, because my skin gets tight."*

Physical burden of psoriasis. Study participants often referred to pain, both on the skin and arthritic joint pain (e.g. Nelson, Barker, Griffiths, Cordingley, & Chew Graham, 2013; Pariser et al., 2016). Descriptions of pain varied, for example, participants used words such as "dull", "stabbing" and "burning"; pain was described as worse with movement (e.g.

Bewley, Burrage, Ersser, Hansen, & Ward, 2014; Uttjek, Nygren, Stenburg, & Dufaker, 2007).

Multiple studies included reports of itch (e.g. Cather et al., 2017; Globe, Bayliss, & Harrison, 2009). In studies ranking symptoms, participants frequently named itch as their worst symptom (e.g. Amatya & Norlind, 2008; Kouwenhoven, vender Loeg, & van de Kerkof, 2018). Participants described itch as having an emotional impact (e.g. Wahl, Berit, & Hanestad, 2002; Watson & de Bruin, 2007). Itch interrupted sleep and affected concentration (Globe et al., 2009; Watson & de Bruin, 2007). An additional physical symptom that people with psoriasis found difficult was shedding (e.g. Campbell, Warburton, Amos, & Roland, 1996; Khoury, Danielsen, & Skiveren, 2014). Participants spoke about the embarrassment of leaving a trail of skin and how this was a constant reminder to them of their illness (e.g. Khoury et al., 2014; Pariser et al., 2016). A number of studies reported that people with psoriasis had poor sleep and low energy (Cather et al., 2017; Pariser et al., 2016).

Limited activities of daily living. People with psoriasis reported limitations to activities of daily living (e.g. Bewley, Burrage, Ersser, Hansen, & Ward, 2014; Simpson et al., 2017). As previously discussed, this includes not engaging in activities that show the body, such as swimming or sport. Pain, physical discomfort and mobility difficulties also limited people's activities (e.g. Pariser et al., 2016; Wahl et al., 2002).

Some study participants shared a fear that they would not find a job (Uttjek, Nygren, Stenburg, & Dufaker, 2007). In those who did work, psoriasis interfered with work and education (e.g. Globe, Bayliss, & Harrison, 2009; Pariser et al., 2016). People with psoriasis found it difficult to balance work commitments with time needed for appointments and treatment, people also missed work and school due to suffering with symptoms (e.g. Pariser et al., 2016; Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017). There were instances of psoriasis making it difficult to do physical jobs, or limiting the choice of available jobs (e.g. Ghorbanibirgani, Fallahi-Khoshknab, Zarea, & Abedi, 2016; Wahl, Berit, & Hanestad, 2002). Treatment made it difficult for people to do jobs that involved handling materials, due to having cream on their hands (Kouwenhoven, vender Loeg, & van de Kerkof, 2018; Thorneloe et al., 2017). Some participants described financial difficulties due to not working, or medical care costs (Ghorbanibirgani et al., 2016; Pariser et al., 2016).

Having psoriasis influenced people's choice of clothing, including preventing them from wearing short sleeves or skirts (e.g. Cather et al., 2017; Uhlenhake et al., 2010). They also had to consider the fabric and colour of clothes (Globe et al., 2009; Watson & de Bruin, 2007). Overall, people with psoriasis described having a worse quality of life and experiencing reduced pleasure (e.g. Ghorbanibirgani et al., 2016; Khoury et al., 2014). They spoke about missed opportunities and a feeling of "missing out" on life (Bundy et al., 2014; Khoury et al., 2014).

Experiencing the Healthcare System

Studies often explored participants' experiences of the healthcare system. This included praise but also feeling let down by services and having difficulties with healthcare staff. Participants described a wish to receive more information about their illness and its treatment (e.g. Ersser, Cowdell, Latter, & Healy, 2010, p.1046):

> *"No-one really advises you to do anything, you're left very much to your own devices"*

Dissatisfaction with the healthcare system. Included studies were conducted within a variety of national healthcare systems; however, there was a common theme of dissatisfaction. Participants reported difficulties getting access to a specialist, and feeling there was a lack of regular review of psoriasis (e.g. Nelson, Chew-Graham, Griffiths, & Cordingley, 2012; Simpson et al., 2017). Patients described consultations as too brief and experienced this as dismissing (e.g. Khoury, Skov, & Moller, 2017; Nelson, Barker, Griffiths, Cordingley, & Chew Graham, 2013). Khoury et al. (2017) report that participants had frequently changing healthcare staff and would have preferred consistency to build trust and feel secure.

Relationships with health-care staff. Several people with psoriasis reported appreciating their relationship with health-care staff, and stating that good relationships were beneficial to their physical and emotional health (e.g. Nelson, Chew-Graham, Griffiths, & Cordingley, 2012; Watson & de Bruin, 2007). Some participants respected clinicians' knowledge and skills, and appreciated their support (e.g. Khoury, Skov, & Moller, 2017; Pariser et al., 2016).

Participants, however, also reported difficulties with health-care staff. This included feeling that doctors did not have sufficient knowledge to help them (e.g. Ersser, Cowdell, Latter, & Healy, 2010; Nelson, Barker, Griffiths, Cordingley, & Chew Graham, 2013). There was a feeling of lack of understanding by clinicians (e.g. Bundy et al., 2014; Nelson, Chew-Graham, Griffiths, & Cordingley, 2012). This included experiencing a lack of empathy for the challenges of engaging in psoriasis treatment and a disregard for the psychosocial impact of psoriasis (Ersser et al., 2010; Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017). Participants described poor communication from their healthcare team, for example, lack of information about side effects or the reasons behind treatment choices (e.g. Nelson et al., 2013; Uhlenhake et al., 2010). They also reported not feeling listened to by healthcare professionals, and having their opinions about treatment ignored (Khoury, Danielsen, & Skiveren, 2014; Simpson et al., 2017).

A wish for knowledge. Related to communication from professionals, studies reported that people with psoriasis felt they had a lack of knowledge about psoriasis and its treatment (Khoury, Skov, & Moller, 2017; Watson & de Bruin, 2007). Frequently, they shared a wish for more knowledge and an opinion that this would be beneficial (Nelson, Chew-Graham, Griffiths, & Cordingley, 2012; Wahl, Berit, & Hanestad, 2002). Some participants believed that increased knowledge could help them feel more in control of psoriasis, manage symptoms better, and participate in decisions about treatment (e.g. Ersser, Cowdell, Latter, & Healy, 2010; Pariser et al., 2016).

Coping with the Burden of Treatment

When participants reported on psoriasis treatment, they described it as a burden; these negative experiences led to doubts about treatment and people taking control of their own treatment, at times against medical advice (e.g. Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017, p.673):

"I just gave up because it wasn't getting any better and it wasn't working so I wasn't prepared to keep paying for the treatments which were doing nothing for me."

Treatment as burdensome. A recurrent theme in the data was the burdensome nature of treatment. Participants discussed the time and effort required, particularly for frequent application of topical treatments (e.g. Bundy et al., 2014; Wahl, Berit, & Hanestad, 2002). Collecting prescriptions, attending appointments, changing clothes, and hospital admissions also took time and effort (e.g. Campbell, Warburton, Amos, & Roland, 1996; Pariser et al., 2016). Thorneloe, Bundy, Griffiths, Ashcroft, and Cordingley (2017) report that this left participants with less time and energy for other activities. Other reported burdens of treatment were the cost, the time burden on family and friends, and preoccupation of the mind (e.g. Pariser et al., 2016; Simpson et al., 2017).

People with psoriasis frequently spoke about treatment as unpleasant, particularly describing topical treatment as greasy, messy, and leaving them feeling unclean (e.g. Bewley, Burrage, Ersser, Hansen, & Ward, 2014; Uhlenhake, Kurkowski, & Feldman, 2010). Participants reported that topical treatment looked and smelled unpleasant, causing feelings of embarrassment (e.g. Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley 2017; Wahl, Berit, & Hanestad, 2002). People reported unpleasant side effects from treatments such as burns, hair loss, and skin thinning (e.g. Pariser et al., 2016; Watson & de Bruin, 2007). Some participants spoke about constantly monitoring skin and a need to be prepared, for example, by carrying spare clothes (e.g. Bundy et al., 2014; Magin, Adams, Heading, Pond, & Smith, 2009).

Varying opinions of treatment. Study participants and authors often referred to doubts about psoriasis treatment. They had commonly experienced treatment not working effectively and/or had developed a belief that treatment would not work (e.g. Amatya & Norlind, 2008; Watson & de Bruin, 2007). For some, this poor control of symptoms led them to question whether treatment or medical appointments were necessary or worth the required effort (e.g. Ersser, Cowdell, Latter, & Healy, 2010; Nelson, Chew-Graham, Griffiths, & Cordingley, 2012). People with psoriasis worried about the long-term side effects of treatment such as possible organ damage (e.g. Kouwenhoven, vender Loeg, & van de Kerkof, 2018; Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017). In some cases, these fears contributed to people stopping therapy or using natural remedies instead (Khoury, Skov, & Moller, 2017; Uhlenhake, Kurkowski, & Feldman, 2010).

Although less common, some participants reported treatment working and being beneficial (e.g. Amatya & Norlind, 2008; Pariser et al., 2016). Some participants reported that symptom management had wider effects such as improving their mood or quality of life (Cather et al., 2017; Pariser et al., 2016).

Taking control of treatment. People with psoriasis described changing or adapting their treatment without medical advice dependent on symptom severity, to give themselves more time for other things (e.g. Ersser, Cowdell, Latter, & Healy, 2010; Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017). Some participants accessed alternative treatments such as tanning beds or natural remedies (Thorneloe et al., 2017; Uhlenhake, Kurkowski, & Feldman, 2010). Participants also took control of their treatment by changing doctors or asking for referrals to specialists (Uhlenhake et al., 2010; Watson & de Bruin, 2007). Some study participants described how they had given up with treatment entirely (e.g. Nelson, Barker, Griffiths, Cordingley, & Chew Graham, 2013; Wahl, Berit, & Hanestad, 2002). Reasons for this were the burden of treatment or feeling that treatment was not working (e.g. Bewley, Burrage, Ersser, Hansen, & Ward, 2014; Nelson et al., 2013).

Discussion

The aim of this meta-synthesis was to identify, evaluate, and synthesise qualitative studies that have investigated the experience of living with psoriasis. There are therefore two outcomes to the review: the quality appraisal of current literature, and the synthesis of relevant data. Though these outcomes have not been integrated, they are both valuable contributions to our understanding of the research area.

Twenty-two studies were identified and, from their data, superordinate themes and subthemes were identified. Themes are described in detail in the synthesis. Overall, this meta-synthesis highlights the broad ranging and challenging impact of living with psoriasis. Central to this experience was the visible nature of the condition and feelings of being stigmatised, leading to escapist strategies, hiding, and avoidance. Amongst description of these difficulties, there was evidence of people adapting to and coping with psoriasis, and stories of personal growth. The meta-synthesis design allows for identification of these lesser-explored experiences, which might warrant further research. This discussion will provide reflection on selected themes from the data that have particular theoretical and clinical importance, limitations of the meta-synthesis, and indications for future research.

Aspects of The Common Sense Model (CSM) of illness representations (Diefenbach & Leventhal, 1996) were frequently present in the themes identified from the data. Participants reported beliefs about the control and timeline of psoriasis, often describing it as uncontrollable and life-long. They also discussed the identity of the disease, describing unpleasant symptoms and at times taking on psoriasis as their own identity. Participants feared wide-ranging consequences for their work, relationships, and activities of daily living. The qualitative data reviewed indicated that these illness representations linked to emotional distress and influenced health behaviours, such as disengaging from treatment. These representations are in keeping with findings from quantitative research (Fortune, Richards, Griffiths, & Main, 2002; Scharloo et al. 1998; 2002). The CSM therefore appears to have utility in considering the experience of living with psoriasis, however as a cognitive model it appears to omit the influence of others, society, and culture.

Reference to coping was common throughout the generated themes. Strategies identified include positive reinterpretation and growth, planning or active coping, disengagement, and humour. These wide-ranging coping strategies are equivalent to those reported by Fortune, Richards, Main, and Griffiths (2002) who used a quantitative design to investigate coping with psoriasis and reported that use of avoidance and emotion-focused coping related to increased anxiety and disability. The qualitative literature reviewed also highlighted that coping by becoming withdrawn and avoiding activities led to a sense of missing out, and low mood.

Instances of acceptance as coping were reported in the reviewed literature, and both authors and participants described this strategy as useful. However, participants' descriptions of acceptance of psoriasis at times equated to "giving up" or developing hopelessness. The utility of acceptance as a coping strategy is often debated in health psychology literature (e.g. Nakamura & Orth, 2005). In their writings on adjustment to living with illness, Radley and Green (1987) distinguish between acceptance that is characterised by accommodation, such as modifying goals in consideration of illness, and resignation, where loss of activity is accompanied by feeling overwhelmed. This continuum of experience was reflected in the synthesised literature and provides important considerations for supporting people with psoriasis to accept their illness without becoming resigned to it.

The visible appearance of psoriasis, and consequences of this, were a key feature of living with psoriasis identified by the meta-synthesis. This theme was raised in discussions about relationships, engaging in activities, opinions about treatment, feelings about the self, and the emotional impact of the condition. This highlights the significance of distress about appearance in psoriasis, which is supported by quantitative research (e.g. Miles, 2002; Polenghi et al., 1994; Wojtyna, Lakuta, Marcinkiewicz, Bergler-Czop, & Brezezinska-Wcislo, 2017). The visibility of psoriasis was related to people's experience of stigmatisation. In the synthesised literature, participants spoke about both enacted stigma (feelings of stigma due to another's behaviour) and perceived stigma (a feeling which does not related to behaviour by another; Scrambler & Hopkins, 1986). Stigma was central to the experience of living with psoriasis, and had numerous consequences. This is supported by quantitative research in the area which has found relationships between stigma and increased psychological distress, quality of life, and disability in people with psoriasis (Alpsoy et al., 2017, Lakuta, Marcinikiewicz, Bergler-Czop, & Brzezinska-Wcislo, 2017; Liasides & Apergi, 2016). The meta-synthesis therefore builds on quantitative research to thicken the understanding of how the visibility of psoriasis links to stigmatisation and its consequences.

Limitations of Included Studies

The majority of studies in the review were rated as moderate or high in quality, however, quality assessment found that studies showed a tendency for poor clarification of the data analysis method used, making it difficult to ascertain whether systems for coding and generating themes in the included studies were thorough and free from bias. Authors rarely commented on reflexivity, meaning the opportunity for undisclosed bias in the included research studies is high. It can be seen by reviewing the studies that contributed to each theme (see Appendix B), that no themes were generated based solely on low quality studies. Future qualitative research in the area should ensure methodological explanations are thorough, and comment on reflexivity, to reduce chances of bias.

The literature reviewed was mostly conducted in westernised, English-speaking countries and therefore, as with all qualitative research, generalisation of results should be done with caution. There is a need for more research in a variety of cultures, particularly to capture experiences of those from cultures with different healthcare provision and knowledge and beliefs about illness.

Limitations of the Meta-Synthesis

The reported meta-synthesis utilised a second independent rater in the quality appraisal of studies in an attempt to increase objectivity, however, a second rater only reviewed 23% of included studies and this limits confidence in objectivity of quality appraisal. Due to the amount of peer-reviewed studies available in the field, the grey literature was not included in this meta-synthesis, meaning novel findings from unpublished studies may have been missed and there may have been an influence of publication bias. The large amount of rich data generated by this meta-synthesis is a strength of the study, and made possible by broad inclusion criteria. This broad approach however did not allow full and detailed exploration of each aspect of the experience of living with psoriasis. It will be important that future research studies include a mixture of those exploring specific experiences, and those that aim to capture the “bigger picture”.

Clinical Implications and Future Directions

This meta-synthesis has highlighted that living with psoriasis is a biopsychosocial experience and that the disease can have wide-ranging and important effects on quality of life. Participants often felt misunderstood by clinicians and felt that health-care professionals overlooked the psychosocial effects of psoriasis. Educating healthcare staff about the broad-ranging impact of the illness may help improve understanding and, in turn, improve communication between clinicians and patients. Findings regarding experiences of health-care and treatment have important implications for services. Patients expressed dissatisfaction in a number of areas including lack of information, changing staff, short consultations, and lack of referrals to specialists. Consultation with people with psoriasis and service-evaluations that ask about patient’s needs and wishes may support health-care services to make changes and increase satisfaction.

People with psoriasis reported how they experience emotional distress and an altered sense of self because of their illness, causing difficulties in engaging in a full life. Further research in to psychological interventions to support this patient group is required. The experience of stigma appears to be central to the experience of living with psoriasis, exploration of stigma in psoriasis (and other skin conditions) and the nature of the relationship between stigma and psychological wellbeing is therefore another area for further research.

References

Alpsoy, E., Polat, M., FettahlioGlu-Karaman, B., Karadag, A.S., Kartal-Durmazlar, P., YaiCin, B. … & Semoi, Y. (2017). Internalized stigma in psoriasis: a multicentre study. *The Journal of Dermatology, 44,* 885-891. https://doi.org/10.1111/1346-8138.13841

Amatya, B. & Nordlind, K. (2008). Focus groups in Swedish psoriatic patients with pruritis. *The Journal of Dermatology, 35,* 1-5. DOI: 10.1111/j.1346-8138.2007.00402.x

Armstrong, A.W., Schupp, C., Wu, J., & Bebo, B. (2012). Quality of life and work productivity impairment among psoriasis patients: findings from the National Psoriasis Foundation survey data 2003-2011. *PLoS ONE, 7,* e52935. DOI: 10.1371/journal.pone.0052935

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Medical Research Methodology, 8.* https://doi.org/10.1186/1471-2288-8-21

Barnett-Page, E. & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology, 9,* 59. https://doi.org/10.1186/1471-2288-9-59

Bewley, A., Burrage, D.M., Ersser, S.J., Hansen, M., & Ward, C. (2014). Identifying individual psychosocial and adherence support needs in patients with psoriasis: a multinational two-stage qualitative and quantitative study. *Journal of the European Academy of Dermatology and Venereology, 28.* 763-770. https://doi.org/10.1111/jdv.12174

Broadbent, E., Petrie, K.J., Main, J., Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research, 60,* 631-637. https://doi.org/10.1016/j.jpsychores.2005.10.020

Bundy, C., Borthwick, M., McAteer, H., Cordingley, L., Howells, L., Bristow, P., & McBride, S. (2014). Psoriasis: Snapshots of the unspoken: Using novel methods to explore patients' personal models of psoriasis and the impact on well-being. *British Journal of Dermatology, 171*(4), 825–831. https://doi.org/10.1111/bjd.13101

Campbell, S.M., Warburton, B., Amos, C.E., & Roland, M.O. (1996). Who cares for people with psoriasis?: A qualitative study of the impact of psoriasis on patients' lives. *European Journal of General Practice*, *2*, 101–103. https://doi.org/10.3109/13814789609161538

Cather, J.C., Ryan, C., Meeuwis, K., Potts Bleakman, A.J., Naegeli, A.N., Edson-Heredia, E. … & Fretzin, S. (2017). Patients' Perspectives on the Impact of Genital Psoriasis: A Qualitative Study. *Dermatology and Therapy*, *7*, 447–461. https://doi.org/10.1007/s13555-017-0204-3

Critical Appraisal Skills Programme. (2017). *CASP Checklists.* Retrieved from http://www.casp-uk.net/casp-tools-checklists

Darjani, A., Heidarzadeh, A., Golchai, J., Sadr-Eshkevari, S., Alizadeh, N., Arami, M., & Nichhah, N. (2014). Quality of life in psoriastic patients: a study using the short form-36. *International Journal of Preventative Medicine*, *5,* 1146-1152.

