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“Have Patients with Chronic Skin Diseases Needs Been Met?”

A Thesis on Psoriasis and Eczema Patient Care in Dermatology Service

This thesis is submitted to The University of Lancaster for the degree of PhD in the Faculty of Medical and Human Sciences

PhD student name: Taha Hassan Aldeen, Consultant Dermatologist

August 2023

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Declaration

A free licence (License ID CUQoL3683) has been kindly granted by Cardiff University to use Professor Finlay's DLQI questionnaire for the purposes of this research (PhD Student Number 1413056) in accordance with the terms and conditions of the licence.

Part of this thesis has been published in the Clinical Research in Dermatology Journal (2020) Vol 3, Issue 1, Page 1-6, under the following title: - Assessing Comorbidities, Quality of Life, and the Needs of Patients with Psoriasis and Eczema at Each Consultation; Can Their Needs be Assessed and Met Online?

http://insight.cumbria.ac.uk/id/eprint/5901/1/Taylor_assessing_commorbidities.pdf

The abstract of this thesis was also presented as a poster at the 99th Annual Meeting of the British Association of the Dermatologists (BAD), 2nd – 4th July 2019, and it was published in the British Journal of Dermatology (BJD) Supplement 1, July 2019, Abstract Po16 page 32.

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About the researcher

I am Taha Aldeen, I have been working in the National Health Service (NHS) in the UK for more than 25 years including 12 years in dermatology. Since 2016 I have been working as a consultant dermatologist at Barking, Havering and Redbridge University Hospitals (BHRUH) NHS Trust in Essex, UK.

My passion for dermatology evolved in medical school when I came across one patient with severe psoriasis. He was a young man, but his disfiguring skin disease was regarded as a stigma. He was suffering from pain and fear, unable to work or to complete his education and was regarded as a disabled person and a burden on his culture and on his family.

Beside my clinical work, I was always fascinated by research and I completed two master's degrees and have conducted several cross-sectional studies in the UK. My last study was on psoriasis patients in South Yorkshire and it demonstrated that these patients had unmet needs and often underreported, unmanaged metabolic and psychological comorbidities.

In order to support such patients, I felt that there was a need for a pragmatic study to understand how skin disorders affect the lives of such patients. Therefore, I sponsored myself and enrolled in a part-time PhD course. My objective was to contribute to the field I loved and trained in by supporting the needs of patients with chronic skin diseases.

List of Abbreviations

AD	Atopic Dermatitis (eczema)
APPGS	All Party Parliamentary Group on Skin
BAD	British Society of Dermatologists
CBT	Cognitive Behaviour Therapy
CCG	Clinical Commissioning Group
CCH	Care Close Home
CHS	Community Health Service
CI	Confidence Interval
DCS	Dermatology Community Service
DALYs	Disability Adjusted Life Years
DLQI	Dermatology Life Quality Index
DoH	Department of Health
EMR	Electronic Medical Records
GP	General Practitioner
GPwSI	GPs with a Special Interest
HADS	Hospital Anxiety and Depression Scale
HIV	Human Immune Deficiency Syndrome
HRQOL	Health-Related Quality of Life
IL	Interleukin
IT	Information Technology
MI	Motivational Interviewing
NAO	National Audit Office
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
No.	Number
OR	Odds Ratio
PASI	Psoriasis Area and Severity Index
PCT	Primary Care Trust
PEST	Psoriasis Epidemiology Screening Tool
Ps	Psoriasis
PsA	Psoriatic Arthritis
PST	Problem Solving Therapy
QOL	Quality of Life
RCP	Royal College of Physicians
RCT	Randomised Controlled Trial
RR	Relative Risk
SCORAD	SCORing Atopic Dermatitis
SDM	Shared Decision Making
SD	Standard Deviation
SDT	Self-determination Theory
SET	Self-efficacy Theory
SRT	Self-regulation Theory
UK	United Kingdom
US	United States of America
UVL	Ultraviolet Light
WHO	World Health Organisation

Taha H Aldeen

Abstract

Background Common chronic skin diseases such as eczema and psoriasis usually require long term medical care. They are often associated with psychological and metabolic comorbidities, which can impact on patient quality of life (QOL) and on the self-management of these diseases. Regular assessment of patient needs, comorbidities and feedback is a critical step in the development of decision-analytic models. Currently, no intervention is available to regularly assess such patients' needs and comorbidities and support their involvement in the decision-making and self-management of their morbidity and comorbidities. The aim of this research is to involve the patients in decision making of their care and to support their self-management by the use of a paper questionnaire (study tool) at each consultation.

Objective To explore the acceptability and potential of a self-developed paper questionnaire that constituted a study tool for addressing the needs, comorbidities, and feedback of patients with psoriasis and eczema and supporting their involvement in decision making and self-management of their chronic conditions.