De Korte, J., Mombers, F.M.C., Bos, J.D., & Sprangers, M.A.G. (2004). Quality of life in patients with psoriasis: a systematic literature review, *Journal of Investigative Dermatology Symposium Proceedings*, *9,* 140-147. https://doi.org/10.1046/j.1087-0024.2003.09110.x

Diefenbach, M.A. & Leventhal, H. (1996). The common-sense model of illness representation: theoretical and practical considerations. *Journal of Social Distress and the Homeless*, *5,* 11-38. https://doi.org/10.1007/BF02090456

Erikson, E.H. (1994). *Identity and the life cycle.* WW Norton & Company.

Ersser, S.J., Cowdell, F.C., Latter, S.M., & Healy, E. (2010). Self-management experiences in adults with mild-moderate psoriasis: an exploratory study and implications for improved support. *British Journal of Dermatology*, *163*, 1044–1049. https://doi.org/10.1111/j.1365-2133.2010.09916.x

Fortune, D.G., Richards, H.L., Griffiths, C.E.M., & Main, C.J. (2002). Psychological stress, distress and disability in patients with psoriasis: consensus and variation in the contribution of illness perceptions, coping and alexithymia. *British Journal of Clinical Psychology*, *41*, 157-174. https://doi.org/10.1348/014466502163949

Fortune, D.G., Richards, H.L., Main, C.J., & Griffiths, C.E.M. (2000). Pathological worrying, illness perceptions and disease severity in patients with psoriasis. *British Journal of Health Psychology*, *5*, 71-82. http://dx.doi.org/10.1348/135910700168775

Ghorbanibirgani, A., Fallahi-Khoshknab, M., Zarea, K., & Abedi, H. (2016). The lived experience of psoriasis patients from social stigma and rejection: A qualitative study. *Iranian Red Crescent Medical Journal*, *18*. https://doi.org/10.5812/ircmj.27893

Globe, D., Bayliss, M.S., & Harrison, D.J. (2009). The impact of itch symptoms in psoriasis: results from physician interviews and patient focus groups. *Health and Quality of Life Outcomes*, *7*. https://doi.org/10.1186/1477-7525-7-62

Griffiths, C.E.M. & Barker, J.N.W. (2007). Pathogenesis and clinical features of psoriasis. *The Lancet*, *370*, 263-271. https://doi.org/10.1016/S0140-6736(07)61128-3

Griffiths, C.E.M. & Richards, H.L. (2001). Psychological influences in psoriasis. *Clinical and Experimental Dermatology*, *26*, 338-342. https://doi-org.sheffield.idm.oclc.org/10.1046/j.1365-2230.2001.00834.x

Gudjonsson, J.E. & Elder, J.T. (2007). Psoriasis: epidemiology. *Clinics in Dermatology*, *25*, 535-546. https://doi.org/10.1016/j.clindermatol.2007.08.007

Gupta, M.A., Schork, N.J., & Gupta, A.K. (1993). Suicidal ideation in psoriasis. *International Journal of Dermatology, 32*, 188-190. https://doi-org.sheffield.idm.oclc.org/10.1111/j.1365-4362.1993.tb02790.x

Khoury, L.R., Danielsen, P.L., & Skiveren, J. (2014). Body image altered by psoriasis. A study based on individual interviews and a model for body image. *Journal of Dermatological Treatment, 25*, 2-7. https://doi.org/10.3109/09546634.2012.739278

Khoury, L.R., Skov, L., & Møller, T. (2017). Facing the dilemma of patient-centred psoriasis care: a qualitative study identifying patient needs in dermatological outpatient clinics. *British Journal of Dermatology*, *177*, 436–444. https://doi.org/10.1111/bjd.15292

Kouwenhoven, T.A., van der Ploeg, J.A.M., & van de Kerkhof, P.C.M. (2018). Treatment goals in psoriasis from a patient perspective: a qualitative study. *The Journal of Dermatological Treatment*, 1–15. https://dx.doi.org/10.1080/09546634.2018.1544408

Krueger, G., Koo, J., Lebwohl, M., Menter, A., Stern, R.S., & Rolstad, T. (2001). The impact of psoriasis on quality of life: results of a 1998 National Psoriasis Foundation patient-membership survey. *Archives of Dermatology*, *137*, 280-284. https://doi.org /10-1001/pubs.Arch Dermatol.-ISSN-0003-987x-137-3-dst0024

Lakuta, P., Marcinkiewicz, K., Bergler-Czop, B., & Brzezinska-Wcislo, L. (2017). How does stigma affect people with psoriasis? *Advances in Dermatology and Allergology, 34*, 36-41. https://doi.org/10.5114/pdia.2016.62286

Langley, R.G.B., Krueger, G.G., Griffiths, C.E.M. (2005). Psoriasis: epidemiology, clinical features, and quality of life, *Annals of the Rheumatic Disease*, 64, ii18-ii23. http://dx.doi.org/10.1136/ard.2004.033217

Lavda, A.C., Webb, T.L., & Thompson, A.R. (2012). A meta-analysis of the effectiveness of psychological interventions for adults with skin conditions. *The British Journal of Dermatology, 167*, 970-797. https://doi.org/10.1111/j.1365-2133.2012.11183.x

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping.* Springer Publishing Company.

Liasides, J., & Apergi, F.S. (2016). Predictors of quality of life in adults with acne: the contribution of perceived stigma. *Acta Dermato-Venereologica, 96,* 138.

Magin, P., Adams, J., Heading, G., Pond, D., & Smith, W. (2009). The psychological sequelae of psoriasis: results of a qualitative study, *14*, 150–161. https://doi.org/10.1080/13548500802512294

Martin, M.L., Gordon, K., Pinto, L., Bushnell, D.M., Chau, D., & Viswanathan, H.N. (2015). The experience of pain and redness in patients with moderate to severe plaque psoriasis. *Journal of Dermatological Treatment*, *26*, 401–405. https://doi.org/10.3109/09546634.2014.996514

Miles, J. (2002). Psoriasis: the role of shame on quality of life. In P.Gilbert & J. Miles (Eds.), *Body Shame Conceptualisation, Research and Treatment* (pp. 109-127). London, UK: Routledge.

Miniszewska, J., Juczyski, Z., Ograczyk, A., Zalewska, A. (2013). Health-related quality of life in psoriasis: important role of personal resources. *Acta Dermato-Venereologica, 93*, 551-556. https://doi.org/10.2340/00015555-1530

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7):e1000097. https://doi.org/10.1371/journal.pmed.1000097

Mruck, K., & Breuer, F. (2003). Subjectivity and reflexivity in qualitative research – The FQS issues. *Forum: Qualitative Social Research. 4,* 22-31. http://dx.doi.org/10.17169/fqs-4.2.696

Nakamura, Y., & Orth, U. (2005). Acceptance as a coping reaction: adaptive or not? *Swiss Journal of Psychology, 64,* 281-292. https://doi.org/10.1024/1421-0185.64.4.281

Nelson, P.A., Barker, Z., Griffiths, C.E.M., Cordingley, L., & Chew Graham, C.A. (2013). "On the surface": a qualitative study of GPs' and patients' perspectives on psoriasis, *BMC Family Practice, 14.* https://doi.org/10.1186/1471-2296-14-158

Nelson, P.A., Chew-Graham, C.A., Griffiths, C.E.M., & Cordingley, L. (2013). Recognition of need in health care consultations: A qualitative study of people with psoriasis. *British Journal of Dermatology, 168,* 354–361. https://doi.org/10.1111/j.1365-2133.2012.11217.x

National Institute for Health and Care Excellence (2017). Psoriasis: Assessment and Management. Retrieved from https://www.nice.org.uk/guidance/cg153

Pariser, D., Schenkel, B., Carter, C., Farahi, K., Brown, T. M., & Ellis, C. N. (2016). A multicenter, non-interventional study to evaluate patient-reported experiences of living with psoriasis. *Journal of Dermatological Treatment, 27*, 19–26. https://doi.org/10.3109/09546634.2015.1044492

Polenghi, M.M., Molinari, E., Gala, C., Guzzi, R., Garuta, C., & Finzi, A.F. (1994). Experience with psoriasis in a psychosomatic dermatology clinic. *Acta Dermato-Venereologica Supplementum, 186,* 65-66. DOI: 10.2340/000155551866566

Radley, A. & Green, R. (1987). Illness as adjustment: a methodology and conceptual framework. *Sociology of Health & Illness, 9, 179-209.* https://doi.org/10.1111/1467-9566.ep11346972

Rapp, S.R., Feldman, S.R., Exum, M.L., Fleischer, A.B., & Reboussin, D.M. (1999). Psoriasis causes as much disability as other major medical diseases. *Journal of the American Academy of Dermatology, 41,* 401-407. https://doi.org/10.1016/S0190-9622(99)70112-X

Scharloo, M., Kaptein, A.A., Weinman, J., Bergman, W., Vermeer, B.J., Rooijmans, H.G.M. (2002). Patients' illness perceptions and coping as predictors of functional status in psoriasis: a 1 year follow up. *British Journal of Dermatology, 142*, 899-907. https://doi.org/10.1046/j.1365-2133.2000.03469.x

Scharloo, M., Kaptein, A.A., Weinmann, J., Hazes, J.M., Willems, L.N.A., Bergman, W. & Rooijmans, H.G.M. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research*, *44,* 573-585. https://doi.org/10.1016/S0022-3999(97)00254-7

Scrambler, G., & Hopkins, A. (1986). Being epileptic: coming to terms with stigma. *Sociology of Health and Illness, 8,* 26-43. https://doi.org/10.1111/1467-9566.ep11346455

Simpson, J. K., Wilson, M., Ahmed, A. A., Mizara, A., Clarke, A., & McBride, S. R. (2017). An exploratory study using framework analysis to investigate health-seeking behaviour in patients with psoriasis. *British Journal of Dermatology*, *177,* 742–750. https://doi.org/10.1111/bjd.15307

Thomas, J. & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8,* 45. https://doi.org/10.1186/1471-2288-8-45

Thorneloe, R. J., Bundy, C., Griffiths, C. E. M., Ashcroft, D. M., & Cordingley, L. (2017). Nonadherence to psoriasis medication as an outcome of limited coping resources and conflicting goals: findings from a qualitative interview study with people with psoriasis. *British Journal of Dermatology*, *176,* 667–676. https://doi.org/10.1111/bjd.15086

Uhlenhake, E. E., Kurkowski, D., & Feldman, S. R. (2010). Conversations on psoriasis what patients want and what physicians can provide: a qualitative look at patient and physician expectations. *Journal of Dermatological Treatment*, *21*, 6–12. https://doi.org/10.3109/09546630903085328

Uttjek, M., Nygren, L., Stenberg, B., & Dufåker, M. (2007). Marked by visibility of psoriasis in everyday life. *Qualitative Health Research*, *17*, 364–372. https://doi.org/10.1177/1049732306297674

Wade, D.T. & Halligan, P.W. (2017). The biopsychosocial model of illness: a model whose time has come. *Clinical Rehabilitation, 31,* 995-1004. https://doi.org/10.1177/0269215517709890

Wahl, A.K., Berit, E.G., & Hanestad, R. (2002). The bodily suffering of living with severe psoriasis: In-depth interviews with 22 hospitalized patients with psoriasis. *Qualitative Health Research*, *12*(2), 250–261. https://doi.org/10.1177/104973202129119874

Walker, R. (1999). Models in health psychology: an introduction. *Journal of Diabetes Nursing*, *3*, 188-191.

Watson, T., & de Bruin, G.P. (2007). Impact of cutaneous disease on the self-concept: an existential-phenomenological study of men and women with psoriasis. *Dermatology Nursing / Dermatology Nurses' Association*, *19*.

Wojtyna, E., Lakuta, P., Marcinkiewicz, K., Bergler-Czop, B., & Brzezinska-Wcislo, L. (2017). Gender, body image and social support: biopsychosocial determinant of depression among patients with psoriasis. *Acta Dermato-Venereologica*, *97*, 91-97. https://doi.org/10.2340/00015555-2483

Zimmer, L. (2006). Qualitative meta-synthesis: a question of dialoguing with texts. *Journal of Advanced Nursing*, *53*, 311-318. https://doi.org/10.1111/j.1365-2648.2006.03721.x

Appendix A

Excerpt from Reflective Log

“Data extraction:

- Lots of medical type data that is less rich in context and meaning.
- I’m noticing less interest in medical information or information about symptoms and types of treatment however continuing to extract and code.
- Had thoughts about whether looking at solely psychosocial effects of psoriasis would have been a more focussed and clear meta-synthesis however biological aspects do also seem important. Likely my own interest that is more towards the psychosocial areas due to my professional background.
- I am interested in information about the self and identity, spending more time reflecting on this and considering it. In meeting with expert researcher will ask for them to look over initial extractions to check not biased in focus”

Appendix B

Table Illustrating Studies Contributing to each Theme

(Shading indicates the study contributed to the listed theme)

	Campbell et al. (1996)	Wahl et al. (2002)	Uttjek et al. (2007)	Watson & De Bruin (2007)	Amatya & Norlind (2008)	Globe et al. (2009)	Magin et al. (2009)	Ersser et al. (2010)	Uhlenhake et al. (2010)	Nelson et al (2012)	Nelson et al. (2013)	Bewley et al. (2014)	Bundy et al. (2014)	Khoury et al. (2014)	Martin et al. (2015)	Ghorbanibirgani et al. (2016)	Pariser et al. (2016)	Cather et al. (2017)	Khoury et al. (2017)	Simpson et al. (2017)	Thorneloe et al. (2017)	Kouwenhoven et al. (2018)
Psoriasis as an uncontrollable force			■	■			■	■	■	■			■	■		■				■	■	■
Altered mood and identity	■	■	■	■	■	■	■	■	■	■			■	■		■	■	■	■	■	■	■
A need to hide	■	■	■			■	■				■			■		■	■	■			■	■
Experienced or expected negative reactions	■	■	■	■			■			■				■		■	■	■	■		■	
A reduced social life		■	■	■	■		■			■	■	■	■	■		■	■	■	■		■	■
Finding ways to cope	■		■	■			■						■	■			■	■	■	■	■	■
Physical burden of psoriasis	■	■	■	■	■	■		■	■	■	■	■		■	■		■	■		■		■
Limited activities of daily living	■	■	■	■		■	■	■	■			■	■	■		■	■	■	■	■	■	■
Dissatisfaction with healthcare system	■									■	■			■					■	■		
Relationships with healthcare staff	■			■			■	■	■	■	■	■	■	■			■		■	■	■	
A wish for knowledge	■	■		■				■	■	■	■	■					■		■	■		
Treatment as burdensome	■	■		■			■	■	■			■	■				■			■	■	■
Varying opinions of treatment		■		■	■			■	■	■	■	■					■	■	■	■	■	■
Taking control of treatment		■		■				■	■		■	■									■	

Appendix C

Worked Example of Theme Generation

Example Quotes	Codes	Subtheme	Superordinate Theme
“ You always have to be prepared and carry around panty liners...when it’s bad, if I have on a pair of shorts and I sit down on a cushion, you know, things might leak through [due to oozing]. That’s what I call high maintenance.” (Participant quote; Cather et al., 2017)	Need to be prepared		
“ Constantly being ‘on guard’ was frequently reported” (Authors’ comment; Bundy et al., 2014)	Monitoring		
“there were obsessive-compulsive symptoms related to skin care or to appearance-checking behaviours” (Authors’ comment; Magin et al., 2009)			
“This led to a loss of faith in medical topical treatments, and doctors” (Authors’ comment; Bewley et al., 2014)	Doubts about treatment	Varying opinions of treatment	
“You don’t want to use these ointments for the rest of my life, at least I don’t. It won’t work anyway.” (Participant quote; Kouwenhoven et al., 2018)			
‘ ... Sometimes I feel that the treatments aren’t stopping the psoriasis from increasing and sometimes I feel that the psoriasis is quite resistant and will increase, despite using the treatment ... I’m not sure overall, whether they are stopping it from getting worse.’ (Participant quote, Thorneloe et al., 2017)	Varying response to treatment		
“Most participants reported using topical treatments that did not work and expressed their dissatisfaction with treatments on offer.” (Authors’ comment; Simpson et al., 2017)			
“The effects it [methotrexate] can have on your internal organs, I think those are quite severe side-effects. I had high blood pressure when I was using cyclosporine. That’s a major side effect that I rather not have. I’ll stick with ointment and phototherapy.” (Participant quote; Kouwenhoven et al., 2018)	Worry about long-term impact of treatment		
“ A few of the participants suffered so greatly from anxiety at the thought of enduring side-effects that they refused systematic medical treatment” (Authors’ comment; Khoury et al., 2017)			

Example Quotes	Codes	Subtheme	Superordinate Theme
“Adherence to psoriasis therapies depleted personal coping resources, including time and motivation available for other illness tasks. Participants reported the frequent collection of repeat topical prescriptions and high-frequency applications as time-consuming and requiring significant effort, which limited the time and motivation available to engage in social activities” (Authors’ comment; Thorneloe et al., 2017)	Time and effort for treatment	Treatment as burdensome	Coping with the burden of treatment
‘Psoriasis shaped my child & teenage years, 4–6 hours of treatment (smelly treatment at that), the long itchy painful nights & the 12–18 week stints in hospital...’ (Participant quote; Bundy et al., 2014)			
“What people don’t realize is that the treatment is sometimes worse than the psoriasis and worst of all, it does not work.” (Participant quote; Watson & de Bruin, 2007)	Treatment as unpleasant		
“Furthermore, treatment can be embarrassing. Some ointments have a bad smell, discolor the skin, or make it sticky. This was often an additional burden in terms of a patient’s body experience.” (Authors’ comment; Wahl et al., 2002)			
‘I just gave up because it wasn’t getting any better and it wasn’t working so I wasn’t prepared to keep paying for the treatments which were doing nothing for me.’ (Participant quote; Thorneloe et al., 2017)	Other burdens of treatment		
“In addition to daily treatment of the disease, in many cases it was necessary to wash and change clothes far more frequently than what is otherwise considered normal.” (Authors’ comment; Wahl et al., 2002)			

Example Quotes	Codes	Subtheme	Superordinate theme
‘I was quite confident, I was quite happy to go and see the doctor, there might be a new medicine on the block or treatment, and I was quite looking forward to going; it made me feel good inside’ (Participant quote; Simpson et al., 2017)	Benefit of treatment		
“Sedating anti- histamines helped for a few days in some patients.” (Authors’ comment; Amatya & Norlind, 2008)	Changing treatment	Taking control of treatment	
‘If I’m working from home for a week, then I might miss my scalp stuff for a couple of days, purely because I think no one is going to see it.’ (Participant quote; Thorneloe et al., 2017)			
‘if it flares I’ll belt it for a couple of days and then I’ll get to the point where I can’t be bothered’ (Participant quote, Ersser et al., 2010)	Giving up on treatment		
“One important element in this context, however, is the fact that many patients gave up home treatment when the emotional aspect took the upper hand” (Authors’ comment; Wahl et al., 2002)			

Section 2

Research Report

Psychological Flexibility and the Impact of Perceived Stigma for People Living with Skin Conditions

Abstract

Objectives

Stigmatisation is frequently reported by people living with a range of skin conditions and it is known to play a significant role in adjustment. This study aims to investigate the relationship between stigma and wellbeing in people with skin conditions. It also aims to identify whether being more psychologically flexible interacts with any relationship between stigma and wellbeing.