Method A mixed method study was conducted and included a postal survey on adult male and female patients with psoriasis and eczema, using the study tool, which is a paper questionnaire and contains the Dermatology Life Quality Index (DLQI) and seven supplementary open-ended questions to capture patients' views, feedback, comorbidities, coping status and needs. The survey was followed by semi-structured face-to-face interviews with a sample of the patients who had participated in the survey. The aims of the interviews were two-fold: 1. to gain a deeper understanding of their experience of living with and managing their skin disease; and 2. to gather patient feedback on the service they received as well as their views on using the new study tool or any alternative intervention to address and support their self-management. The final study was a pilot which involved presenting a proposal of an online version of the study tool to a group of healthcare experts asking them to critically review the extent to which the online model responded to patients expressed needs.

Results Of the 114 patients who participated in the postal survey 108 (94.7%) of them expressed physical, metabolic and psychological comorbidities. Stress was identified as the dominant disease-triggering factor in 72 (63%) participants. Thirty-three (28.9%) of participants reported that they could not cope with their chronic illness. Eighteen (15.7%) participants suffered from anxiety, and 12 (10.5%) had depression and suicidal thoughts. Twenty-nine (25%) participants addressed their needs for support at home, and 16 (14%) of them asked for support at work. In the patient feedback section, 21 (18.4%) and 9 (7.8%) participants rated the service they received from their general practitioner (GP) and dermatologist as poor, respectively. In the interviews, all the participants 22 (100%) welcomed the use of the study tool on a regular basis to address their needs, comorbidities and feedback. Nineteen (86.3%) of them suggested that they would prefer using an online version of the tool or patient portal system as a convenient way of remote and interactive communication with the healthcare provider, particularly during the worsening of their skin condition. In the final pilot study, the healthcare experts agreed that the proposed online version of the study tool could be a convenient platform for such patients to support their self-management. They discussed the potential importance of such a tool if it provided them with access to supportive services such as patient information on skin diseases and self-management, access to local mental health service and other relevant psoriasis and eczema patients' support groups and charities.

Conclusion This novel mixed method research identified knowledge gaps in managing patients with psoriasis and eczema. It provided a new tool that has the potential to regularly engage and assess patients' unmet needs, comorbidities and feedback. The tool can involve patients in decision-making and offers them the autonomy to disclose heterogeneous needs that may support their self-management. All the interviewees welcomed regular use of the study tool and the majority of them suggested that they would prefer using an online version of the tool if it was available. Future research is needed to assess the impact of the study tool in filling important gaps in patient self-management and in health service improvement.

1. CHAPTER ONE - INTRODUCTION

1.1 Introduction

This thesis builds on and is grounded in my on-going interest and experience of research into chronic skin diseases particularly psoriasis and eczema. To support the needs of patients with psoriasis and eczema the thesis explores the personal, medical and psychological challenges facing such patients. This includes understanding their views and assessing their needs, comorbidities, coping mechanisms and feedback with a view to support their needs to self-management of their chronic illness.

The thesis reflects my interest in the lifelong journey of people who acquire incurable chronic disfiguring and uncomfortable skin conditions. It includes an exploration of patients' personal and psychological reactions toward the symptoms of the disease; society's values and reactions towards healthy, unhealthy or diseased skin; and the National Health Service (NHS) approach to managing psoriasis and eczema.

As a practitioner in the NHS, I wanted to look more closely at how patients reported their care, in particular the impact of chronic disease on their personal, social, occupational, family life, their treatment challenges, their needs and satisfaction with health care provision at primary and secondary levels. The thesis uses patient views and feedback to identify opportunities to enhance service quality and patient quality of life (QOL). The latter will be explored in detail in the next chapter.

This thesis is divided into eight chapters. This first chapter starts with an introduction to the two investigated skin diseases: psoriasis and eczema, explaining their epidemiology, and management including patients' challenges with such diseases. The chapter also discusses the global and the national burden of chronic skin diseases highlighting the NHS's resources and limitations. Chapter-1 ends with a list of aims and objectives of this research and a summary.

The second chapter reviews the literature to explore the pathogenesis “roots” of the psychological comorbidity associated with psoriasis and eczema by examining the histology, immunology and neurophysiology of healthy skin in relation to psoriasis and eczematous skin and discusses the impact of the chronic skin diseases on the patient's psychology. The literature review highlights the relevant empirical and theoretical publications around the challenges in managing these chronic skin conditions. It discusses the dermatology service limitations, patients' and health professionals' feedback. The chapter ends with exploring the role of self-management in supporting patient care, reporting knowledge gaps, adopting a conceptual framework and a research proposal.

The third chapter discusses the methodology of the research and justifies the use of a mixed methods study. The research design is discussed with a particular emphasis on the challenges of conducting quantitative and qualitative research and developing a paper questionnaire (study tool). The fourth and the fifth chapters discuss the details of the postal survey (Study-1) and the interviews (Study-2) conducted in this research, respectively. The sixth chapter presents a synthesis of the research findings and discusses these in context of the wider literature. This chapter also presents a proposal of an online version of the study tool and a pilot study to discuss the proposal (Study-3). The seventh chapter presents a reflection on the research process and the evaluation of the methodological decision making. The last chapter suggests the potential impact of the current research on patient healthcare, recommendations for future research and the final conclusions.

1.2 Understanding psoriasis and eczema

As the focus of this research is on supporting patients having psoriasis and eczema, understanding the epidemiological dimensions and management challenges of these two common skin diseases will be first reviewed and discussed.