Design and Methods

One hundred and five adults with a skin condition completed the Patient Health Questionnaire, Generalised Anxiety Disorder Assessment, EQ5D5L Visual Analogue Scale, Perceived Stigmatisation Questionnaire, and Comprehensive Assessment of Acceptance and Commitment Therapy Processes. Data were analysed using regression, moderation, and mediation analyses.

Results

As hypothesised, higher feelings of stigmatisation were related to increased anxiety and depression and lower levels of self-rated health. There was no evidence that psychological flexibility moderated the relationship between stigma and wellbeing outcomes. Mediation analysis showed psychological flexibility mediated the relationship between stigma and anxiety, depression, and self-rated health.

Conclusions

This is the first study to demonstrate that lower psychological flexibility in people with skin conditions is associated with increased feelings of stigma. It is concluded that increased feelings of stigma in people with skin conditions is related to increased anxiety and depression and lower self-reported health, at least in part, due to the relationship between stigma and psychological flexibility. Psychological interventions that aim to increase psychological flexibility (such as Acceptance and Commitment Therapy) could therefore be beneficial for people with skin conditions.

Practitioner Points

- Feeling stigmatised is an important part of living with a skin condition that can significantly influence someone’s wellbeing.
- Psychological flexibility is a potential target for reducing feelings of stigma or improving wellbeing in people with skin conditions, thus, Acceptance and Commitment Therapy interventions should be developed and tested for this patient group.

Keywords

Skin, Dermatology, Stigma, Psychological Flexibility, ACT, Acceptance and Commitment Therapy

Introduction

Evidence of a psychological impact of living with a skin condition is widely reported in dermatology literature. For example, Fried et al. (1995) found that approximately half of a sample of people living with psoriasis felt depressed and anxious in relation to their diagnosis. Research with patients with atopic dermatitis has found evidence of psychological distress, including, depression, anxiety, neuroticism, and hypochondriasis; these patients' scores on distress measures were also found to be higher than in the general population (Ahmar & Kurban, 1976; Arima et al., 2005; Maksimovic et al., 2012). Evidence of psychological distress and reduced quality of life has also been found in patients with hidradenitis suppurativa (Alavi, Anooshirvani, Kim, Coutts, & Shibbald, 2015; Wolkenstein, Loundou, Barrau, Auquier, & Revuz, 2007). Picardi, Lega, and Tarolla (2013) found that risk of suicide was higher in patients with skin conditions than in the general population; they were able to attribute this increase to emotional distress, as well as the social effects of skin disease such as stigmatisation and reduction in activity. In their review of the psychosocial impact of skin conditions, Hong, Koo, and Koo (2008) conclude that living with a chronic skin condition can have a significant negative impact on quality of life, including increasing psychological and social distress. The authors found that health services and the public often overlooked this impact.

Stigma in Skin Conditions

Research with people with a number of skin conditions, including psoriasis, alopecia, vitiligo, atopic dermatitis, and acne, has reported experiences of feeling stigmatised (Ginsburg & Link, 1989; Liasides & Apergi, 2016; Pahwa, Mehta, Khaitan, Sharma, & Ramam, 2013; Van Beugen et al., 2016; Wittkowski, Richards, Griffiths, & Main, 2004). A systematic review on stigma in skin conditions concluded that stigmatisation is a “common and important problem in dermatology” (Dimitrov & Szepietowski, 2017, p.1115). This review reported experiences of stigma in 20 dermatological conditions. Dimitrov and Szepietrowski (2017) report that visibility of the skin disease and cultural factors such as societal attitudes towards skin disease were notable contributors towards feelings of stigmatisation.

Goffman (2009) defines stigmatised people as people who are not fully socially accepted and therefore constantly striving to change their identity. Jones et al. (1984) conceptualised stigma as varying along six dimensions: aesthetics (potential for a disgust reaction), concealment (visibility of the stigmatising characteristic), course (temporary vs permanent), disruptiveness (amount the stigma interferes with a smooth social interaction), origin (e.g. accidental or deliberate) and peril (does it cause a personal threat e.g. being contagious). Packankis et al. (2018) empirically tested these dimensions and found support for Jones et al.’s model. Packankis et al. found that stigmatised people varied along these dimensions in one of five patterns that had varying levels of psychosocial impact. Through factor analysis, Ginsburg and Link (1989) found feelings of stigmatisation in psoriasis involved six experiences: anticipation, feeling of being flawed, sensitivity to others’ attitudes, guilt and shame, secretiveness, and positive attitudes. Hrehorow, Salomon, Matusiak, Reich, and Szepietoski (2012) report that the most “bothersome” effects of stigma for psoriasis patients were feeling stared at, anticipating rejection, and feeling guilt and shame.

Stigma can be “enacted” (a consequence of the actions of others), or “perceived” (not a consequence of an others action, e.g. Scrambler & Hopkins, 1986). In a sample of people living with epilepsy, Scrambler and Hopkins (1986) found that unhappiness and anxiety related more to perceived than enacted stigma. Although the literature indicates that dermatology patients experience both enacted and perceived stigma, patients with vitiligo were found to be more likely to report perceived stigma and this therefore could be interpreted as more burdensome than enacted stigma (Kent, 1999).

Research has found that feelings of stigma relate to poorer quality of life and increased psychological distress in dermatology patients with a range of conditions, including acne, atopic dermatitis, vitiligo, and psoriasis (Alpsoy et al., 2017; Davern & O’Donnell, 2018; Kent & Al-Abadie, 1996; Richman & Leary, 2009; Wittkowski et al., 2004). Stigma was found to contribute to “burdensome” feelings of being different from others in people living with psoriasis (Parkhouse, 2019). Fortune, Main, O’Sullivan, and Griffiths (1997) found that stress from anticipating other people’s reactions to psoriasis was the best predictor of disability in this population, over and above other medical and health status variables. Another study in psoriasis found that stigmatisation explained 33% of the variance in depressive symptoms in a sample of patients, over and above the impact of demographic variables, length of living with the disease, and amount of social support (Lakuta, Marcinikiewicz, Bergler-Czop, & Brzezinska-Wcislo, 2017). Vardy et al. (2002) found that experience of stigma in people with psoriasis completely mediated the relationship between severity of illness and quality of life. Stigma was the largest contributor to predicting quality of life, above disease and demographic variables, in a study of patients living with acne (Liasides & Apergi, 2016).

Although these relationships between perceived stigma and psychological distress or quality of life are correlational and so we cannot attribute causality, authors in the field frequently conclude that interventions aimed at reducing the impact of perceived stigmatisation are likely to be beneficial to people living with skin conditions.

Acceptance and Commitment Therapy and Perceived Stigma

Acceptance and Commitment Therapy (ACT) is a third-wave cognitive and behavioural therapy that aims to improve wellbeing by increasing “psychological flexibility” (Twohig, 2012). ACT literature defines psychological flexibility as the “ability to be in contact with the present moment and inner experiences that are occurring, without needless defence, and, depending upon the context, persisting or changing in the pursuit of goals or personal values” (Hayes, Luoma, Bond, Masuda, & Lillis, 2006, p.7). Increasing psychological flexibility is achieved by targeting six psychological processes of change: acceptance of thoughts and feelings, defusion from thoughts, being present, self as context (a way of viewing ones thoughts and feelings as only part of oneself), knowing ones values, and committing to action in accordance with ones values (Harris, 2009).

Increasingly, research is demonstrating that ACT can reduce feelings of stigma in patient groups that commonly feel stigmatised (Luoma & Platt, 2015). Group ACT interventions have been found to reduce feelings of stigma in people living with HIV, lung cancer, obesity, and substance misuse problems (Chambers et al., 2012; Hayes, Bunting, & Rye, 2008; Luoma, Kohlenberg, Lillis, Hayes, Bunting, & Masuda, 2009; Skinta, Lezama, Wells, & Dilley, 2015). Within dermatology, research into psychological flexibility has identified ACT as a possible intervention for appearance anxiety for those living with a visible difference (Shepherd, Reynolds, Turner, O’Boyle, & Thompson, 2019).

Authors in the field have suggested that increased psychological flexibility could be the mechanism of change for reduced feelings of stigma after ACT interventions. Mediation analysis showed that change in psychological flexibility mediated changes in stigma pre- versus post- an ACT workshop for obese patients (Lillis et al., 2009). In their sample of patients with lung cancer, Chambers et al. (2012) hypothesise that increased psychological flexibility lead to an "acceptance of distressing thoughts" about cancer and therefore less fusion with feelings of stigma following an ACT intervention.

In their narrative review of ACT and self-stigma, Luoma and Platt (2015) conclude that ACT reduces feelings of stigma by "weakening the influence of self-disparaging thoughts, decreasing avoidance, and increasing psychological flexibility" (p.99). Considering the ACT model, one could say that "weakening the influence of self-disparaging thoughts" equates to defusion from thoughts, and that "decreasing avoidance" equates to accepting thoughts and feelings and engaging in committed action. As such, psychological flexibility can encompass all these observed mechanisms of change.

Krafft, Ferrell, Levin, and Twohig (2018) conducted a meta-analytic review of psychological inflexibility and stigma. They found a positive medium-to-large association between psychological inflexibility and stigma, suggesting inversely that being more psychologically flexible relates to feeling less stigmatised. When the authors narrowed their analysis to include self-stigma only (rather than stigma from others), effect sizes were larger. Krafft et al. outline that ACT effects the influence of stigma by targeting ones' relationship with stigmatizing thoughts or attitudes. They echo findings from previous studies by concluding that mediation research supports psychological flexibility and its components as processes of change in reducing stigma via ACT.

Psychological Flexibility, Stigma, and Wellbeing

Further to a relationship between psychological flexibility and stigma, the literature has proposed that psychological flexibility could have a mediating effect on the relationship between stigma and wellbeing. Valvano et al. (2016) found that cognitive fusion (one of the six processes that underlie psychological flexibility) mediated the effects of stigma on wellbeing in people with Multiple Sclerosis. They hypothesise that becoming cognitively fused to stigmatising thoughts about themselves was harmful to patient's wellbeing and conversely, the ability to "cognitively defuse" from these negative thoughts may be protective. However, the cross-sectional nature of the study precludes assumptions regarding the direction of the relationship between cognitive fusion and stigma. One limitation noted by Valvano et al. is that they focussed solely on cognitive fusion and did not explore other aspects of psychological flexibility.

The Current Study

The current study builds on the evidence that feelings of stigma have been reduced through ACT, and emerging evidence that psychological flexibility may influence the effect of stigma on wellbeing. This study aims to investigate the relationship between stigma and wellbeing in people with skin conditions. It also aims to identify whether being more psychologically flexible moderates any relationship between stigma and wellbeing in adults living with a skin condition.

In contrast to Valvona et al. (2016), who explored only cognitive fusion, this study will explore psychological flexibility in its entirety. Valvona et al. found that cognitive fusion mediated the effects of stigma on wellbeing. A mediating effect suggests that stigma has an effect on wellbeing, at least in part, *through* cognitive fusion. As the current study is concerned with the broader concept of psychological flexibility, it is not proposed that psychological flexibility is a mediator via which stigma effects wellbeing. It is instead proposed that psychological flexibility plays a moderating role. Moderation indicates that a specified variable has an effect on the direction or strength of a relationship between two other variables (Baron & Kenny, 1986). This study therefore hypothesises that psychological flexibility affects the strength of the relationship between feelings of stigma and wellbeing (see Figure 1 for conceptualised diagram).

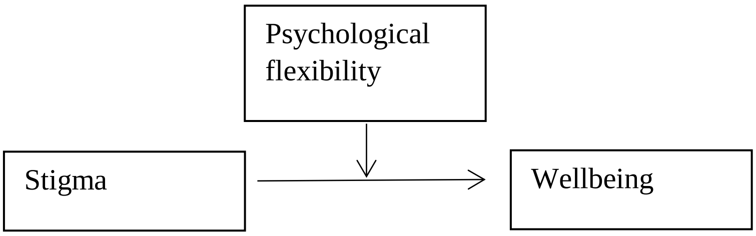


Figure 1 Illustration of hypothesised moderating relationship

The proposed study is therefore a theoretical proof of concept study that would assist in the decision as to whether or not to develop an ACT intervention with the aim to reduce the impact of stigmatisation on wellbeing. If a moderating effect of psychological flexibility is found, this indicates that further study into ACT interventions for people with skin conditions could be beneficial.

Aims

The study aims to test the following hypotheses:

1- Adults with skin conditions who report higher levels of perceived stigma will report lower levels of wellbeing, after controlling for demographic variables and disease severity. This will be indicated by:
   a) higher reported symptoms of anxiety
   b) higher reported symptoms of depression
   c) lower self-reported health state
2- Psychological flexibility will moderate the relationship between perceived stigma and wellbeing in adults with skin conditions. It is hypothesised that higher levels of psychological flexibility will relate to a reduced impact of stigma on psychological wellbeing as indicated by measures of anxiety, depression and self-reported health state.

Method

Design

This cross-sectional survey study examined the relationship between stigma, wellbeing outcomes (depression, anxiety, and self-reported health) and psychological flexibility. The reported study was nested within a multi-centre European study coordinated by the European Society for Dermatology and Psychiatry (ESDAP, see Appendix A for the ESDAP study protocol). The ESDAP study aimed to gather epidemiological data regarding the psychosocial burden of skin disease. The current study utilised only data collected in the United Kingdom (UK), does not use the full data set collected, and includes specific measures only administered in the UK for the purpose of this study. In addition, the present study had different inclusion criteria from the ESDAP study (see Appendix B for full clarification of the independence of this research project).

Ethical Considerations

The National Health Service Research Ethics Committee gave ethical approval for the reported study (see Appendix C). Participants gave informed consent to take part in the study and a researcher informed them the choice to take part would not affect their healthcare provision; they were able to stop or withdraw from the study at any point during completion of the questionnaires (see Appendix D). If participants shared mental health difficulties during the study, they were signposted to local services.

Participants

Participants were recruited from the outpatient dermatology department of the Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust. Patients attending outpatient appointments were approached consecutively on days when the study was running until the required sample size was reached. Data collection took place over a total of 12 days from July to September 2018. Where possible, minimal data was collected from participants who declined to complete the full survey (see Procedure).

Cohen (1992) recommends sample sizes based on expected effect size and the number of variables in a multiple regression. Medium effect sizes were assumed based on a similar study with a sample of patients with Multiple Sclerosis (Valvona et al., 2016). Cohen suggests a sample of 102 participants to give sufficient power for the proposed method of statistical analysis, and this is commensurate with Field's (2009) recommendation of 10-15 participants per variable when conducting multiple regression analysis. The proposed analysis includes a maximum of seven variables, and consequently a sample size of 105 participants was sought.

Inclusion criteria. Participants were recruited based on inclusion criteria: over 18 years of age, sufficient English to complete questionnaires and provide consent, and diagnosis of a chronic dermatological condition.

Exclusion criteria. We excluded participants without a primary diagnosis of a chronic dermatological condition from the reported study. We therefore did not invite patients with a primary psychiatric diagnosis (e.g. trichotillomania, delusional parisitosis etc.), a benign skin lesion, or suspected or diagnosed skin cancer to take part.

Procedure

During clinic appointments, dermatologists invited consecutive patients attending the clinic to take part in the study if they met the required criteria. If patients declined to take part in the full survey study, dermatologists sought verbal consent to record minimal data (age, gender, skin condition and severity, and reason for not taking part, see Appendix E).

If patients gave verbal consent, dermatologists recorded their skin condition and severity. Participants then met with a member of the research team (see acknowledgements) who took full informed consent for the study (see Appendix F). Participants completed the survey with a member of the research team available to answer any questions if required.

Self-report measures. The survey tool can be seen in Appendix G. In addition to the measures listed below, participants completed the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983) and the Dysmorphic Concern Questionnaire (Mancuso, Knoesen, & Castle, 2010) for use in the ESDAP study (data relating to these measures will not be reported here).

Demographic information. Participants provided their age, gender, education level, and employment status. Further questions about participants' skin conditions were also included for use in the ESDAP study.

The Patient Health Questionnaire (PHQ-9). The Patient Health Questionnaire – 9 is a self-administered questionnaire that measure symptoms of depression. Participants are required to rate the frequency of nine symptoms of depression on a scale from "not at all" to "nearly every day". Total scores can be interpreted as indicative of "mild", "moderate", "moderately severe", or "severe" depression (Kroenke, Spitzer, & Williams, 2001). It has been reported to have excellent internal reliability (Cronbach's alpha = 0.89) and test-retest reliability (r = 0.84; Kroenke et al., 2001). Construct validity of the PHQ-9 as assessed by functional status has been classed as "very good" (Kroenke et al., 2001).

The Generalised Anxiety Disorder Assessment (GAD-7). The Generalised Anxiety Disorder Assessment 7 (GAD-7) is a self-administered questionnaire that measures symptoms of generalised anxiety disorder. The questionnaire asks participants to rate the frequency of nine symptoms of anxiety on a scale from "not at all" to "nearly every day". Total scores can be interpreted as representing "mild", "moderate", or "severe" anxiety (Spitzer, Kroenke, Williams, & Lowe, 2006). Internal consistency has been found to be excellent in the general population (Cronbach's alpha = 0.89; Lowe et al., 2008). The GAD-7 has shown good reliability (test-retest r = 0.83) and construct validity, as illustrated by correlation to functional impairment (Spitzer et al., 2006).

EQ5D5L Visual Analogue Scale (VAS). The EQ5D5L VAS is an assessment of self-reported health (Herdman et al., 2011). The vertical visual analogue scale requires participants to rate their health that day from zero (“the worst health you can imagine”) to 100 (“the best health you can imagine”). The validity of the EQ5D5L in dermatological populations has been evaluated as good (Yang, Brazier, & Longworth, 2015). Yang et al. report that the EQ5D5L showed moderate-to-strong correlations with other health-related quality of life measures and could detect significant changes in health status over time. It should be noted that these findings relate to the whole EQ5D5L; the VAS is a subtest within this measure and validation data is not available for this subscale alone.

Perceived Stigmatisation Questionnaire (PSQ). The Perceived Stigmatisation Questionnaire (PSQ) has 21-items that assess perceived stigmatisation and social experience (Lawrence, Fauerbach, Heinberg, Doctor, & Thombs, 2006). Within a sample of adult burn survivors, the PSQ has been found to show excellent internal consistency (Cronbach’s alpha = .93) and to correlate with related psychosocial constructs, suggesting good convergent and discriminant validity (Lawrence et al., 2006).

Comprehensive Assessment of Acceptance and Commitment Therapy Processes (CompACT). The CompACT (Francis, Dawson, & Golijani-Moghaddam, 2016) is a 23-item measure of psychological flexibility. Correspondents respond to questions on a 7-point Likert scale from “strongly disagree” to “strongly agree”. It has three factors that correspond to the ACT “triflex”, comprised of the six elements of psychological flexibility. The three factors taken from the triflex are “being present”, “opening up”, and “doing what matters” (Francis et al., 2016).

The CompACT generates subscale scores and an overall measure of psychological flexibility. Internal consistency of the CompACT total score when used in a non-clinical population has been found to be excellent (Cronbach’s alpha = .91; Francis et al., 2016). CompACT subscale and total scores have been found to converge/diverge appropriately with existing ACT measures such as The Acceptance and Action Questionnaire (AAQ-II; Francis et al., 2016). The AAQ-II is a more commonly used measure of ACT processes; however, it includes items measuring distress, which limits its construct validity (Wolgast, 2014). As we are looking for correlations with psychological distress measures this would be problematic in the current study.