1.2.1 Psoriasis

In 2016, the World Health Organization (WHO) reported psoriasis as a severe global problem (WHO, 2016). Psoriasis is a common, lifelong, incurable, and disfiguring skin disease (Griffiths *et al.,* 2021). It affects around 125 million people worldwide (up to 3% of the total population), and around 1.7% of the UK population have psoriasis (Armstrong & Read, 2020). The global prevalence of psoriasis however varies substantially among different countries, and it can range from 0.14% in east Asia to 11.4% in the Scandinavian region (Iskandar *et al.,* 2021). Approximately 30-35% of psoriasis patients can also develop psoriatic arthritis (PsA; Villani *et al.,* 2015). The disease equally affects men and women and from any race (Augustin *et al.,* 2015). The onset of psoriasis may be at any age, but usually has two peaks. The first peak (type I) at approximately 15 years, which affects around 75% of psoriasis cases and tends to cause a severe type of psoriasis. The second peak (Type-II) at approximately 60 years (Griffiths *et al.,* 2017, 2021). The disease usually persists across the life course, with unpredictable fluctuations in its extent and severity (Egeberg *et al.,* 2019).

The aetiology of psoriasis remains elusive. Genetic and environmental factors are involved in the onset of the disease (Griffiths *et al*., 2021; Lowes *et al*., 2014). Around a third of patients with psoriasis have a family history of the same disease and the inherited risk of the disease increases if both parents have psoriasis (Griffiths *et al.,* 2021). The concordance rate in monozygotic twins (35-73%) and in dizygotic twins (15-30%) suggests that environmental factors play an important role in psoriasis susceptibility (Gupta *et al.,* 2014). Multiple human leukocyte antigen (HLA) genes are strongly associated with the risk of psoriasis, especially HLA-C*06:02, which is associated with early onset psoriasis (Rendon & Schäkel, 2019).

Psoriasis is often triggered by environmental assaults mainly stress related in a genetically predisposed person (Griffiths *et al*., 2017). Other triggering factors include skin trauma, infections, obesity, smoking, excess alcohol intake, certain drugs and having immunosuppressive conditions including AIDS (Hayes & Koo, 2010; Jobling, 2007). The burden of psoriasis spans personal, physical, psychological and social aspects. Patients with psoriasis live most of their adult life with this chronic debilitating illness including its stigma (Alpsoy *et al*., 2017; van Beugen *et al.,* 2017).

Recently, Villacorta and colleagues (2020) measured the total work productivity loss related to psoriasis in France, Germany, Spain, Italy, the UK and the USA. They used the data of 936 participants who completed the Work Productivity and Activity Impairment questionnaire and the DLQI score. The mean percentages of total Work Productivity Loss (WPL) for respondents with mild, moderate and severe psoriasis were 10.1%, 18.9% and 29.4%, respectively. Their multivariate regression showed that one unit increase in DLQI score increases total WPL by 1.8% ($p < 0{\cdot}001$; Villacorta *et al*., 2020).

Clinically, psoriasis has many phenotypes including plaque, guttate, palmo-planter, generalised pustular, flexural, nail and erythrodermic psoriasis. However, almost 85% of psoriasis patients have plaque type or psoriasis vulgaris (Griffiths *et al*., 2017, 2021). Patients with psoriasis vulgaris presented with generalised symmetrical itchy salmon-pink, skin patches covered with white-silver coloured scales anywhere on the body, but mainly on the extensor surface of the limbs, back, scalp, ears and genitals.

Psoriasis skin patches often bleed easily and cause shading of the skin scales on the clothes, furniture and bed sheets causing distress to the patients at home, work and in public places (Moon *et al.,* 2013). Psoriasis patients usually tend to hide their skin rash in public places by wearing long garments with long sleeves and closed collared shirts. Such clothes might be difficult to tolerate during hot weather (Kouris *et al.,* 2017; Krueger *et al.,* 2001).

Psoriasis arthritis (PsA) can cause chronic pain in any joint, but mainly of the fingers, toes, wrists, elbows, knees, ankles and lower lumber spine (Villani *et al.,* 2015). Chronic psoriatic arthritis can lead to severe joint deformity and affects the patient's mobility, daily performance at home and at work, loss of job and independence (Amin *et al*., 2020). As early systemic treatment of psoriatic arthritis can prevent joint deformity (Iragorri *et al*., 2019), NICE recommended that psoriasis patients with chronic joint pain should be referred to a rheumatologist for assessment and to rule out psoriatic arthritis at an early stage (NICE, 2012). Almost 50% of patients with psoriasis vulgaris and up to 90% of patients with psoriatic arthritis develop dystrophic nail changes that may affect their daily manual activities (James *et al.,* 2006; Jensen *et al.,* 2016).

Psoriasis is not only a skin disease, but a chronic systemic illness associated with multiple comorbidities (Amin *et al.,* 2020). It is categorised as an immune-mediated inflammatory disease (IMID) and shares similar pro-inflammatory mediators with other chronic diseases (Lowes *et al.,* 2014).