Analysis

The relationship between stigma and wellbeing (anxiety, depression, and self-reported health) was investigated using hierarchical regression analysis, controlling for any effects of age, gender and clinician-rated severity of illness. Where relationships were found between stigma and wellbeing, moderation analysis was conducted to test the hypothesis that psychological flexibility moderates the relationship between feelings of stigma and wellbeing.

Statistical analysis was completed in IBM SPPS Statistics 25.

Results

Data screening

Data were checked for missing values, impossible values, and errors. Where questionnaires were attempted, there were no missing or impossible values. Some participants did not attempt all questionnaires or provide all demographic data. These participants were not excluded from analysis or replaced so as not to manipulate sample selection.

Demographics

Participants (*N* = 105) presented with 29 different primary skin conditions (for full list see Appendix H). The most common diagnoses were psoriasis (*N* = 23), eczema (*N* = 16) and alopecia (*N* = 11). People with acne (*N* = 7), rosacea (*N* = 3), and urticaria (*N* = 2) were also represented in the sample.

Participants were 57% female (*N* = 60), their age ranged from 19 to 90 years with a mean age of 53.9 years (*SD* = 18.0). The majority of participants' highest level of education was GCSE equivalent or below (63%, *N* = 66) and most participants were currently employed (41%, *N* = 43) or retired (40%, *N* = 42). Clinician's ratings of the severity of participants' skin disease was most commonly moderate (45%, *N* = 44) or severe (34%, *N* = 36). See Table 1 for more detailed reporting of education, employment status, and clinician rated severity.

Table 1
Additional Participant Demographics Information

Highest level of education	*N*	%
GCSE or below	66	63
A Level or equivalent	10	10
Degree or above	29	27
Employment status	*N*	%
Unemployed	15	14
Retired	42	40
Sick leave	1	1
In education	2	2
Employed	43	41
Missing	2	2
Clinician rated severity of skin disease	*N*	%
Mild	20	19
Moderate	47	44
Severe	36	34
Missing	2	2

Comparison to non-participants. There were no differences found in percentage of males and females between participants and those who did not complete the survey but consented to minimal data being collected from their dermatologist (*N* = 53), percentages of males and females were identical across both groups. A t-test found no significant difference in age between participants (*M* = 53.9 years, *SD* = 18.0) and non-participants (*M* = 54.6 years, *SD* = 20.7); *t*(150) = .23, *p* = .82.

A chi-squared test showed a significant difference in clinician-rated severity of skin disease between participants and non-participants, $X^2(2, N = 151) = 6.48$, p = .039. Examination of the data suggests this is due to a higher percentage of low severity skin disease in the non-participants and/or medium severity in participants; this was supported by examination of expected values calculated through cross-tabulation (see Table 2).

Table 2
Clinician Rated Severity for Participants and Non-participants

	Low Severity	Medium Severity	High Severity
Non-participants % (N)	38 (18)	29 (14)	33 (16)
Participants % (N)	19 (20)	46 (47)	35 (36)

Descriptive Statistics

Descriptive statistics for the measures used in the regression analysis can be seen in Table 3. Histograms were examined for skewness. Measures of psychological distress (anxiety and depression) were positively skewed. Ratings of self-reported health were negatively skewed (see Appendix I). There was a notable outlier in the stigma data, with one participant scoring very highly on the Perceived Stigmatisation Questionnaire (49, *z* = 3.15). All reported analyses were re-run with the outlier removed and conclusions drawn were the same, reported results therefore include the outlier as it was deemed a genuine, although extreme, score. Internal consistency, as indicated by Cronbach's alpha, was found to be excellent for responses to the PHQ-9, GAD-7, and PSQ, and acceptable for the CompACT (George & Mallery, 2003; see Table 3).

Table 3

Descriptive Statistics for Regression Measures

Variable	Mean	SD	Min	Max	α*
Depression (PHQ 9 score, *N* = 102)	7.77	7.45	0	27	.92
Self-rated health (VAS score, *N* = 101)	66.7	20.7	0	100	-
Anxiety (GAD 7 score, *N* = 102)	6.67	6.13	0	20	.93
Stigma (PSQ score, *N* = 98)	14.4	11.0	0	49	.90
Psychological flexibility (CompACT score, *N* = 99)	82.4	18.5	39	123	.78

*Cronbach's alpha

Correlation Analysis

Correlation analysis was first performed to examine relationships between variables of interest. As multiple variables violated criteria for normality due to skew, a non-parametric test was used (Spearman's rank). Correlations were interpreted in line with Cohen's (1988) criteria, in which r = .10 to .29 reflects a small effect, r = .30 to r = .49 reflects a medium effect, and r = .50 to r = .10 reflects a large effect.

Depression was significantly positively correlated with anxiety (large effect) and stigma (medium effect), and negatively correlated with self-reported health (large effect). Anxiety was significantly positively correlated with stigma (small effect), and negatively correlated with self-reported health (large effect). Self-reported health was significantly negatively correlated with stigma (small effect). Psychological flexibility was significantly negatively correlated with depression (large effect), anxiety (large effect), and stigma (small effect) and positively correlated with self-reported health (medium effect, see Table 4).

Table 4
Spearman's Rank Correlation for Regression Measures

	Anxiety	Self-reported health	Stigma	Psychological flexibility
Depression	.82**	-.59*	.35**	-.63**
Anxiety	-	-.55**	.24*	-.71**
Self-reported health	-	-	-.27**	.47**
Stigma	-	-	-	-.29**

Note. *significant at p < .05 **significant at p < .01

Regression Analysis

Anxiety, depression, and self-reported health variables were log transformed prior to regression analysis as they did not meet criteria for normality due to skew.

Stage one. Demographic variables (age, gender and clinician rated severity) were entered as predictors into three models, one for each outcome variable (depression, anxiety, and self-rated health). Age and clinician rated severity were checked for multicollinearity however were not significantly correlated therefore this assumption of regression was not violated.

Depression. The demographic variables model did not explain a significant proportion of variance in log depression scores, R^2 = -.03, F(3,96) = .17, p = .92. No individual demographic variables were significantly predictive of depression, as supported by confidence intervals crossing zero (see Table 5).

Self-reported health. The demographic variables model did not explain a significant proportion of variance in log self-reported health scores, R^2 = -.02, F(3,95)

= .31, *p* = .82. No individual demographic variable were significantly predictive of self-reported health, as supported by confidence intervals crossing zero (see Table 6).

Anxiety. The demographic variable model did not explain a significant proportion of variance in log anxiety scores $R^2 = .02$, $F(3,96) = 1.73$, $p = .17$. Gender and severity of illness were not significantly predictive of log anxiety scores, as supported by confidence intervals crossing zero (see Table 7). Age was significantly predictive of log anxiety score, $\beta = -.23$, $t(96) = -2.26$, $p = .03$, and was retained as a predictive variable for stage two of regression. When entered in to the model as a lone predictor, age explained 4% of the variance in log anxiety scores $R^2 = .04$, $F(1,98) = 5.09$, $p = .026$.

Stage two. Stigma was added to each model as a predictor at stage two.

Depression. Stigma explained a significant proportion (12%) of variance in log depression score $R^2 = .12$, $F(1,95) = 14.0$, $p < .001$. Stigma was significantly predictive of log depression score $\beta = .36$, $t(95) = 3.75$, $p < .001$ (see Table 5).

Self-rated health. Stigma explained a significant proportion (5%) of variance in log self-rated health score $R^2 = .05$, $F(1,96) = 6.25$, $p = .014$. Stigma was significantly predictive of log self-rated health score $\beta = .25$, $t(96) = 2.5$, $p = .014$ (see Table 6).

Anxiety. When stigma was added after age as a predictor of log anxiety score, the model explained a significant proportion (10%) of variance in log anxiety score $R^2 = .10$, $F(1,93) = 6.16$, $p = .003$. Age remained significantly predictive of log anxiety score $\beta = -.21$, $t(93) = -2.06$, $p = .042$. After controlling for age, stigma was significantly predictive of log anxiety score $\beta = .23$, $t(93) = 2.34$, $p = .021$ (see Table 7).

Table 5

Regression Table for Outcome Variable Depression

	B	*SE B*	β	R^2	ΔR^2	*F*	*95% CI* Lower	*95% CI* Upper
Stage One	-	-	-	-.026	.005	.17	-	-
Gender	.012	.21	.006	-	-	-	-.41	.43
Age	-.004	.006	-.068	-	-	-	-.015	.008
Severity of Illness	-.022	.080	-.029	-	-	-	-.18	.14
Stage Two	-	-	-	.12	.13	14.0***	-	-
Stigma	.034	.009	.36***	-	-	-	.016	.052

Note. ***significant at p<.001

Table 6

Regression Table for Outcome Variable Self-Reported Health

	B	*SE B*	β	R^2	ΔR^2	*F*	*95% CI* Lower	*95% CI* Upper
Stage One	-	-	-	-.022	.010	.31	-	-
Gender	.013	.16	.009	-	-	-	-.31	.33
Age	.001	.004	.023	-	-	-	-.008	.010
Severity of Illness	.055	.061	.095	-	-	-	-.067	.18
Stage Two	-	-	-	.051	.061	6.25**	-	-
Stigma	.017	.007	.25**	-	-	-	.003	.030

Note. ** significant at p < .01

Table 7
Regression Table for Outcome Variable Anxiety

	B	*SE B*	β	R^2	ΔR^2	*F*	*95% CI* Lower	*95% CI* Upper
Stage One	-	-	-	.022	.051	1.73	-	-
Gender	-.071	.20	-.037	-	-	-	-.46	.32
Age	-.012	.005	-.23*	-	-	-	-.023	-.001
Severity of Illness	-.012	.075	-.016	-	-	-	-.16	.14
Stage Two	-	-	-	.098	.052	6.16**	-	-
Age	-.011	.005	-.21*	-	-	-	-.022	-.0004
Stigma	.020	,008	.23*	-	-	-	.003	.037

Note. * significant at p<.05, ** significant at p<.01

For all models, scatter plots showed the variables met criteria for linearity. There were no multivariate outliers in any of the models, as evidenced by no Mahalanobis' distances below the critical alpha value of .001. Plots of residuals showed the models to meet criteria for homoscedasticity and normal distribution.

These regression analyses results provide support for the first study hypotheses, in that increased feelings of stigma is predictive of higher anxiety and depression, and lower self-reported health.

Moderation analysis. A moderated regression analysis was conducted to assess whether psychological flexibility (total score on the CompACT questionnaire) moderated the relationship between stigma and wellbeing outcomes. Psychological flexibility was first added as a predictor into the above models. To test for moderation, stigma, psychological flexibility and their interaction were then entered together in a single block to the three models. Variables were mean-centred prior to computing the interaction terms in order to minimize any problems of multicollinearity. A significant interaction term would indicate that there is moderation.

Depression. Entered together, stigma and psychological flexibility were found to explain 40% of the variance in log depression scores $R^2 = .39$, $F(2,94) = 31.30$, $p < .001$. Stigma remained significantly predictive of log depression score $\beta = .19$, $t(94) = 2.27$, $p < .05$. Psychological flexibility was significantly predictive of log depression score $\beta = -.55$, $t(94) = -6.51$, $p < .001$. When the interaction term was added to the model, the model explained 38% of variance in log depression scores $R^2 = .38$, $F(3,93) = 20.63$, $p < .001$. The interaction term was not a significant predictor of depression (see Table 8). There is therefore no evidence that psychological flexibility significantly moderates the relationship between stigma and depression.

Self-reported health. Stigma and psychological flexibility explained 17% of variance in log self-reported health $R^2 = .17$, $F(2,95) = 10.6$, $p < .001$. In this model stigma was no longer predictive of self-reported health $\beta = .12$, $t(95) = 1.19$, $p = .24$. Psychological flexibility was significantly predictive of log self-reported health $\beta = -.37$, $t(95) = -3.75$, $p < .001$. When the interaction term was added to the model, the model explained 16% of variance in log self-reported health $R^2 = .16$, $F(3,94) = 7.2$, $p <.001$. The interaction term was not a significant predictor of self-reported health (see Table 9). There is therefore no evidence that psychological flexibility significantly moderates the relationship between stigma and self-reported health.

Anxiety. When stigma and psychological flexibility were added after age as a predictor of log anxiety score, the model explained a significant proportion (51%) of variance in log anxiety score $R^2 = .51$, $F(3,92) = 33.4$, $p < .001$. Age remained significantly predictive of log anxiety score $\beta = -.19$, $t(92) = -2.57$, $p = .012$. Stigma was no longer predictive of log anxiety score β = .0003, *t*(92) = .004, *p* = 1.00. Psychological flexibility was significantly predictive of log anxiety score *β* = -.68, *t*(92) = -8.81, *p* < .001. When the interaction term was added to the model, the model explained 50% of variance in log anxiety score R^2 = .50, *F*(3, 91) = 28.92, *p* <.001. The interaction term was not a significant predictor of anxiety (see Table 10). There is therefore no evidence that psychological flexibility significantly moderates the relationship between stigma and anxiety.

These moderation analyses do not support the second study hypothesis. There is no evidence from these results that psychological flexibility moderates the relationship between stigma and anxiety, depression, or self-reported health.

Table 8
Results of Moderation Analysis for Outcome Variable Depression

Variable	*B*	*SE B*	β	*95% CI* Lower	*95% CI* Upper
Stigma	.018	.008	.20*	.002	.035
Psychological flexibility	-.030	.005	-.55***	-.039	-.021
Stigma x Psychological flexibility	.00006	.0004	.011	-.001	.001

Note. * significant at p < .05, *** significant at p < .001

Table 9
Results of Moderation Analysis for Outcome Variable Self-Reported Health

Variable	*B*	*SE B*	β	*95% CI* Lower	*95% CI* Upper
Stigma	.010	.007	.15	-.004	.024
Psychological flexibility	-.015	.004	1.38***	-.023	-.007
Stigma x Psychological flexibility	.0003	.0003	.079	-.0004	.001

Note. *** significant at p < .001

Table 10

Results of Moderation Analysis for Outcome Variable Anxiety

Variable	*B*	*SE B*	β	*95% CI* Lower	*95% CI* Upper
Block one					
Age	-.010	.004	-.19*	-.018	-.002
Block two					
Stigma	.0005	.007	.006	-.013	.014
Psychological flexibility	-.034	.004	-.68***	-.042	-.027
Stigma x Psychological flexibility	.00007	.0004	.017	-.001	.001

*Note. * significant at p < .05, *** significant at p < .001*

Mediation analysis. In the moderation models, psychological flexibility was predictive of depression, anxiety and self-rated health. With the addition of psychological flexibility, stigma was no longer a significant predictor of anxiety or self-reported health. This suggests some common variance between stigma and psychological flexibility, suggesting a mediational analysis might be appropriate. A post-hoc mediation analysis was therefore undertaken. As per Preacher and Hayes (2009), stigma was entered simultaneously with the potential mediator of psychological flexibility in to three models, one for each outcome variable. Bootstrapping procedures were then used to assess for the significance of any mediated effects.

Depression. The path from stigma to psychological flexibility was significant *B* = -.54, *SE* = .17, *p* = .002. The direct effect of psychological flexibility on depression was significant *B* = -.030, *SE* = .004, *p* < .001. The effect of stigma on depression, *B* = .034 *SE* = .009, *p* < .001, remained significant when psychological flexibility was controlled for *B* = .018, *SE* = .008, *p* = .025, indicating any mediation would be partial. Using bootstrapping procedures, the mediating effect was found to be significant *B* = .020, *SE* = .005 *CI* = .006 to .028.

Self-reported health. The path from stigma to psychological flexibility was significant *B* = -.59, *SE* = .16, *p* < .001. The direct effect of psychological flexibility on self-reported health was significant *B* = -.015, *SE* = .004, *p* < .001. The effect of stigma on self-reported health, *B* = .017, *SE* = .007, *p* = .014, was reduced to non-significance when psychological flexibility was controlled for *B* = .008, *SE* = .007, *p* = .24, indicating mediation. Using bootstrapping procedures, the mediating effect was found to be significant *B* = .008, *SE* = .003, *CI* = .002 to .016.

Anxiety. For the anxiety model, age was added simultaneously as a covariate. The path from stigma to psychological flexibility was significant *B* = -.57, *SE* = .17, *p* < .001. The direct effect of psychological flexibility on anxiety was significant *B* = -.034, *SE* = .004, *p* < .001. The effect of stigma on anxiety, *B* = .020, *SE* = .008, *p* = .022, was reduced to non-significance when psychological flexibility was controlled for *B* = .00001 *SE* = .007, *p* = 1.00, indicating mediation. Using bootstrapping procedures, the mediating effect was found to be significant *B* = .020, *SE* = .006 *CI* = .009 to .032.

Discussion

This study found a relationship between increased feelings of stigma and higher symptoms of depression and anxiety, and reduced self-reported health, in people living with skin conditions. This echoes previous research in to the effects of stigma in skin conditions (Alpsoy et al., 2017; Davern & O'Donnell, 2018; Kent & Al-Abadie, 1996; Richman & Leary, 2009; Wittkowski et al., 2004). We cannot conclude the direction of the observed relationship through this cross sectional study. Increased anxiety and depression, or lower self-reported health, may cause people to perceive themselves as more stigmatised or, alternatively, feelings of stigmatisation might lead to increased anxiety and depression and lower self-reported health. A bidirectional relationship is also highly likely, in which stigmatisation and wellbeing affect each other in a self-perpetuating manner.

There was no support found for the second hypothesis of the study; psychological flexibility did not moderate the relationship between stigma and wellbeing outcomes. This means that the level of psychological flexibility in people with skin conditions did not affect the strength of the relationship between stigma and depression, anxiety, or self-reported health. Regression and correlational analysis did, however, show a relationship between stigma and psychological flexibility, as has been reported in previous research with non-dermatological stigmatised groups (Krafft, Ferrell, Levin, & Twohig, 2018; Lillis et al., 2009). Moderation analysis results provided a rationale for a post-hoc mediation analysis. Psychological flexibility significantly mediated the relationship between stigma and symptoms of depression and anxiety, and self-reported health. In the case of depression, this was a partial mediation.

These results indicate that stigma is related to anxiety and self-reported health through associations with psychological flexibility (see Figure 2 for illustration). Without the mediator of psychological flexibility, the relationships between stigma and anxiety and self-reported health were no longer significant. Stigma is also related to depression through its relationship with psychological flexibility, however, there is also a significant direct relationship between stigma and depression (or a relationship through unknown other mediators, see Figure 2 for illustration).

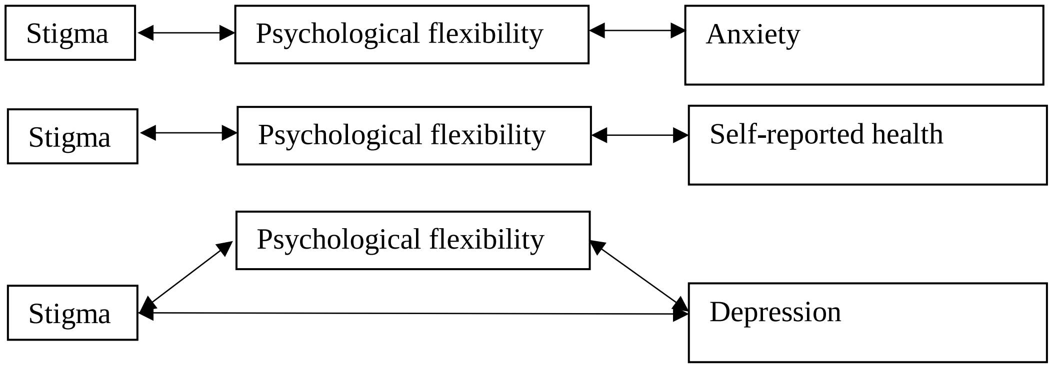


Figure 2. Illustration of significant relationships found through mediation analysis

It is important to note that we cannot distinguish the directionality of the relationships between variables found in this mediation analysis (causality), due to the cross-sectional nature of this study. We can conclude that in people with skin conditions, increased psychological flexibility is related to less feelings of perceived stigma and this is related to a positive effect on wellbeing, or conversely that poorer psychological flexibility is related to increased feelings of perceived stigma and worse wellbeing. This mediating relationship echoes the findings of Valvano et al. (2016) who found a mediating role of cognitive fusion (one aspect of psychological flexibility) in the relationship between stigma and depression, anxiety, and quality of life in people with Multiple Sclerosis (MS). As in this reported study, Valvano et al. state that they cannot attribute directionality to their model, however suggest that considering psychological flexibility as accounting for wellbeing, rather than the reverse, is more consistent with Acceptance and Commitment Therapy theory. Valvano et al. (2016) propose a mechanism in which people with MS who are more “fused” to stigma-related thoughts (poorer cognitive defusion) are more susceptible to increased depression, anxiety, and quality of life. One limitation acknowledged by

Valvano et al. is that they only explored one area of psychological flexibility. Valvano et al.'s proposed mechanism may be applicable to this study's findings in people with skin conditions; however, as this study used a broader measure of psychological flexibility, we must also consider the other aspects of the concept.

As well as cognitive fusion, psychological flexibility also includes "acceptance", "self-as-context" and "doing what matters" and as such, any of these concepts may contribute to the mediating role of psychological flexibility. The ability to accept and live alongside difficult thoughts and feelings relating to stigma ("acceptance") may support people with skin conditions to experience less impact of stigma on their wellbeing. Alternatively, being able to have contact with the present moment and see thoughts and feelings as only part of oneself ("self-as-context") could lessen the impact of stigma. Finally, being able to live according to ones values despite stigma ("doing what matters") could be the aspect of psychological flexibility that mediates the relationship between stigma and wellbeing. Most likely, a combination all of these aspects of psychological flexibility can play a role in protecting people from the impact of stigma on wellbeing, and it may vary person-to-person. The current study did not allow for investigation into different aspects of psychological flexibility. This limitation provides a potential useful avenue for future research.

It is notable that only a partial mediation effect was found for the wellbeing measure of depression, whereas full mediation was observed in anxiety and self-reported health. This suggests that psychological flexibility does not represent the full mechanism by which stigma is related to symptoms of depression, as it does for anxiety or self-reported health. This is an important finding, as it suggests that any interventions targeting psychological flexibility with the aim to lessen the impact of stigma on wellbeing may be more effective for feelings of anxiety or quality of life rather than low mood. Theoretically, it also indicates that stigma may be directly related to low mood, or may be related to low mood due to unknown mediators other than psychological flexibility.

The demographic variables of age, gender, and clinician's rating of skin condition severity were explored as part of regression analysis. Age was only significantly related to increased anxiety and there was no significant relationships between gender and wellbeing. Interestingly, clinician-rated severity was also not related to scores on measures of depression, anxiety, or self-reported health. This indicates that the objective severity of someone's skin disease does not give an indication of how likely they are to experience difficulties with their emotional wellbeing. This echoes previous findings that showed the lack of a direct relationship between the extent of psoriasis and measures of quality of life, or mood (Garcia-Sanchez et al., 2017; Lakunta, Marcinkiewicz, Bergler-Czop, & Brezezinska-Wcislo, 2017). These findings have important clinical implications for identifying patients in need of emotional or psychological support, and highlight the importance of not making assumptions based upon severity of skin condition.

Strengths of this study include the participant number providing significant power for the statistical analyses and the inclusion of people with a broad range and severity of skin conditions. Recruiting from a clinical setting allows confidence that participants had a diagnosed skin condition. Comparison to non-participants found that the age and gender of participants was not significantly different from other attendees at the dermatology clinic, suggesting the sample provides good representation of the population of people with skin conditions in terms of these characteristics. People who decided to take part in the study were less likely to have a low-severity skin condition, and more likely to have a medium-severity skin condition than those who did not take part. This may indicate that those with low-severity skin conditions are less motivated to take part in research. When considering generalisability of these findings and implications for clinical practise it is therefore important to consider that the sample in this research may underrepresent the experiences of people with low-severity skin conditions. A large proportion of the participants in this study were retired (40%), this compares to only 18.2% of people in the UK being over retirement age in 2017 (Office for National Statistics, 2018). This proportion of retirees may be representative of the population of people who attend outpatient appointments with a skin condition, however as we did not collect this data from people who did not participate in the study, we cannot conclude this with confidence. It is likely that retirees are overrepresented in this research, perhaps due to them having more time available for research. This should be considered in interpreting findings and future research should make efforts to recruit a sample whose working status is representative of the population of people with skin conditions.

There are some further limitations to consider regarding interpretation of the results. Firstly, as we are limited in interpretation of the mediation analysis due to the cross-sectional nature of the data. Use of this type of data does not allow comments to be made on directionality of relationships and future research would benefit from utilising data collected at multiple time points. Additionally, the visual analogue scale (VAS) of self-reported health was selected as a brief overall measure of general quality of life; however, it is clearly health-specific and may not fully capture this concept. Validity and reliability data for use of the VAS independent of the full EQ5D5L are not available and therefore results relating to this measure should be interpreted with some caution. The CompACT was selected as it was the best available measure of psychological flexibility that did not include aspects of psychological distress. Anecdotally, participants found this questionnaire difficult to understand. Measuring psychological flexibility requires gaining information from people about relatively abstract concepts and metacognition, and as such it is understandable that questions can become complex. Future research may need to consider how to measure psychological flexibility in a way that is accessible to people with a broad range of reading abilities or educational backgrounds.

Clinical Implications and Indications for Future Research

This research contributes to the large body of evidence that stigma is an important part of the lived experience of having a skin condition, that can affect people's wellbeing (e.g. Alpsoy et al., 2017; Davern & O'Donnell, 2018; Kent & Al-Abadie, 1996; Richman & Leary, 2009; Wittkowski et al., 2004). It is important therefore that professionals working with people with skin conditions, in physical and mental health settings, are aware of the importance of stigma and discuss its impact with patients. Research in to the nature of stigmatisation in skin conditions indicates that feelings of perceived stigma often relate to the conditions' visibility (Ginsburg and Link, 1989; Hrehorow, Salomon, Matusiak, Reich, & Szepietoski, 2012), and therefore any interventions targeting stigma will need to consider this.

The mediating role of psychological flexibility in the relationship between stigma and wellbeing highlights it as a potential target for change. Acceptance and Commitment Therapy (ACT) interventions that aim to increase psychological flexibility could therefore be a useful intervention for people with skin conditions experiencing psychological distress, as it has been in other stigmatised conditions (e.g. Chambers et al., 2012; Hayes, Bunting, & Rye, 2008; Luoma, Kohlenberg, Lillis, Hayes, Bunting, & Masuda, 2009; Skinta, Lezama, Wells, & Dilley, 2015). Consequently, this study provides the first clear theoretical evidence to support the development and testing of ACT as an intervention to assist people living with skin conditions in managing the impact of stigma, with the aim to reduce psychological distress and improve quality of life.

References

Ahmar, H., & Kurban, A.K. (1976). Psychological profile of patients with atopic dermatitis. *British Journal of Dermatology, 95*, 373-377. https://doi.org/10.1111/j.1365-2133.1976.tb00838.x

Alavi, A., Anooshirvani, N., Kim, W.B., Coutts, P., & Sibbald, R.G. (2015). Quality-of-life impairment in patients with hidradenitis suppurativa: a Canadian study. *American Journal of Clinical Dermatology, 16*, 61-65. https://doi.org/10.1007/s40257-014-0105-5

Alpsoy, E., Polat, M., FettahlioGlu-Karaman, B., Karadag, A.S., Kartal-Durmazlar, P., YaiCin, B. … & Semoi, Y. (2017). Internalized stigma in psoriasis: a multicentre study. *The Journal of Dermatology, 44*, 885-891. https://doi.org/10.1111/1346-8138.13841

Arima, M., Shimizu, Y., Sowa, J., Narita, T., Nishi, I., Iwata, N., … & Matsunaga, K. (2005). Psychosomatic analysis of atopic dermatitis using a psychological test. *The Journal of Dermatology, 32*, 160-168. https://doi.org/10.1111/j.1346-8138.2005.tb00738.x

Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistic consideration. *Journal of Personality and Social Psychology, 51*, 1173-1182. http://dx.doi.org/10.1037/0022-3514.51.6.1173

Chambers, S.K., Morris, B.A., Clutton, S., Foley, E., Giles, L., Schofield. P., O’Connell, D., & Dunn, J. (2015). Psychological wellness and health-related stigma: a pilot study of an acceptance-focused cognitive behavioural intervention for people with lung cancer. *European Journal of Cancer Care, 24*, 60-70. http://dx.doi.org/10.1111/ecc.12221

Cohen, J. (1988). Statistical power analysis for the behavioral sciences (2nd ed.). Hillsdale, NJ: Lawrence Earlbaum Associates.

Cohen, J. (1992). A power primer. *Quantitative Methods in Psychology, 112*, 155-159. http://doi.org/10.20982/tqmp.03.2.p079

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, *24,* 385-396. http://dx.doi.org/10.2307/2136404

Davern, J., & O'Donnell, A.T. (2018). Stigma predicts health-related quality of life impairment, psychological distress, and somatic symptoms in acne sufferers. *PLoS ONE*, *13,* e0205009. https://doi.org/10.1371/journal.pone.0205009

Dimitrov, D., & Szepietowski, J.C. (2017). Stigmatization in dermatology with a special focus on psoriatic patients. *Advances in Hygiene and Experimental Medicine*, *71*. 1015-1022. https://doi.org/10.5604/01.3001.0010.6879

Field, A. (2009). *Discovering statistics using SPSS*. Sage publications.

Fortune, D.G., Main, C.J., O'Sullivan, T.M., & Griffiths, C.E. (1997). Quality of life in patients with psoriasis: the contribution of clinical variables and psoriasis-specific stress. *British Journal of Dermatology, 137*, 755-760. https://doi.org/10.1046/j.1365-2133.1997.19472062.x

Francis, A.W., Dawson, D.L., & Golijani-Moghaddam, N. (2016). The development and validation of the Comprehensive assessment of Acceptance and Commitment Therapy processes (CompACT). *Journal of Contextual Behavioral Science*, *5*, 134-145. https://doi.org/10.1016/j.jcbs.2016.05.003

Fried, R.G., Friedman, S., Paradis, C., Hatch, M., Lynfield, Y., Duncanson, C., & Shalita, A. (1995). Trivial or terrible? The psychosocial impact of psoriasis.

International Journal of Dermatology, 34, 101-105. https://doi.org/10.1111/j.1365-4362.1995.tb03588.x

Garcia-Sanchez, L., Montiel-Jarquin, A.J., Vazquez-Cruz, E., May-Salazar, A., Gutierrez-Gabriel, I., Loria-Castellanos, J. (2017). Quality of life in patients with psoriasis. *Gaceta Medica de Mexico, 153,* 185-189.

George, D. & Mallery, P. (2003). *SPSS for Windows Step by Step: A Simple Guide and Reference.* Boston: Allyn & Bacon.

Ginsburg, I. H., & Link, B. G. (1989). Feelings of stigmatization in patients with psoriasis. *Journal of the American Academy of Dermatology, 20,* 53-64. https://doi.org/10.1016/S0190-9622(89)70007-4

Goffman, E. (2009). *Stigma: Notes on the Management of Social Identity.* Simon and Schuster.

Harris, R. (2009). *ACT Made Simple: An Easy-to-Read Primer on Acceptance and Commitment Therapy.* Oakland, CA: New Harbinger.

Hayes, S.C., Luoma, J.B., Bond, F.W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: model, processes and outcomes. *Behaviour Research and Therapy, 44*, 1-25. https://doi.org/10.1016/j.brat.2005.06.006

Herdman, M., Gudex, C., Lloyd, A., Janssen, M., Kind, P., Parkin, D., Bonsei, G., & Badia, X. (2011). Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Quality of Life Research, 20,* 1727-1736. https://doi.org/10.1007/s11136-011-9903-x

Hong, J., Koo, B., & Koo, B. (2008). The psychosocial and occupational impact of chronic skin disease. *Dermatologic Therapy, 21*, 54-59. https://doi.org/10.1111/j.1529-8019.2008.00170.x

Hrehorow, E., Salomon, J., Matusiak, L., Reich, A., & Szepietoski, J. C. (2012). Patients with psoriasis feel stigmatized. *Acta Dermato Venereologica, 92,* 67-72. https://doi.org/10.2340/00015555-1193

Jones, E.E., Farina, A., Hastorf, A.H., Markus, H., Miller, D.T., & Scott, R.A. (1984). *Social stigma: The psychology of marked relationships.* New York, NY: W.H. Freeman.

Kent, G. (1999). Correlates of perceived stigma in vitiligo. *Psychology and Health, 14*, 241-251. https://doi-org.sheffield.idm.oclc.org/10.1080/08870449908407325

Kent, G., & Al-Abadie, M. (1996). Factors affecting responses on dermatology life quality index items among vitiligo sufferers. *Clinical and Experimental Dermatology, 21*, 330-333. https://doi.org/10.1111/j.1365-2230.1996.tb00116.x

Krafft, J., Ferrell, J., Levin, M.E., & Twohig, M.P. (2017). Psychological inflexibility and stigma: a meta-analytic review. *Journal of Contextual Behavioral Science, 7,* 15-28. https://doi.org/10.1016/j.jcbs.2017.11.002

Kroenke, M.D., Spitzer, R.L., & Williams, J.B. (2001). The PHQ-9 validity of a brief depression severity measure. *Journal of General Internal Medicine, 16,* 606-613. https://doi.org/10.1046/j1525-14972001016009606x

Lakuta, P., Marcinkiewicz, K., Bergler-Czop, B., & Brzezinska-Wcislo, L. (2017). How does stigma affect people with psoriasis? *Advances in Dermatology and Allergology, 34,* 36-41. https://doi.org/10.5114/pdia.2016.62286

Lawrence, J.W., Fauerbach, J.A., Heinberg, L.J., Doctor, M., & Thombs, B.C. (2006). The reliability and validity of the Perceived Stigmatization Questionnaire (PSQ) and the Social Comfort Questionnaire (SCQ) among an adult burn survivor sample. *Psychological Assessment*, *18,* 106-111. https://doi.org/10.1037/1040-3590.18.1.106

Liasides, J., & Apergi, F.S. (2016). Predictors of quality of life in adults with acne: the contribution of perceived stigma. *Acta Dermato-Venereologica, 96,* 138.

Lillis, J., Hayes, S.C., Bunting, K., & Masuda, A. (2009). Teaching acceptance and mindfulness to improve the lives of the obese: A preliminary test of a theoretical model. *Annals of Behavioural Medicine*, *37,* 58-69. http://dx.doi.org/10.1007/s12160- 009-9083-x

Lowe, B., Decker, O., Muller, S., Brahler, E., Schellberg, D., Herzog, W., & Herzberg, P.Y. (2008). Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. *Medical Care, 46*, 266-274. https://doi.org/10.1097/mlr.0b013e318160d093

Luoma, J.B., Kohlenberg, B.S., Hayes, S.C., Bunting, K., & Rye, A.K. (2008). Reducing self-stigma in substance abuse through acceptance and commitment therapy: Model, manual development and pilot outcomes. *Addiction Research and Theory*, *16*, 149-165. http://dx.doi.org/10.1080/16066350701850295

Luoma, J.B., & Platt, M.G. (2015). Shame, self-criticism, self-stigma, and compassion in Acceptance and Commitment Therapy. *Current Opinion in Psychology*, *2*, 97-101. https://doi.org/10.1016/j.copsyc.2014.12.016

Maksimovic, N., Jankovic, S., Marinkovic, J., Sekulovic, L.K., Zivkovic, Z., & Spiric, V.T. (2012). Health-related quality of life in patients with atopic dermatitis. *The Journal of Dermatology*, *39*, 42-47. https://doi.org/10.1111/j.1346-8138.2011.01295.x

Mancuso, S.G., Knoesen, N.P., & Castle, D.J. (2010). The Dysmorphic Concern Questionnaire: A screening measure for body dysmorphic disorder. *The Australian and New Zealand Journal of Psychiatry, 44,* 535-542. https://doi.org/10.3109/00048671003596055

Office for National Statistics (2018). *Overview of the UK Population: November 2018.* Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/november2018

Pahwa, P., Mehta, M., Khaitan, B.K., Sharma, V.K., & Ramam, M. (2013). The psychosocial impact of vitiligo in Indian patients. *Department of Dermatology and Venereology, 79,* 679-685. https://doi.org/10.4103/0378-6323.116737

Pachankis, J.E., Hatzenbuehler, M.L., Wang, K., Burton, C.L., Crawford, F.W., Phelan, J.C., & Link, B.G. (2018). The burden of stigma on health and well-being: a taxonomy of concealment, course, disruptiveness, aesthetics, origin, and peril across 93 stigmas. *Personality and Social Psychology Bulletin, 44,* 451-474. https://doi.org/10.1177/0146167217741313

Parkhouse, A.R. (2019). Experiences of stigma-stress among people living with psoriasis in the United States. *American Journal of Health Behavior, 43,* 243-257. https://doi.org/10.5993/AJHB.43.2.2

Picardi, A., Lega, I., & Tarolla, E. (2013). Suicide risk in skin disorders. *Clinics in Dermatology, 31,* 47-56. https://doi.org/10.1016/j.clindermatol.2011.11.006

Preacher, K.J., & Hayes, A.F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models.