A population-based study was conducted on a UK general practice database to examine the association between psoriasis and metabolic syndrome. The latter is a cluster of cardiovascular risk factors and is diagnosed by having 3 or more of the following disorders: obesity, abnormal blood lipids profile, insulin resistance and hypertension. The study included 44,715 individuals of whom 4,065 had psoriasis and 40,650 were controls. Of the psoriasis patients, 2,044 had mild psoriasis, 1,377 had moderate psoriasis, and 475 had severe psoriasis. The study found psoriasis was associated with metabolic syndrome in a "dose-response" manner, with adjusted Odds Ratio (adj. OR) varied from 1.22, (95% CI 1.11-1.35) to 1.98, (95% CI 1.62-2.43), in mild and severe psoriasis, respectively. They recommended screening psoriasis patients for metabolic syndrome (Langan *et al*., 2012). Indeed, in the same year NICE recommend screening all psoriasis patients for metabolic syndrome (NICE, 2012).

Currently there is no cure for psoriasis; hence, patients may feel hopeless and tend to isolate themselves socially, which can make them depressed (Sahi *et al.,* 2020). The current treatments available for psoriasis are able to control the skin rash but are time sensitive and so after a period of time need to be replaced by alternatives (Feldman *et al.,* 2016; Frantz *et al*., 2019; Smith *et al.,* 2017).

Three main therapeutic options are available to control the skin rash in psoriasis and they include topical therapy (in the form of ointments, creams, gel, lotions, shampoo and sprays); light therapy (ultraviolet light); and systemic therapy (in the form of oral medication, subcutaneous, intramuscular or intravenous injections; NICE, 2012; Psomadakis & Han, 2019). Treatment selection can be very challenging as they are not free from side effects, especially systemic therapy, which requires regular clinical and blood test monitoring every few months by a specialist (Rendon & Schäkel, 2019).

In the UK, BAD and NICE appraise clinical trials and medical therapies and issue guidelines that should be followed by UK clinicians (NICE, 2012). Nonetheless, each patient needs to be assessed individually and should be involved in treatment decisions (Elwyn *et al*., 2012; van der Kraaji *et al.,* 2020). Many factors need to be considered before prescribing psoriasis therapy, including psoriasis phenotype, patient age, sex, fertility status, lifestyle, occupation, metabolic, cardiovascular and psychological comorbidities, joints pain or mobility status, risk of adverse events, past medical history, previous response to treatment, severity of the disease, goals of treatment and patient preference (Parisi *et al.,* 2013).

Topical therapy is the first line treatment for mild types of psoriasis (Frantz *et al*., 2019; Psomadakis & Han, 2019). However, many patients are reluctant to use topical therapy as they are oily, stain clothes and bed sheets, are messy, create shiny skin, need regular application each day, may interfere with daily activities, and sometimes are ineffective or lose potency with time (Devaux *et al*., 2012).

Light therapy or phototherapy is an artificial ultraviolet (UV) radiation delivered by the Phototherapy Unit. The latter can deliver ultraviolet A (UVA) and/or ultraviolet B (UVB) wavelengths. There are 3 main types of phototherapies: Broadband UVB (BUVB), Narrowband UVB (NBUVB) and PUVA (Psoralen + UVA; Zhang & Wu, 2018). Phototherapy can be used to treat many skin conditions including psoriasis. However, it requires around 30 visits to a phototherapy unit in a nearby hospital. This may not be possible for full-time employed patients (Armstrong & Read, 2020). Phototherapy has certain contraindications. It also requires patients to stand in a special phototherapy booth or cabinet for a few minutes at each visit. This can be unfeasible for patients with poor mobility (Monk & Hussain, 2019).

Systemic therapy for psoriasis includes conventional systemic drugs (e.g., Methotrexate, Fumaderm, Cyclosporine and Acitretin) and biologic drugs (Griffiths *et al.,* 2021). Though rare, most systemic therapy can have potentially serious side effects. They require regular follow-up visits and blood test monitoring by a specialist (Armstrong & Read, 2020). Systemic therapy may lose its potency over a period of months or years (Frantz *et al.,* 2019) and some of them cannot be prescribed to pregnant women or to patients with immune suppressive disorders or cancers (Al-Janabi, & Yiu, 2022). Failure of this therapy can lead to relapse of the skin rash, distress, depression or feelings of hopelessness (Kurd *et al.*, 2010). Treatment failure usually requires switching the failing systemic drug to alternative regimens (NICE, 2012).

In the last two decades biologic drugs or therapy has been introduced as a very effective therapy for many chronic diseases including psoriasis and eczema (Light *et al.,* 2019). This therapy can significantly reduce the inflammatory process in patients' immune systems by blocking certain immune cell receptors or inflammatory cytokines (Al-Janabi, & Yiu, 2022). They include tumour necrosis factor-α inhibitors (e.g., etanercept, adalimumab, certolizumab, and infliximab), interleukin (IL) inhibitors IL-12 and 23 (e.g., ustekinumab), IL-23 inhibitors (e.g., guselkumab, tildrakizumab, and risankizumab), and IL-17 inhibitors (e.g., secukinumab, ixekizumab, bimekizumab, and brodalumab; Armstrong & Read, 2020). These biologics have been approved for treatment of psoriasis (Sbidian *et al.,* 2020). Although, biologics are more expensive than the above conventional drugs (Smith *et al.,* 2017) they are more effective and have less side effects than the conventional drugs (Al-Janabi, & Yiu, 2022).

1.2.2 Eczema

Eczema is also known as atopic dermatitis or atopic eczema. It is a very common chronic relapsing skin disease characterised by dry itchy skin rash (Langan *et al.,* 2020). Eczema affects both sexes equally and it is more prevalent in children than adults. The UK has a high prevalence of eczema, affecting 11-20% of children and 5-10% of adults (Cork *et al.,* 2020). The global prevalence of eczema however varies substantially among different countries. It can range from 0.9% in India to 24.6% in Colombia (Leung & Bieber, 2003). The aetiology of eczema is still unclear. However, as with psoriasis a combination of genetic and environmental factors can trigger eczema (Thyssen *et al.,* 2020). Around half of eczema patients have mutations in the Filaggrin gene, which codes for Filaggrin, a protective protein present in skin that strengthens the connection between skin cells. Without such proteins, skin loses its defence function in protecting against environmental allergens and against body water loss. The latter is the main cause of dry itchy skin in eczema (Pyun, 2015).

Several triggers are known to be responsible for the flare of the disease such as stress, exertion, sweating, extreme weather, certain drugs and foods, infections, dust mites, allergens (which may come into contact with the skin directly or through airborne pollution) and skin irritants including soaps, detergents, and excessive washing with water (Silverberg, 2017; Thyssen *et al*., 2020).

Clinically, eczema patients present with slightly scaly dry skin with groups of red papules, vesicles, nodules, or patches and multiple skin scratch marks (Chu *et al*., 2017). Just like psoriasis, the distribution of the skin rash in eczema is usually generalised and symmetrical (Pyun, 2015). The presentations (phenotypes) of eczema however are dependent on the age of the person and their ethnic background (Fishbein *et al*., 2020). In Caucasian children, the first places to be affected by the rash are often the face and the flexures of the limbs (Thyssen *et al*., 2020), whilst in Asian and African children, eczematous rash usually starts in the extensor surfaces of the limbs. As the child grows older, the rash tends to localise to the flexure parts of the body (James *et al*., 2006). Eczema however has the following less common subtypes: *Seborrhoeic dermatitis*, *Nodular prurigo*, *Discoid* eczema, *Pompholyx*, *Asteatotic eczema*, *Juvenile planter dermatosis* and *Pitryiasis alba* (Chu *et al*., 2017; Leung & Bieber, 2003).

Persistent itchy skin rash is the most common and uncomfortable symptom of eczema and constant scratching can lead to impaired rest during the day and night (Egeberg *et al*., 2019).

Constant scratching can also lead to excoriations (small skin ulcers) and lichenification (dry, thickened, irregular and inflamed skin). Patients' nails may look shiny due to frequent rubbing of their itchy skin with the nails' plates rather than scratching the skin with the nail ends (Leung & Bieber, 2003). Severe eczema can cause blistering, weeping, oozing, crusting, scaling and disfigured red-brown thick skin resulting from chronic scratching (Fishbein *et al*., 2020).

Children with severe eczema are susceptible to develop secondary skin infections at the site of their inflamed weepy broken skin (Cork *et al.,* 2002; Egeberg *et al*., 2019; Pyun, 2015). The most common secondary infections are impetigo and eczema herpeticum (Chu *et al*., 2017; Griffiths *et al*., 2017). The latter is a potentially life-threatening condition needing urgent hospital admission, intravenous therapy and close monitoring (Fishbein *et al*., 2020; Leung & Bieber, 2003; Silverberg, 2017).

As in psoriasis, the chronic uncomfortable skin rash in eczema can limit patient daily activity and performance at home, work, school, public places, and leisure centres. The stigma associated with the skin rash can discourage the patients from exposing their skin while practising sport, swimming or having social or sexual relationships (Suarez *et al.,* 2012; van der Kraaji *et al*., 2020). Eczema is often associated with comorbidities including asthma, hay fever and food allergies. Eczema sufferers also have a higher risk for cardiovascular diseases, certain malignancies, autoimmune diseases, mental health disorders including depression (Andersen *et al*., 2017; Augustin *et al*., 2015; Egeberg *et al*., 2019; Leung & Bieber, 2003; Silverberg, 2017; Silverberg *et al*., 2019; Suarez *et al*., 2012).

The diagnosis of eczema is relatively straightforward, involving an examination of the affected sites and by taking a patient history (Fishbein *et al*., 2020; Leung & Bieber, 2003). However, in the case of doubt a skin biopsy may help to differentiate eczema from other clinically similar chronic skin diseases such as Psoriasis**,** Cutaneous T-cell lymphoma, Allergic Contact Dermatitis, Scabies, Pityriasis versicolor and Pityriasis rosea (Chu *et al*., 2017; Fishbein *et al*., 2020; Silverberg, 2017).