Behavior Research Methods, *40*, 879-891. http://dx.doi.org/10.3758/BRM.40.3.879

Richman, L.S., & Leary, M.R. (2009). Reactions to discrimination, stigmatisation, ostracism and other forms of interpersonal rejection a multimotive model. *Psychological Review, 116,* 365-383. https://doi.org/10.1037/a0015250

Scrambler, G., & Hopkins, A. (1986). Being epileptic: coming to terms with stigma. *Sociology of Health and Illness, 8,* 26-43. https://doi.org/10.1111/1467-9566.ep11346455

Skinta, M.D., Lezama, M., Wells, G., & Dilley, J.W. (2015). Acceptance and compassion-based group therapy to reduce HIV stigma. *Cognitive and Behavioural Practice, 22,* 481-490. https://doi.org/10.1016/j.cbpra.2014.05.006

Shepherd, L., Reynolds, D.P., Turner, A., O'Boyle, C.P., & Thompson, A.R. (2019). The role of psychological flexibility in appearance anxiety in people who have experienced a visible burn injury. *Burns, 45,* 942-949. https://doi.org/10.1016/j.burns.2018.11.015

Spitzer, R.L., Kroenke, K., Williams, J.B.W., & Lowe, B. (2006). A brief measure for assessing generalized anxiety disorder- The GAD-7. *Archives of Internal Medicine*, *166,* 1092-1097. https://doi.org/10.1001/archinte.166.10.1092

Twohig, M.P. (2012). Acceptance and commitment therapy: introduction. *Cognitive and Behavioural Practice*, *19,* 499-507. https://doi.org/10.1016/j.cbpra.2012.04.003

Valvano, A., Floyd, R.M., Penwell-Waines, L., Stepleman, L., Lewis, K., & House, A. (2016). The relationship between cognitive fusion, stigma, and well-being in people with multiple sclerosis. *Journal of Contextual Behavioural Science, 5*, 266-270. http://dx.doi.org/10.1016/j.jcbs.2016.07.003

Van Beugen, S., Maas, J., van Laarhoven, A. I.M., Galesloot, T.E., Rinck, M., Becker, E.S. ... & Bosch, J.A. (2016). Implicit stigmatisation-related biases in individuals with skin conditions and their significant others. *Health Psychology, 35,* 861-865. http://dx.doi.org/10.1037/hea0000404

Vardy, D.A., Besser, A., Amir, M., Gesthalter, B., Biton, A., & Buskila, D. (2002). Experiences of stigmatization play a role in mediating the impact of disease severity on quality of life in psoriasis patients. *British Journal of Dermatology, 147,* 736-742. https://doi.org/10.1046/j.1365-2133.2002.04899.x

Wolgast, M. (2014). What does the acceptance and action questionnaire (AAQ-II) really measure? *The Psychological Record, 60,* 249-272. https://doi.org/10.1016/j.beth.2014.07.002

Wolkenstein, P., Loundou, A., Barrau, K., Auquier, P., & Revuz, J. (2007). Quality of life impairment in hidradenitis suppurative: a case study of 61 cases. *Journal of the American Academy of Dermatology, 56,* 621-623. https://doi.org/10.1016/j.jaad.2006.08.061

Wittkowski, A., Richards, H.L., Griffiths, C.E.M., & Main, C.J. (2004). The impact of psychological and clinical factors on quality of life in individuals with atopic dermatitis. *Journal of Psychosomatic Research, 57,* 195-200. https://doi.org/10.1016/S0022-3999(03)00572-5

Yang, Y., Brazier, J., & Longworth, L. (2015). EQ-5D in skin conditions: an assessment of validity and responsiveness. *The European Journal of Health Economics, 16,* 927-939. https://doi.org/10.1007/s10198-014-0638-9

Appendix A

ESDAP study protocol

14 Dec 2016 Study Protocol all

The Psychosocial Burden of Skin Disease: Stigmatisation and body image. An international multicenter study

An international project from the European Society for Dermatology and Psychiatry (ESDaP).

Background

The psychological impact of skin disease is an issue of increasing concern worldwide [1-3]. Our group has recently demonstrated this fact following a far reaching assessment of the psychological comorbidity in common skin diseases in 13 European countries[4]. Further investigation of the psychosocial burden of skin disease is crucial not only for patient management and to ensure an improved understanding of the social consequences of skin disease, but also for community health procedures, policy and strategy.

Stigmatisation

Patients with chronic skin disease can display a fear of negative evaluation and perceived Stigmatisation as a condition-related stressor which may distinguish them from many other chronic somatic conditions. Those patients affected often display visible skin lesions as part of their skin disease that purport to have feelings of vulnerability for social rejection together with the fear of negative evaluation by others either within their peer group or outside. The perceived Stigmatisation is best described as experiences of social disapproval, discrediting, or devaluation based on an attribute or physical mark [5]. Patients with chronic skin diseases regularly report experiences of perceived Stigmatisation, for example, others staring at them, receiving negative comments or avoiding physical contact [6-8].

Culture, society and other social influences appear to play a role in this stress experience, based upon common misconceptions e.g. that skin diseases are contagious or a consequence of poor hygiene [9]. It is well-known that perceived Stigmatisation experiences are common among patients with chronic diseases, since the majority of patients report to have experienced at least some experience of Stigmatisation [6-8]. In addition, perceived Stigmatisation is higher where physical and psychological well-being and functioning in daily life is reduced such as in daily life in patients with chronic skin diseases, such as atopic dermatitis and psoriasis[8] [10-12]. When considering inter-individual differences, research in psoriasis patients indicated that younger patients, those who have no partner, those with a lower educational level as well as patients who may experience higher levels of social inhibition and negative affectivity might be more vulnerable for this experience of perceived Stigmatisation[10].

Finally, Stigmatisation may also affect other areas of functioning other than only the self-reported well-being of the patients. For example, a Stigmatisation-related implicit bias regarding the disgusted reactions of others has recently been shown in patients with chronic skin conditions of psoriasis[13]. A more systematic research of Stigmatisation amongst patient groups can produce an important insight into the possible social and cultural difference of Stigmatisation experience in patients with skin diseases. This will enable healthcare professionals to finally develop screening and intervention procedures to better support patients in coping with these Stigmatisation experiences.

Body image disorders

Dissatisfaction with the body or the skin is common. Most people are not fully satisfied with their body appearance or their skin but accept and live with the realization that their body is imperfect.

For some people the degree of dissatisfaction is so high that it culminates in a preoccupation with a perceived defect of their body which interferes dramatically with their daily life and routine. This is known as body dysmorphic disorder (BDD). BDD is a recognized psychiatric condition and categorized as part of the obsessive-complulsive and related disorders in the latest edition of the Diagnostic and Statistical Manual of Mental Disorders [14]. The conditions occurs in around 2% in the general population in the developed world and recent data suggests that this occurrence could be increasing [14-17]. The prevalence is varying in different patient settings and, amongst dermatological patients, the prevalence is estimated to be higher at 12 % [16 18].

BDD is a distressing condition which can be connected to any part of the body and often linked to shame. Depression, social anxiety and suicidal ideation are frequently co-morbidities. In addition there is a higher rate of suicide among patients with BDD [19 20].

Persons with BDD frequently consult a dermatologist but are rarely seen by a psychiatrist or mental health specialist. Patients with BDD are often dissatisfied with their treatment and “doctor shop”. They are convinced that their problem is physical and not mental. Also, BDD patients consume substantial resources in health care systems and are challenging to help [14]. Therefore it is important for the clinicians to understand when the patient is suffering from the condition in order to provide adequate treatment and also to be able to distinguish the BDD condition from the more trivial condition of dissatisfaction with body.

There are few instruments to assess body image disorders: the Body Dysmorphic Disorder Questionnaire [16 21 22], the Cutaneous Body Image Satisfaction assessing dissatisfaction with the skin [23]. Our group has previously used the Dysmorphic Concern Questionnaire. This has the advantage of being brief and validated not only amongst patients but also among non-patients [15 24].

The psychological burden of skin disease

Recently our group demonstrated the psychological implications of the 10 most common skin conditions among dermatological out patients in 13 European countries. The result demonstrated that patients with common skin conditions had significantly more depression, anxiety and suicidal ideation than controls [4]. Skin diseases are the fourth leading cause of non-fatal disease in the recent Global Burden of Disease Study 2010 [3]. Therefore there is a requirement to explore in different parts of the world aspects of the psycho-social burden of skin disease. This will achieve greater knowledge and understanding of the aspects of living with skin disease over time and enable healthcare professionals to target appropriate intervention programmes.

Most skin conditions in the world are non-fatal and chronic. Globally, the most prevalent conditions are infections of the skin, acne, pruritus, and eczema [3 25]. The psycho-social impact of common skin disease is expected to be large worldwide but little research or exploration in this area has been undertaken.

Rationale of the study

The presence of psychological comorbidities in patients with skin diseases is demonstrated with the presence of a large outpatient population in dermatology departments. There is a need to explore further the psychosocial burden of skin diseases in a large scale study or project. Stigmatisation and body image disorder are powerful measures of the burden of dermatological conditions and have been hugely underestimated worldwide.

2. Objectives

The primary objective of the present study is to describe the psychosocial burden of skin diseases in different cultures by assessing Stigmatisation of patients with skin disease and secondly by estimating the prevalence of body image disorder in dermatological patients.

3. Methods

Study design

An observational cross-sectional multi-centre study of prevalent cases of skin diseases will be organised and conducted by members of the European Society for Dermatology and Psychiatry (ESDaP). Patients will be recruited from dermatological outpatient clinics in different countries.

Procedure

Recruitment

Cases

At the dermatological out-patient clinic at each centre in each participating country, consecutive patients will be invited to participate in the study on one or more random days until the required number of 250 respondents is reached. All patients will be fully briefed by a research assistant and will be accepted onto the study by signing a written consent form. Dermatologists will describe the study in minimal detail and obtain verbal consent prior to recording information about the patient. Full written consent will then be obtained when the patient speaks to the researcher. Each patient will be examined by a dermatologist who will record the diagnosis; and, if required any secondary diagnosis will be recorded.

Control group

A control group of 125 subjects total for each centre will be included from amongst hospital employees at the same institution, recruited by announcement on specific days. However, they will not derive from the same department or be employed at the university (i.e. academics and non- academics, not students).

Inclusion criteria

Eligible patients must meet the following inclusion criteria (both cases and controls):

-Over 18 years of age

-Competent to read and write the language of the questionnaire

Exclusion criteria

-Controls with a skin condition under treatment

Informed consent

Informed consent will be obtained from relevant nursing staff or the research assistant from patients and controls.

Randomisation

Randomisation is unnecessary for this study design.

All consecutive patients on specific days in the general dermatology clinics will be approached. The drop-out rate will be recorded (noting age and gender) and reasons why they do not wish to participate.

Clinical assessment of patients

The dermatologist making the diagnosis will objectively evaluate and record each condition as “mild”, “moderate” or “severe”. The presence of other conditions including the following treated co-morbidities will be recorded:

- Cardio-vascular disease.
- Chronic respiratory disease.
- Diabetes
- Rheumatologic disease.

Clinicians will also be required to answer questions on whether signs of depression, anxiety and feelings of dysmorphic concern are present in the patient.

Self-reported measures

Each patient will complete a questionnaire and give it to the physician at the consultation.

Background information questionnaire filled in by patients and controls will give information on:

-Socio demographic background

-Employment status

-Weight/height

-Comorbidities under treatment

-Itch: presence and characteristics

-Suicidal ideation: presence and frequency

All participants will fill in the following questionnaires (for items, see appendix):

-The Patient Health Questionnaire PHQ-2[26] : a validated questionnaire to assess depression, translated to many languages.

-The General Anxiety Disorder Assessment GAD-2[26]: a validated instrument to assess anxiety, translated to many languages.

-Self-reported Health State: EQ5D-VAS[27] a validated generic quality of life measure used in different medical conditions and with population norms from many countries.

-Perceived Stigmatisation Questionnaire PSQ[28]: 21 items assessing perceived stigmatization and social experience in people with visible difference, not disease specific.

- Dysmorphic Concern Questionnaire DCQ[24] 7 items assessing body image concern

-Perceived Stress Scale[29 30]: 10 items assessing stress.

Patients only will give information on:

-Self-reported severity of condition (“mild”, “moderate”, “severe”)

-Self-reported age of onset

-Self-reported localization of the disease

Statistical analysis

Before the data collection starts, questionnaires (translated into English) from each centre will be forwarded to the Statistical Centre (Institute of Medical Psychology, University of Giessen, Germany) to enable a standardised checking procedure for the identical sets of questionnaires. After collection the data will be checked and entered in an SPSS or Excel database at each site. The final corrected data will be sent to the statistical center.

Data will be merged into a single file and re-checked and cleaned.

SPSS version 24 software will be used to analyse the data. To characterise the study population we will report numbers and percentages for categorical variables, and mean values with standard deviation for continuous variables. To compare Patients and Controls we will use the t-test for continuous variables and the chi-square test for dichotomous variables or nominal scales. To compare the prevalence between the disease groups and Controls we will use the chi-square test for dichotomous variables. Multivariate logistic regression models will be tested to study the associations between the main outcome variables and groups (patients/Controls). In the first instance we will calculate the crude odds ratios (OR) and in the second adjusted OR simultaneously controlling for potential confounding factors (gender, age, socioeconomic status, perceived stress, co-morbidities, depression). The OR will be calculated from the estimated regression coefficients B from the logistic regressions.

Ethics approval and consent to participate

Application for approval from the Ethical Committee at Giessen University will be applied to the whole study and local ethical approval will be obtained where necessary. The study will be conducted in accordance with the Declaration of Helsinki. All eligible patients and controls will be informed verbally and in writing of the purpose of the study, the expected duration and procedure, the right to decline to participate and to withdraw from the research, without any consequences, at any given time once participation has commenced.

4. Results

The results will be disseminated in publications and presentations at national and international meetings. The following publications are planned in international peer-reviewed journals:

1. Stigmatisation experience of dermatological patients in an international multicenter study compared to controls: sociodemographic differences
2. Prevalence of body dysmorphic disorder in dermatological conditions compared to controls in an international multicenter study

3. Discrimination of dermatological patients compared to controls in an international multicenter study
4. Stigmatisation experience and suicidal ideation in dermatological patients in an international multicenter study
5. Body dysmorphic disorder and suicidal ideation in dermatological patients in an international multicenter study
6. Stigmatisation in medical conditions associated with skin disease
7. Differences in Stigmatisation and discrimination according to dermatological disorders and severity
8. Is there a relationship between mental distress and Stigmatisation among dermatological patients and controls?
9. Relationship between Stigmatisation and body dysmorphic disorders in dermatological patients.

5. Research progress

Time frame

Study draft presentation	Brest June 2016	FD UG
Study announcement	Vienna Oct 2016	JK FD UG
Study protocol	Oct-Dec 2016	Study working group
Ethical committee	Jan-April 2017	Working group
Submission study proposal	Nov-Dec 2016	Working group
Invitation centers	Oct- Jan 2016	
Proposal for subtopics	Winter 2017	All
Translation questionnaires	March-June 2017	All
Grant writing	November-April 2017 Deadline COST 7 Dec 2016	Working group
Study agreement	May-June 2017	All
Data collection patients	Sept 2017-April 2019	All
Data collection controls	March 2018- April 2019	All
Data cleaning	April 2019-July 2019	Giessen
Data analysis	Aug 2019- Nov 2019	JK FD
First article	Dec 2019-May 2020	All
Following articles	May 2020- May 2022	All

6. Scientific value

With this original study we will expand the knowledge on the psychosocial burden of common skin diseases in patients in different countries in Europe outide Europe and specifically address the burden of stigmatisation and discrimination of patients with dermatological disorders We will expand and enhance ur understanding of body dysmorphic disease, its prevalence and its relation to mental health problems.

7. Collaboration

The study will be organised duplicating the structure as the previous successful study completed by our group. The Malmø-Lund University, Giessen University and Innlandet Hospital Trust have collaborated in the study. There will be two principal investigators and coordinators JK and FD, a scientific group: Uwe Gieler, JK, FD, A Bewley (BDD), F Sampogna (Methods), A Evers (Stigmatisation), Lars Lien (psychiatry and public health) and a special coordinator for the European centres (LTA), and in addition partners represented by all participating colleagues from the ESDAP.

8. Funding

In work progress

9. References

1. Global, regional, and national disability-adjusted life-years (DALYs) for 315 diseases and injuries and healthy life expectancy (HALE), 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. Lancet 2016;**388**(10053):1603-58.
2. Fitzmaurice C, Dicker D, Pain A, et al. The Global Burden of Cancer 2013. JAMA oncology 2015;**1**(4):505-27.
3. Hay RJ, Johns NE, Williams HC, et al. The global burden of skin disease in 2010: an analysis of the prevalence and impact of skin conditions. The Journal of investigative dermatology 2014;**134**(6):1527-34.
4. Dalgard FJ, Gieler U, Tomas-Aragones L, et al. The psychological burden of skin diseases: a cross-sectional multicenter study among dermatological out-patients in 13 European countries. The Journal of investigative dermatology 2015;**135**(4):984-91.
5. Goffman E. *Stigma. Notes on the Management of Spoiled Identidy*: Penguin Books, 1963.
6. Ginsburg IH, Link BG. Feelings of stigmatization in patients with psoriasis. Journal of the American Academy of Dermatology 1989;**20**(1):53-63.
7. Hrehorow E, Salomon J, Matusiak L, et al. Patients with psoriasis feel stigmatized. Acta dermato-venereologica 2012;**92**(1):67-72.
8. Lu Y, Duller P, van der Valk PGM, et al. Helplessness as predictor of perceived stigmatization in patients with psoriasis and atopic dermatitis. Dermatology and Psychosomatics 2003;**4**:146-50.
9. Halioua B, Sid-Mohand D, Roussel ME, et al. Extent of misconceptions, negative prejudices and discriminatory behaviour to psoriasis patients in France. J Eur Acad Dermatol Venereol 2016;**30**(4):650-4.
10. van Beugen S, van Middendorp H, Ferwerda M, et al. Predictors of perceived stigmatization in patients with psoriasis. The British journal of dermatology 2016.
11. Vardy D, Besser A, Amir M, et al. Experiences of stigmatization play a role in mediating the impact of disease severity on quality of life in psoriasis patients. The British journal of dermatology 2002;**147**(4):736-42.

12. Richards HL, Fortune DG, Griffiths CE, et al. The contribution of perceptions of stigmatisation to disability in patients with psoriasis. J Psychosom Res 2001;**50**(1):11-5.
13. van Beugen S, Maas J, van Laarhoven AI, et al. Implicit stigmatization-related biases in individuals with skin conditions and their significant others. Health psychology : official journal of the Division of Health Psychology, American Psychological Association 2016;**35**(8):861-5.
14. Veale D, Bewley A. Body dysmorphic disorder. BMJ (Clinical research ed) 2015;**350**:h2278.
15. Gieler T, Schmutzer G, Braehler E, et al. Shadows of Beauty - Prevalence of Body Dysmorphic Concerns in Germany is Increasing: Data from Two Representative Samples from 2002 and 2013. Acta dermato-venereologica 2016.
16. Veale D, Gledhill LJ, Christodoulou P, et al. Body dysmorphic disorder in different settings: A systematic review and estimated weighted prevalence. Body image 2016;**18**:168-86.
17. Buhlmann U, Glaesmer H, Mewes R, et al. Updates on the prevalence of body dysmorphic disorder: a population-based survey. Psychiatry research 2010;**178**(1):171-5.
18. Phillips KA, Dufresne RG, Jr., Wilkel CS, et al. Rate of body dysmorphic disorder in dermatology patients. Journal of the American Academy of Dermatology 2000;**42**(3):436-41.
19. Phillips KA, Menard W. Suicidality in body dysmorphic disorder: a prospective study. The American journal of psychiatry 2006;**163**(7):1280-2.
20. Phillips KA, Siniscalchi JM, McElroy SL. Depression, anxiety, anger, and somatic symptoms in patients with body dysmorphic disorder. The Psychiatric quarterly 2004;**75**(4):309-20.
21. Dufresne RG, Phillips KA, Vittorio CC, et al. A screening questionnaire for body dysmorphic disorder in a cosmetic dermatologic surgery practice. Dermatologic surgery : official publication for American Society for Dermatologic Surgery [et al] 2001;**27**(5):457-62.
22. Vulink NC, Rosenberg A, Plooij JM, et al. Body dysmorphic disorder screening in maxillofacial outpatients presenting for orthognathic surgery. International journal of oral and maxillofacial surgery 2008;**37**(11):985-91.
23. Gupta MA, Gupta AK. Evaluation of cutaneous body image dissatisfaction in the dermatology patient. Clinics in dermatology 2013;**31**(1):72-9.
24. Mancuso SG, Knoesen NP, Castle DJ. The Dysmorphic Concern Questionnaire: A screening measure for body dysmorphic disorder. The Australian and New Zealand journal of psychiatry 2010;**44**(6):535-42.
25. Boyers LN, Karimkhani C, Naghavi M, et al. Global mortality from conditions with skin manifestations. Journal of the American Academy of Dermatology 2014;**71**(6):1137-43.e17.
26. Kroenke K, Spitzer RL, Williams JB, et al. The Patient Health Questionnaire Somatic, Anxiety, and Depressive Symptom Scales: a systematic review. Gen Hosp Psychiatry 2010;**32**(4):345-59.
27. Coons SJ, Rao S, Keininger DL, et al. A comparative review of generic quality-of-life instruments. PharmacoEconomics 2000;**17**(1):13-35.
28. Lawrence JW, Fauerbach JA, Heinberg LJ, et al. The reliability and validity of the Perceived Stigmatization Questionnaire (PSQ) and the Social Comfort Questionnaire (SCQ) among an adult burn survivor sample. Psychological assessment 2006;**18**(1):106-11.

29. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. Journal of health and social behavior 1983;**24**(4):385-96.
30. Cole SR. Assessment of differential item functioning in the Perceived Stress Scale-10. Journal of epidemiology and community health 1999;**53**(5):319-20.
31. Schmid-Ott G, Jaeger B, Kuensebeck HW, et al. Dimensions of stigmatization in patients with psoriasis in a "Questionnaire on Experience with Skin Complaints'. Dermatology 1996;**193**(4):304-10.

Appendix B

Description of the Relationship between this Thesis and the ESDAP Research Project

The ESDAP research project is a Europe-wide study and aims to collect data on the psychosocial burden of skin disease (see Appendix A for protocol). Sheffield represents one of the UK sites for collection of this data. The author of this thesis had an agreement with ESDAP to include additional measures to the questionnaire designed for the ESDAP study during data collection in Sheffield (adding full versions of the PHQ-9 and GAD-7, and the CompACT). Some data collected for the ESDAP study is not included in this thesis, although the author supported the collection of this data.

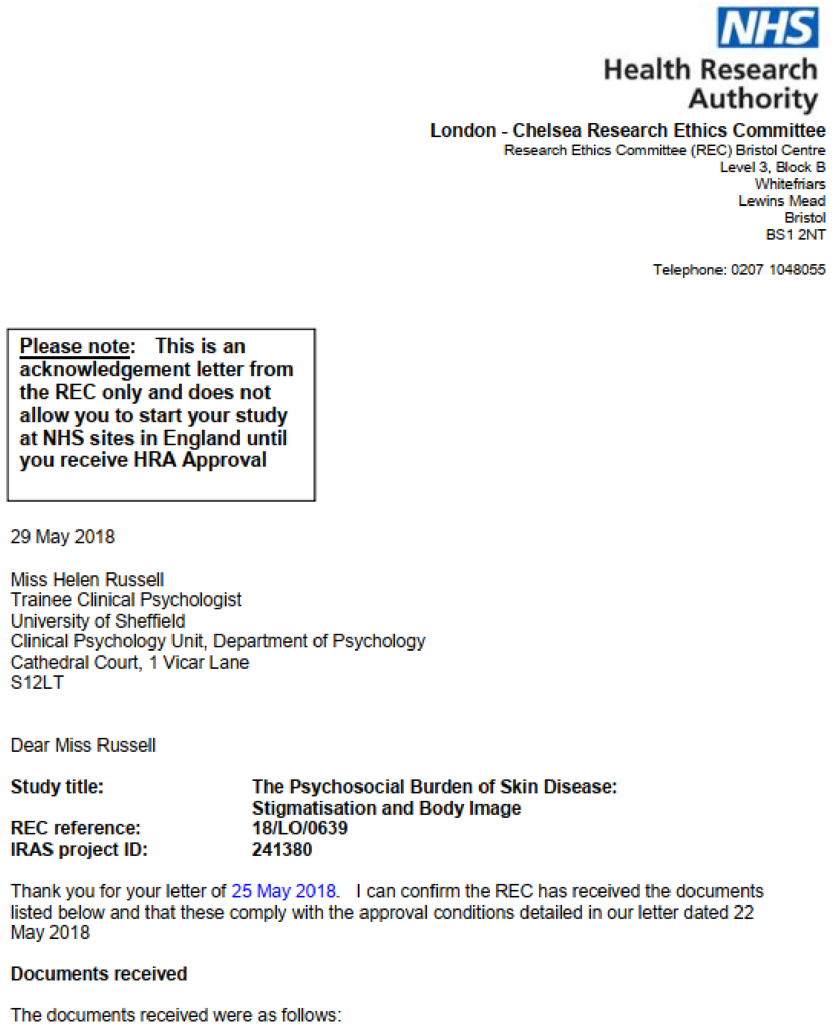
The author, with support from the research team (see Acknowledgments), had responsibility for obtaining ethical approval for the study in Sheffield and designing and coordinating data collection processes. The author collected data from participants, alongside support from the research team.

The author was responsible for transferring data for this thesis from paper forms to electronic databases. The author of the thesis designed and completed data analysis and interpretation independent of the ESDAP team.

The study protocol proposed and approved by the University of Sheffield included explanation of this relationship.

Appendix C

Evidence of Ethical Approval



NHS
Health Research
Authority
London - Chelsea Research Ethics Committee
Research Ethics Committee (REC) Bristol Centre
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207 1048055

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

29 May 2018

Miss Helen Russell
Trainee Clinical Psychologist
University of Sheffield
Clinical Psychology Unit, Department of Psychology
Cathedral Court, 1 Vicar Lane
S12LT

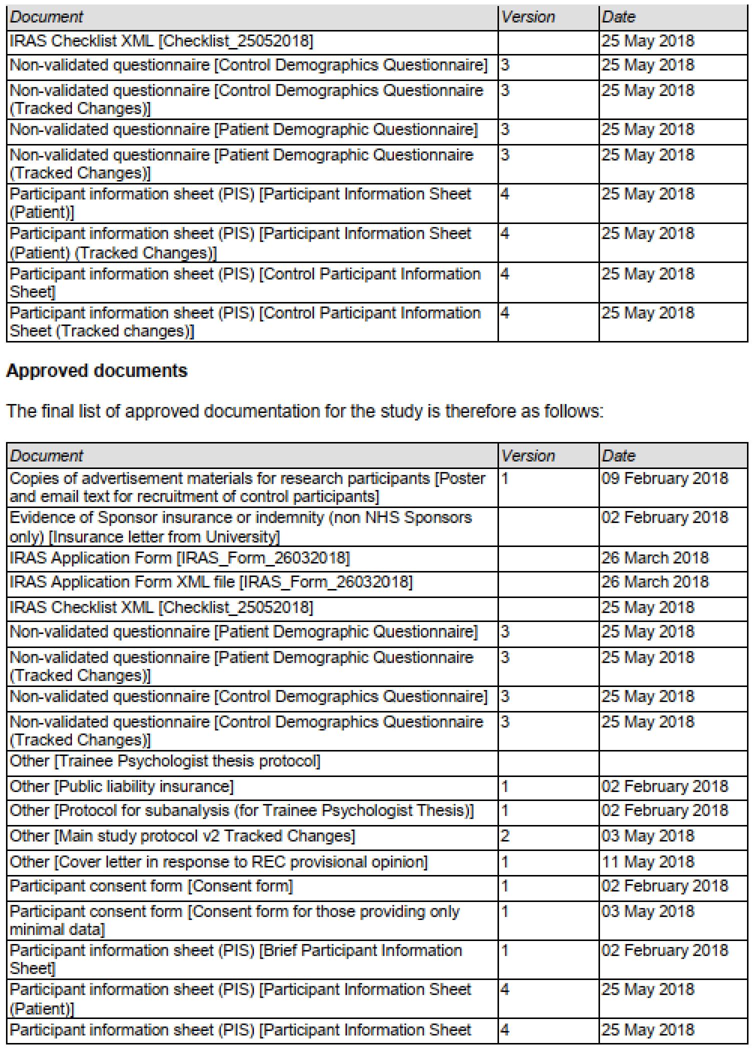
Dear Miss Russell

Study title:	**The Psychosocial Burden of Skin Disease: Stigmatisation and Body Image**
REC reference:	**18/LO/0639**
IRAS project ID:	**241380**

Thank you for your letter of 25 May 2018. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 22 May 2018

Documents received

The documents received were as follows:



Document	*Version*	*Date*
IRAS Checklist XML [Checklist_25052018]		25 May 2018
Non-validated questionnaire [Control Demographics Questionnaire]	3	25 May 2018
Non-validated questionnaire [Control Demographics Questionnaire (Tracked Changes)]	3	25 May 2018
Non-validated questionnaire [Patient Demographic Questionnaire]	3	25 May 2018
Non-validated questionnaire [Patient Demographic Questionnaire (Tracked Changes)]	3	25 May 2018
Participant information sheet (PIS) [Participant Information Sheet (Patient)]	4	25 May 2018
Participant information sheet (PIS) [Participant Information Sheet (Patient) (Tracked Changes)]	4	25 May 2018
Participant information sheet (PIS) [Control Participant Information Sheet]	4	25 May 2018
Participant information sheet (PIS) [Control Participant Information Sheet (Tracked changes)]	4	25 May 2018

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster and email text for recruitment of control participants]	1	09 February 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter from University]		02 February 2018
IRAS Application Form [IRAS_Form_26032018]		26 March 2018
IRAS Application Form XML file [IRAS_Form_26032018]		26 March 2018
IRAS Checklist XML [Checklist_25052018]		25 May 2018
Non-validated questionnaire [Patient Demographic Questionnaire]	3	25 May 2018
Non-validated questionnaire [Patient Demographic Questionnaire (Tracked Changes)]	3	25 May 2018
Non-validated questionnaire [Control Demographics Questionnaire]	3	25 May 2018
Non-validated questionnaire [Control Demographics Questionnaire (Tracked Changes)]	3	25 May 2018
Other [Trainee Psychologist thesis protocol]		
Other [Public liability insurance]	1	02 February 2018
Other [Protocol for subanalysis (for Trainee Psychologist Thesis)]	1	02 February 2018
Other [Main study protocol v2 Tracked Changes]	2	03 May 2018
Other [Cover letter in response to REC provisional opinion]	1	11 May 2018
Participant consent form [Consent form]	1	02 February 2018
Participant consent form [Consent form for those providing only minimal data]	1	03 May 2018
Participant information sheet (PIS) [Brief Participant Information Sheet]	1	02 February 2018
Participant information sheet (PIS) [Participant Information Sheet (Patient)]	4	25 May 2018
Participant information sheet (PIS) [Participant Information Sheet	4	25 May 2018

(Patient) (Tracked Changes)]		
Participant information sheet (PIS) [Control Participant Information Sheet]	4	25 May 2018
Participant information sheet (PIS) [Control Participant Information Sheet (Tracked changes)]	4	25 May 2018
Referee's report or other scientific critique report [Scientific approval letter from University of Sheffield]		02 February 2018
Research protocol or project proposal [Protocol (European)]	2	03 May 2018
Summary CV for Chief Investigator (CI) [CV for Chief Investigator]		02 February 2018
Summary CV for student [Helen Russell (student) CV]		02 February 2018
Summary CV for supervisor (student research) [Academic Supervisor CV]		02 February 2018
Validated questionnaire [Perceived Stress Scale]		
Validated questionnaire [Perceived Stigmatisation Questionnaire]		
Validated questionnaire [Dysmorphic Concern Questionnaire]		
Validated questionnaire [PHQ9 and GAD7]		
Validated questionnaire [CompACT]		
Validated questionnaire [EQ5D VAS]		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

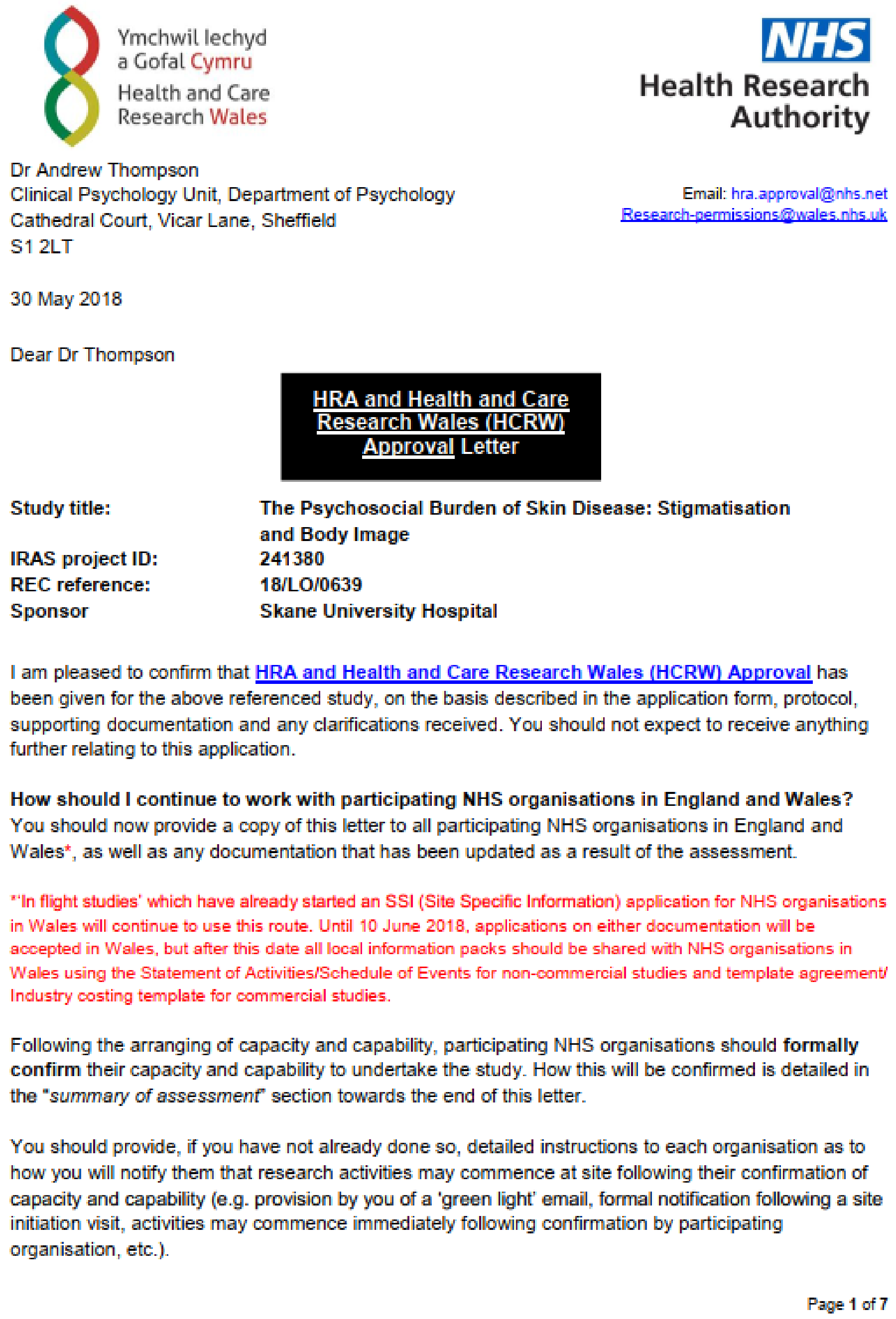
18/LO/0639 **Please quote this number on all correspondence**

Yours sincerely

Sarah Graves

E-mail: nrescommittee.london-chelsea@nhs.net

Copy to: *Miss Helen Russell, University of Sheffield*
Ms Aimee Card



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Andrew Thompson
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Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

30 May 2018

Dear Dr Thompson

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The Psychosocial Burden of Skin Disease: Stigmatisation and Body Image**
IRAS project ID:	**241380**
REC reference:	**18/LO/0639**
Sponsor	**Skane University Hospital**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

*'In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Aimee Card
Tel: 01142265945
Email: aimee.card@sth.nhs.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **241380**. Please quote this on all correspondence.

Yours sincerely

Sharon Northey
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Aimee Card – Acting on behalf of the sponsor and R&D contact*

Appendix D

Text from Participant Information Form

The Psychosocial Burden of Skin Disease

You are being invited to take part in a research study. Before you decide on whether or not to take part, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information.

What is the purpose of the study?

The purpose of this study is to investigate the experiences of people living with skin conditions. Information is being gathered as part of a European-wide study about skin disease and we aim to publish the results in academic journals/conferences. We aim to gain information about participants' skin conditions and also how this impacts on their mood and their body image.

Why have I been invited?

You are invited to take part in this study if you are aged 18 or above and are attending the dermatology clinic for treatment of a dermatological condition.

Do I have to take part?

No, participation in this research is completely voluntary. Whether you take part or not will not affect the treatment you will receive from the dermatology service. If you decide to take part, then you are free to withdraw from the study at any time, without giving a reason and without any negative consequences. You can do this by contacting the lead researcher, using the details given below.

What will happen if I take part?

You will be asked to complete some questionnaires that will take 15-20 minutes and is unlikely to take longer than 30 minutes. The questionnaires will include questions about your age, gender and employment status as well as some brief questions about your skin condition. The remaining questions ask about your mood, your view of your health, how you feel about your body, and your view as to how you are treated by other people. Consent forms and questionnaires will be securely transferred to the University of Sheffield premises.

What are the benefits of taking part?

It is hoped that this study will contribute towards the understanding of the experience of people living with skin conditions and the development of psychological interventions for this population.

What if there is a problem?

We do not foresee any adverse risks to taking part in this study. For some people, completing questionnaires can raise worries, and if this is the case the researcher you speak to will be able to refer you for additional support.

Will all the information be kept confidential?

Yes, the data you provide will be treated in strict confidence and will not be disclosed beyond the researchers involved in the study. Data will be coded so as to be non-identifiable, your name will not be stored with your data and all data will be transferred using locked equipment and secure memory sticks. Data will be stored in locked filing cabinets on University premises and password protected computers until the study and publication of findings is complete. Anonymised data will be securely transferred to University of Giessen for analysis.

All data will be reported anonymously in any future publication of the results and it will not be possible to identify you in any reports on the findings.

The University of Giessen is the sponsor for this study, based in Germany. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Giessen will keep information about you for a maximum of five years. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the study?

The findings from this study will be written up as part of an international project conducted by the European Society for Dermatology and Psychiatry. Some of the data will also be written up as part of a thesis for the Doctorate in Clinical Psychology at the University of Sheffield and we will seek to share the findings through publication in academic journals and conferences.

What if I wish to complain about the way the study has been carried out?

If you have any questions or concerns, please contact the Principal Investigator, Dr Andrew Thompson, Reader in Clinical Psychology, (a.r.thompson@sheffield.ac.uk) in the first instance. If you have any further concerns, please contact the University of Sheffield's Office of the Registrar and Secretary at 0114 222 1101.

If you feel that your complaint has not been handled to your satisfaction following this, you can contact the University's Registrar and Secretary Dr Andrew West, Email: registrar@sheffield.ac.uk and Tel *0114 222 1051*

Contact Information

This research is being conducted by Helen Russell (Trainee Clinical Psychologist at the University of Sheffield) and the European Society for Dermatology and Psychiatry. If you have any questions about the research, you can leave a telephone message with the Research Support Officer on: 0114 222 6650 and he will ask the lead researcher to contact you.

Appendix E

Form for Collection of Minimal Data with Verbal Consent

"Although you have declined to take part in the survey would you be willing for us to use some minimal data so that we have a record of the demographics (such as gender and age) of those declining? We would require information on your age, gender and reason for not taking part. The dermatologist will also record information about your diagnoses and your mood. This information will be kept anonymous and stored on encrypted memory sticks and locked filing cabinets on NHS and University of Sheffield property. It will be reported in the write up of the study which may be published in academic journals and submitted as part of a student's thesis in clinical psychology"

"Do you consent to this information being collected and stored?"