The treatments for eczema follow similar principles to those of psoriasis. They include topical therapy, light therapy, systemic therapy, in addition to the avoidance of potential triggers such as stress, irritants (e.g., commercial soaps and shower gels), food allergens, contact allergens, extreme weather, inhalant airborne allergens and skin infections (Fishbein *et al*., 2020; Frantz *et al*., 2019; Pyun, 2015; Thyssen *et al*., 2020). Nevertheless, avoiding such triggering factors is not an easy task for children with eczema and/or for their families to comply with, as many of these factors are difficult to eliminate from the patient's environment, hence relapse of eczema rash is very common (Cork *et al.,* 2020)

Applying topical treatment for a child requires parents and school nurse support (Barry *et al*., 2019). Therefore, cooperation between the child, their caregivers, parent(s), dermatologists and/or paediatricians and school nurses is required for successful management (Capozza *et al*., 2020; Shi & Lio, 2019; Suga & Sato, 2019). Patients and/or parents should be given written information on treatment and on how to recognise skin infections, particularly eczema herpeticum, which usually requires urgent intravenous treatment (Fishbein *et al*., 2020; Frantz *et al*., 2019; Silverberg, 2017).

Emollients are the main topical treatments for eczema and should be prescribed in large quantities. Parents require education on how to apply and how frequently to apply emollients (Fishbein *et al*., 2020). This can be difficult for working parents who have limited time to apply such treatments on their eczematous child many times a day. Subsequently, poor compliance frequently leads to the failure of this therapy (Capozza, *et al.*, 2020; Chu *et al*., 2017; Powell *et al.,* 2018; Silverberg, 2017; Suga & Sato, 2019).

Additionally, topical therapy in eczema particularly topical steroids can cause side effects such as skin atrophy, striae (stretch marks), infection, hirsutism, acne, folliculitis, hypopigmentation, failure to thrive, Cushing's syndrome, glaucoma, cataracts and hypothalamic-pituitary axis suppression (Moncrieff *et al*., 2018; Suga & Sato, 2019). These side effects often create 'Steroid phobia' in parents caring for children with eczema resulting in underuse or under treatment of eczema (Fishbein *et al*., 2020; Silverberg, 2017). Hence, children with eczema may suffer a prolonged morbidity, ill health and frequent GP and hospital visits. This can also affect child mental health, sleep, confidence, social activities, academic performance and schooling (Pyun, 2015; Silverberg *et al.*, 2019).

Light therapy is used in eczema when topical therapy or other management options have failed. However, light therapy is not always as effective in eczema as in psoriasis and it requires around 30 visits to the hospital which is not always possible for children at school or for their working parents to attend (Fishbein *et al.,* 2020; Leung & Bieber, 2003).

Systemic therapy may be used for severe eczema when the patient does not respond to topical therapy or light therapy (NICE, 2007). It includes conventional systemic drugs (e.g., Azathioprine, Methotrexate or Cyclosporine) and biologic drugs (Fishbein *et al*., 2020; Frantz *et al*., 2019). The latter used to treat severe cases of eczema that failed to respond to the above conventional systemic drugs (Cork *et al.,* 2020). As in psoriasis, biologic drugs in eczema can significantly reduce the inflammatory process in patients' immune systems by blocking certain immune cell receptors or inflammatory cytokines such as interleukin (IL). Dupixent (dupilumab) was the first anti-interleukin (IL)-4 approved for management of eczema (Cork *et al*., 2020). A new class of immunomodulatory drugs that can inhibit one or more of the Janus kinase (JAK) enzymes (JAK1, JAK2, JAK3, TYK2), has been approved for treatment of eczema (Deleanu & Nedelea, 2019; Suga & Sato, 2019). However, most biologics are expensive, not free from side effects and may lose their efficacy over time (Frantz *et al.,* 2019). They require regular clinical and blood tests monitoring by a specialist (Deleanu & Nedelea, 2019; Frantz *et al*., 2019; Silverberg, 2017).

Overall, it is not easy for all parents to look after the treatment of their eczematous child as instructed or needed and to exclude all the triggering factors for eczema from the environment of their child (Na *et al.,* 2019; Schut *et al*., 2014). This may be due to the working commitment of the caregivers or other personal and social factors (Capozza *et al.,* 2020). Therefore, a management plan for treating the eczematous child needs to be discussed carefully and supported by written information to the caregivers and school nurses to ensure compliance with the treatment (van der Kraaji *et al.,* 2020).

Furthermore, management of psoriasis and eczema, can be influenced by the national and international burden of other diseases, pandemic (e.g., COVID-19), and cancers, which have the priority to be managed first. The management of psoriasis and eczema cases is also influenced by the health service management, resources, strategies, guidelines, limitations, politics, economy, and patient income, which will be discussed next (Nuffield Trust, 2018; Oliver, 2017; von Hospenthal, 2013).

1.3 The global burden of skin diseases

Skin diseases are the most common human illnesses across geographies and time, and their disability is substantial worldwide, yet they receive relatively little attention in global health (Johns *et al.,* 2013). In 2017, the global prevalence of common skin diseases was reported as follows in descending order: dermatitis (including eczema, contact, and seborrheic dermatitis), acne, psoriasis, urticaria, viral skin diseases, fungal skin diseases, scabies, skin cancer, pyoderma, cellulitis, decubitus ulcer, and alopecia areata (Karimkhani *et al*., 2017). The worldwide prevalence of skin diseases however varies according to the type, time, age, race, sex, ecological, sociodemographic, public health resources and political variables (Pezzolo & Naldi, 2020).

The prevalence of infectious skin diseases was far more common in developing countries than in developed countries, while skin cancers and precancerous skin conditions were much more common in the Caucasian population (Hay *et al.,* 2014). Although both eczema and psoriasis pose a substantial public health burden owing to their increasing prevalence worldwide and considerable morbidity (Augustin *et al*., 2015; Griffiths *et al*., 2017), eczema remains the leading cause of skin disease disability-adjustment life-years worldwide (Pezzolo & Naldi, 2020).

Skin disease burden was estimated using the metric of disability-adjusted life-year, which is the sum of years of life lost to a disease plus years lived with disability. One disability-adjustment life-year is equivalent to 1 year of healthy life lost (Institute for Health Metrics and Evaluation [IHME], 2013). Skin conditions contributed 1.79% to the global burden of disease measured in disability-adjustment life-years from 306 diseases (Karimkhani *et al.*, 2017) and they continue to be the fourth leading cause of disability and non-fatal disease burden world-wide, especially in resource-poor countries (Seth *et al.,* 2017).

In 2017, Karimkhani and colleagues extracted data from more than 4,000 sources during the years 1980 through 2013 to measure the global burden of skin diseases. They reported that skin and subcutaneous diseases were responsible for 41.6 million disability-adjustment life-years and 39.0 million years lived with disabilities. Dermatitis (which includes eczema, seborrheic and contact dermatitis) was responsible for the largest global burden of disability-adjustment life-years and years lived with disabilities compared with other skin conditions followed by acne and psoriasis, respectively (Karimkhani *et al.*, 2017).

Earlier in Europe, Dalgard and colleagues (2015), conducted an international cross-sectional study in 13 European countries (Belgium, Denmark, France, Germany, Hungary, Italy, Netherlands, Norway, Poland, Russia, Spain, Turkey and the UK). They recruited 4,994 participants (3,635 patients with chronic skin diseases and 1,359 controls). In each dermatology clinic, 250 consecutive adult out-patients were asked to complete a questionnaire, reporting socio-demographic information, negative life events, suicidal ideation, depression and anxiety were assessed with the Hospital Anxiety and Depression Scale. They reported a significantly higher prevalence of clinical depression (10.1% vs. 4.3%), anxiety (17.2% vs. 11.1%), and suicidal ideation (12.7% vs. 8.3%) among patients with common skin diseases compared with controls. The association with depression and anxiety was highest for patients with psoriasis, atopic dermatitis, hand eczema and leg ulcers (Dalgard *et al.,* 2015). These results reflect the need for assessing and managing the psychological comorbidities of skin diseases.

Furthermore, with the increasing aging population in Western countries, skin cancers have become the most common cancers in the world, commonly affecting older Caucasians and it accounts for almost 60% of skin disease-related deaths (WHO, 2018). Non-melanoma skin cancer is the fifth most commonly occurring cancer in humans, whilst melanoma is the nineteenth most common cancer worldwide (World Cancer Research Fund [WCRF], 2019). The prevalence of non-melanoma and melanoma cancers has been increasing in Caucasians living in Australasia, North America and Europe (WCRF, 2019). Around 50% of the dermatology workload in the UK is related to the management of skin cancer or pre-cancer skin conditions (BAD, 2019a; The King's Fund, 2014). The urgent priority for managing skin cancers has a negative impact on the waiting time for managing less urgent skin conditions such as psoriasis and eczema (Edwards & Imison, 2014).

Financially, the burden of skin diseases is significant in both high and low-income countries (Balieva *et al.,* 2016; Lim *et al*., 2017; Seth *et al*., 2017). However, the exact financial loss and health burden in developing countries remains unknown mainly due to inaccurate data and coding systems in both public and private sectors. Many attempts have been made over the last 50 years to determine the costs of skin disease, but systematic reviews of the socio-pharmaco-economic impact reveal few high-quality publications with widely ranging results (Finlay, 2009).

In the UK, skin conditions are the most common diseases encountered by GPs (House of Commons [HoC], 2014). Nearly 13 million people presented to GPs with a skin problem every year (NHS Digital, 2018a). More than 3 million primary care hours are spent on skin conditions, at a cost to the NHS of £723 million each year (Steen *et al*., 2017). Almost £413 million is spent on skin diseases treatment over the counter each year which is equal to 18% of total over the counter sales (Buckley *et al.,* 2018).

In the US, one in four Americans (26%) reported receiving treatment for at least one skin disease in 2013. In the same year, nearly 85 million Americans were seen by a physician for at least one skin disease, and almost $75 billion was spent on skin diseases; compared with $29 billion spent in 2004. Of this total cost ($75 billion), $46 billion was attributable to medical costs (office visits, procedures, tests), $15 billion to prescription drugs, and $4 billion to other skin procedures, and skin cancer screening. Another $10 billion was spent on over the counter products. Furthermore, patients with skin disease and caregivers suffered $11 billion in lost productivity. This does not include additional time for at home care and treatment which was not evaluated (Lim *et al*., 2017).