Yes ☐ No ☐

If Yes please record the following details:

Age: ………………………………….

Gender: ……………………………….

Reason for not taking part: Don't have time ☐

Don't want to disclose personal information ☐

Not interested ☐

Other: …………………………………………………………

Dermatological Diagnosis I **(ICD-10)** ___________

Severity:
Mild ☐

Moderate ☐

Severe ☐

Dermatological Diagnosis II **(ICD-10)** _____________

Severity:
Mild ☐

Moderate ☐

Severe ☐

Do you see depressive signs in the patient? Yes No

Do you see anxiety signs in the patient? Yes No

Is the patient treated for any other chronic condition?

Cardiovascular disease	Yes	☐	No	☐
Chronic respiratory disease	Yes	☐	No	☐
Diabetes	Yes	☐	No	☐
Rheumatological disease	Yes	☐	No	☐
Other disease	Yes	☐	No	☐

If yes, please specify ____________________

Appendix F

Consent form

The Psychosocial Burden of Skin Disease: Stigmatisation and Body Image

Participant name……

I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
I understand that data collected during the study may be looked at by individuals from University of Sheffield, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.	
I agree to take part in the above study.	

___________________________ _________________ ______________________

Name of Participant Date Signature

__________________________ _________________ ___________________

Name of Person taking consent Date Signature

Appendix G

Survey Tool

ID number PG- _______________ **Center** __________ **Date** ___/___/______

Questionnaire

(On all questions tick next to the right answer, you may skip questions you do not wish to answer)

Age: _______________ years

Gender: Male ☐ Female ☐

What is your country of birth? ____________________

What is your country of origin? ____________________

What is your highest level of education?

No qualification ☐ GCSEs (or equivalent) ☐
A Levels (or equivalent) ☐ Undergraduate Degree (or equivalent) ☐

Postgraduate Degree (or equivalent) ☐

What is your marital status?

Single ☐

Married/ with a partner ☐ Do *you live with your partner*? Yes ☐ No ☐

What is your employment status?

Employed ☐
At school/ university ☐
On sick leave ☐
Retired ☐
Unemployed ☐

How is your household income?

Under £20,000 per year ☐

£20,000-£50,000 per year ☐

Over £50,000 per year ☐

Prefer not to answer ☐

Did you experience serious economic difficulties in the last 5 years? Yes ☐ No ☐

Have you had any stressful life events during the last 6 months (serious illness, death of close friend or family member, accident, divorce or other events)?

Yes ☐ No ☐

Approximatively, what is your weight? _______

your height? _______

How old were you (approximatively) when the skin disease started? _________ **years**

Within the last year, how severe has your skin disease been?

Mild ☐

Moderately ☐

Severe ☐

Right now, how severe is your skin disease?

Mild ☐

Moderate ☐

Severe ☐

Have you ever had thoughts of suicide? **Yes** ☐ No ☐

If yes: how often does it happen?

Every day ☐

Every week ☐

Every month ☐

Sometimes during the year ☐

Did you ever have suicidal ideation because of your skin? Yes ☐ No ☐

If yes: how often does it happen?

Every day ☐

Every week ☐

Every month ☐

Sometimes during the year ☐

How often did your skin disease flare during the last year?

Every day ☐

Every week ☐
Every month ☐
Sometimes during the year ☐

Right now, where do you have flare? (you can tick several boxes)

Face/neck ☐
Scalp ☐
Hands/arms ☐
Torso ☐
Legs/feet ☐
Genital area ☐
Other places ☐

Overall, how satisfied are you with your appearance?

Very satisfied ☐
Quite satisfied ☐
Indifferent ☐
Quite unsatisfied ☐
Very unsatisfied ☐

Do you itch now (within the last 24 hours)? Yes ☐ No ☐

<u>If yes, please answer the following questions:</u>

How long has your itch lasted?

Less than 6 weeks ☐
6 weeks or more ☐

How bad is your itch? *(Mark an X in a box)*

0	1	2	3	4	5	6	7	8	9	10

No itch worst
imaginable itch

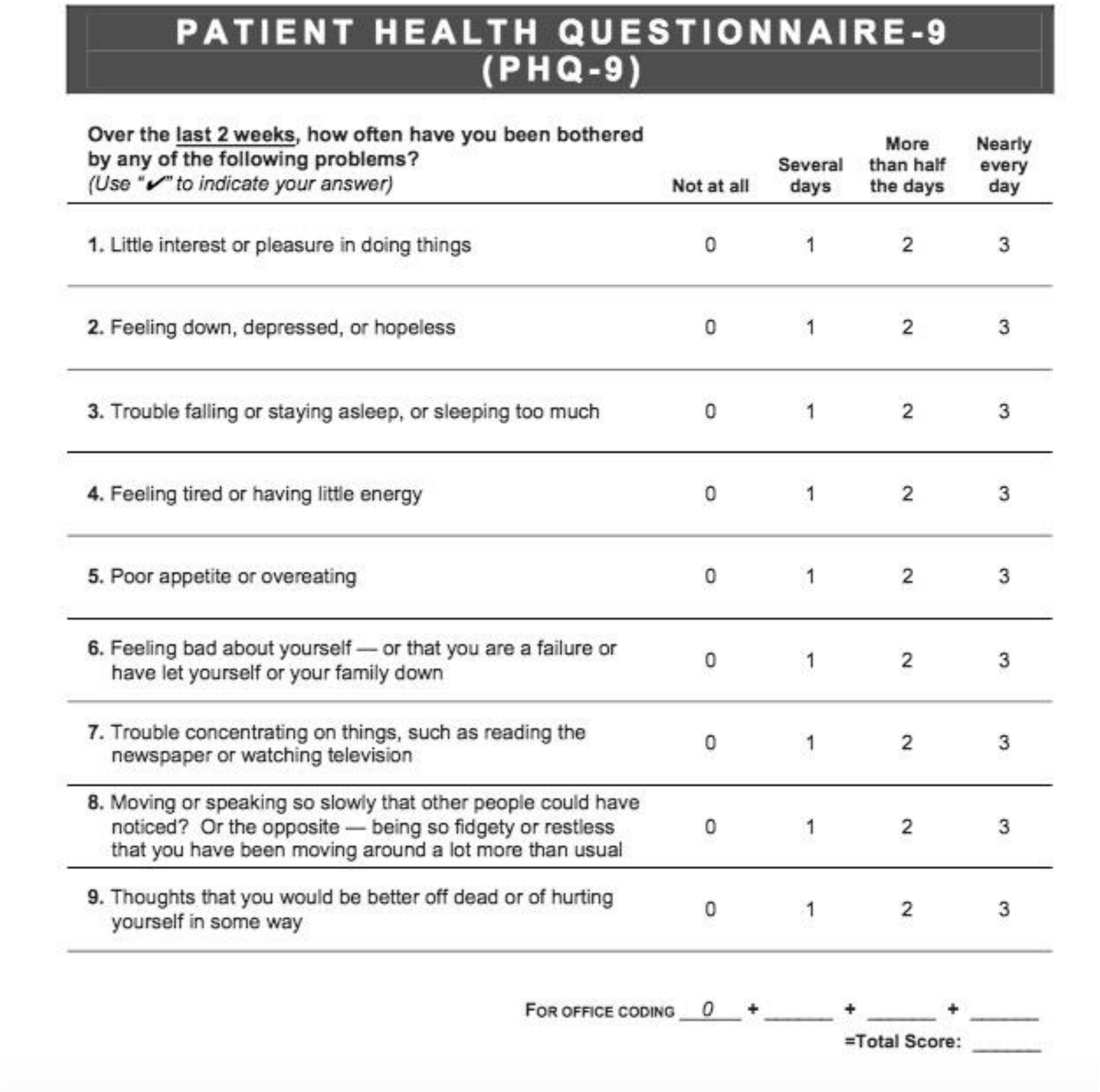
Please select what sensations you feel along with itch

Itch only	Yes	☐	No	☐
Burning	Yes	☐	No	☐
Stinging	Yes	☐	No	☐
Pain	Yes	☐	No	☐

other Yes ☐ No ☐

This questionnaire concerns the last 7 days. Please select only one answer per question

How often have you experienced an itching, burning, stinging, tingling sensation or pain on your skin?	0 never	1 rarely	2 sometimes	3 often	4 always
To what extent has the itching negatively affected you in your everyday life (e.g. if you must wear specific clothing), in your leisure time and/or at work?	0 not at all	1 a little bit	2 somewhat	3 rather	4 very
To what extent does the itching make you feel impaired when dealing with other people (e. g. embarrassed, insecure)?	0 not at all	1 a little bit	2 somewhat	3 rather	4 very
To what extent does the itching have a negative impact on your sleep?	0 not at all	1 a little bit	2 somewhat	3 rather	4 very
To what extent has the itching influenced your enjoyment of life and your mood?	0 not at all	1 a little bit	2 somewhat	3 rather	4 very



PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✓" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING __0__ + ______ + ______ + ______

=Total Score: ______

Over the <u>last 2 weeks</u>, how often have you been bothered by the following problems? *(Use "✔" to indicate your answer")*	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Column totals: ___ **+** ___ **+** ___ **+** ___

= ***Total Score*** _____

(EQ5D5L Visual Analogue Scale removed from electronic copy of thesis due to copyright)

	Never	Almost Never	Some-times	Often	Always
People avoid looking at me					
People I don’t know act surprised or startled when they see me					
People don’t know what to say to me					
People feel sorry for me					
People don’t know how to act around me					
People do “double takes” or turn around to look at me					
People I don’t know stare at me					
People seem embarrassed by my looks					
People are relaxed around me*					
Strangers are polite to me*					
People I don t know say “Hi” to me*					
People are friendly with me					
People I don’t know smile at me in a friendly way*					
People are kind to me*					
People are nice to me*					
People treat me with respect*					
People call me names					
People make fun of me					
People bully me					
People laugh at me					
People pick on me					

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

In the last month, how often have you…

	0	1	2	3	4
…been upset because of something that happened unexpectedly?					
… felt that you were unable to control the important things in your life?					
… felt nervous and “stressed”?					
…felt confident about your ability to handle your personal problems?					
…felt that things were going your way?					
…found that you could not cope with all the things that you had to do?					
… been able to control irritations in your life					
… felt that you were on top of things?					
…been angered because of things that were outside of your control?					
…felt difficulties were piling up so high that you could not overcome them?					

Not at all	Same as most people	More than most people	Much more than most people
0	1	2	3

Have you ever...

Been concerned about some aspects of your physical appearance?	0	1	2	3
Considered yourself malformed or misshaped in some way (nose/hair/skin/sexual organs/overall body build)	0	1	2	3
Considered your body to be malfunctioning in some way (excessive body odour, flatulence, sweating)	0	1	2	3
Consulted or felt you needed to consult for plastic surgeon/dermatologist/physician about these concerns	0	1	2	3
Been told by others/that you are normal in spite of you strongly believing that something is wrong with your appearance or bodily functioning	0	1	2	3
Spent much time worrying about a defect in your appearance/ bodily functioning	0	1	2	3
Spent much time covering up defects in your appearance/bodily functioning	0	1	2	3

(CompACT questionnaire removed from electronic copy of the thesis due to copyright)

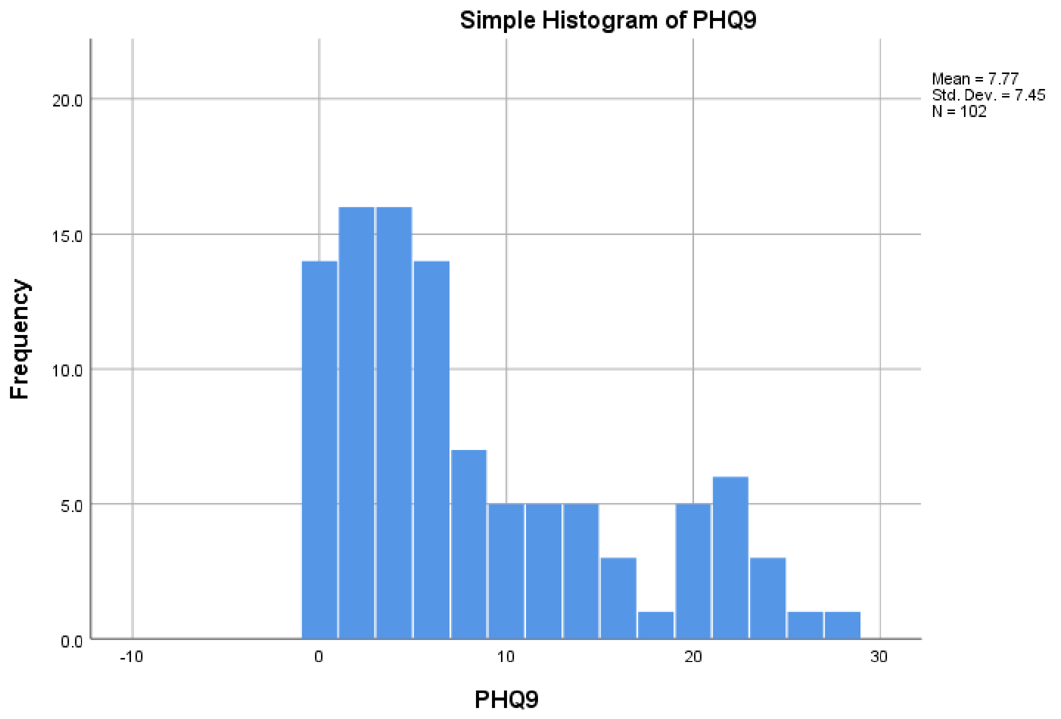
Appendix H

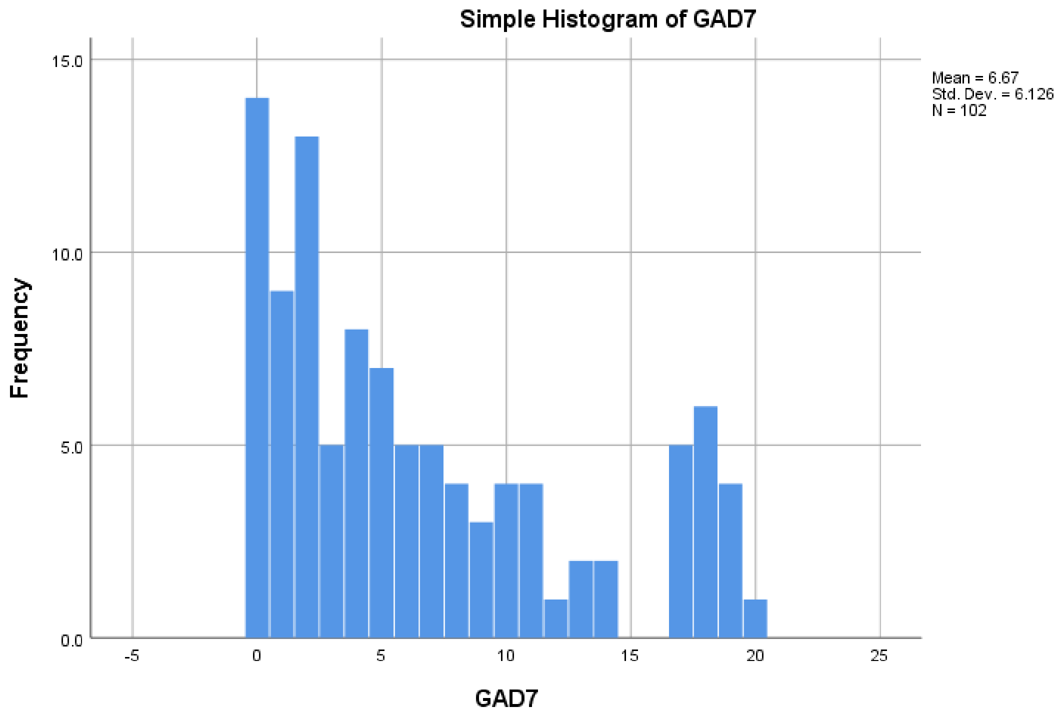
Additional Diagnoses Data

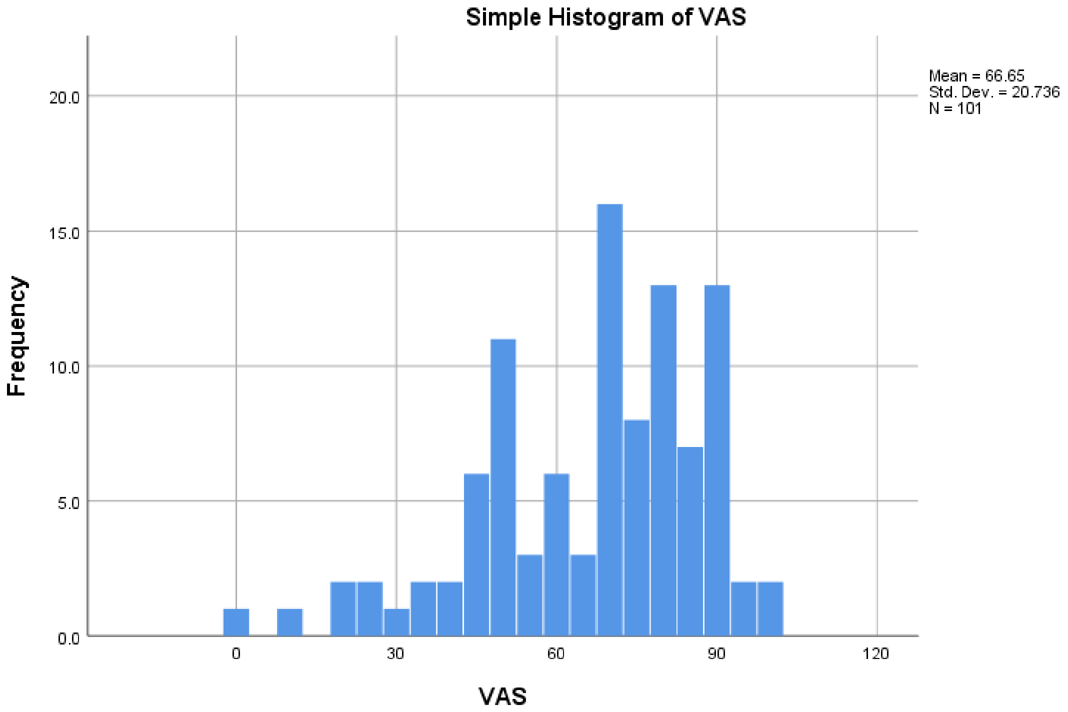
Primary Dermatological Diagnosis	**N**
Psoriasis	23
Eczema	16
Alopecia	11
Acne	7
Actinic Keratoses	7
Lichen Sclerosis	5
Lichen Planus	4
Hydradenitis Supporativa	3
Keloid Scar	3
Lupus	3
Rosacea	3
Prurigo	2
Urticaria	2
Folliculitis	2
Chloasma	1
Cutaneous Vasculitis	1
Darier’s Disease	1
DRESS (Drug Reaction)	1
Erosive Pustular Dermatosis	1
Erythema Multiforme	1
Hyperhidrosis	1
Lichen Simplex Chronicus	1
Morphea	1
Palmoplantar Keratoderma	1
Polycystic Ovary Syndrome	1
Pressure Sore	1
Pruritis	1
Sweet’s Syndrome	1
Vitiligo	1

Appendix I

Histograms of Outcome Variables Examined for Skew






Simple Histogram of VAS
Mean = 66.65
Std. Dev. = 20.736
N = 101
Frequency
20.0
15.0
10.0
5.0
0.0
0
30
60
90
120
VAS