1.4 The National Health Service in the UK

In the UK, the health care system is dominated by the free of charge National Health Service (NHS). It was established in 1948, and over the years, it has become the fifth largest employer in the world. It sees around one million patients per day, employs around 1.4 million staff and has a budget of around £100 billion (The King’s Fund, 2020). The majority of the staff are working in England’s NHS. In 2017, there were around 140,000 doctors (106,131 hospital doctors and 33,921 GPs) and around 300,000 nurses working in the NHS, as well as health care scientists, therapists, pharmacists and laboratory staff (National Audit Officer [NAO], 2016; Nuffield Trust, 2018).

In financial year 2017/18 the total health spending in England was around £125 billion, with £110 billion being spent on the NHS England budget and the rest was spent by Department of Health initiatives, education, training and infrastructure (NHS England, 2018b).

The NHS in England is commissioned by Clinical Commissioning Groups (CCGs), in Primary Care Trusts (von Hospenthal, 2013). Within the NHS, there is a time target set to manage skin diseases (All Party Parliamentary Group on Skin [APPGS], 2013). The target time for managing skin cancer cases referred by a GP to secondary care is within 62 days, whilst the target for managing routine and urgent skin conditions is within 18 weeks (NHS, 2019; Schofield *et al.,* 2009). Breaching this target can subject the healthcare service provider to failure by the Care Quality Commission (CQC), which reviews, assesses and regulates all health and social care services in England (Mannion & Davies, 2018; Nuffield Trust, 2013).

With the increasing demands on the health service and limited resources in many NHS Hospitals or Trusts the waiting time for a patient to be reviewed by a specialist remains high and may take up to one year in some hospitals (NAO, 2016; Oliver, 2017). In contrast, the private health care sector provides a much faster service but is expensive; hence it remains as a limited service to a minority of the UK population (Edwards & Imison, 2014).

Although the NHS is one of the best free health care systems in the world, it has not been free from limitations and criticisms. One of the main limitations is that it has continued to struggle with its limited capacity and resources to cope with the growing demand and primary care referrals (Allder *et al.,* 2011). Whilst the number of medical staff has grown substantially in the NHS and the number of hospital full-time equivalent consultants has risen from 30,650 in 2004 to 49,585 in 2020; there are around 50,000 vacancies across all types of clinical staff, with a 5.9% shortfall between the number of staff that NHS organisations need and the number of staff actually employed (The King's Fund, 2014, 2020).

Staffing shortages are particularly severe in mental health services and in general practice. Apart from retirement, the most common reasons for leaving the NHS were dissatisfaction with working conditions, stress and/or an inability to deliver care of the right standard (Edwards & Imison, 2014; the King's Fund, 2019). The shortage of staff in the NHS has a direct impact on the patient appointment system and on the waiting time to see a physician (NAO, 2016; NHS, 2020). It can also delay access to certain medical and surgical treatments and impair the quality of care in some services, as well as increase the number of patients' complaints (NAO, 2016; NHS, 2018a, 2018b).

To cover staff vacancies the NHS hires costly temporary staff through private bank or locum medical agencies. In 2016/2017, around £2.9 billion was spent on agency staff and about a third of the figure goes on medical locums who can command very high premium rates (Nuffield Trust, 2018). Whilst the locum staff may have similar skills and qualifications to the NHS permanent staff, they cannot maintain continuity of patient care mainly because of their high turnover rate (The King's Fund, 2019; 2020). A patient may be treated by different locum doctors with different clinical and management approaches. Without regular clinical governance in place the high turnover rate can subject both staff and patients to clinical risk and to serious medical incidents (NHS Digital, 2018b).

The limitations associated with the NHS are not restricted to a shortage of resources and staffing, there is also little opportunity for changing its rigid hierarchy and resistance to reform, vision or innovation (Oliver, 2017). The NHS's complex and bureaucratic structure is often criticised by politicians for employing too many highly paid managers who may create unclear complex or fragmented efforts to integrate and transform care (Mannion & Davies, 2018). Organisational complexity presents at different levels of the health service and may reflect its evolution and changing by national bodies governance (Perry *et al.,* 2019). Whilst national bodies are playing an important governance role, their legislation and procedures have been argued to generate significant regulatory barriers, hindering efforts to integrate care, adopt an international successful model of care or to establish substantial modernised care (von Hospenthal, 2013).

Any change or novel idea presented to the NHS may require the submission of a lengthy and complex application, which if progressed would need to undergo a time consuming legislative and funding approval process (Alldel *et al.,* 2011; Perry *et al.,* 2019). Such bureaucracy can discourage many professionals including academic medical staff to invest their research ideas and innovations in the NHS (Nuffield Trust, 2018). This led Sir Stuart Rose, the former chief executive of Marks and Spencer, to conclude that the NHS is drowning in bureaucracy (Oliver, 2017)**.** The NHS is also subject to the electoral cycle, a factor that can lead to regular policy review and change (Mannion & Davies, 2018)**.** Additionally, the culture within the NHS has been argued to be resistant to change (Yassaee *et al.,* 2019). Junior and senior member of

NHS staff including the dermatology staff may oppose innovative projects, particularly if the new ideas affect their job plan, workload or payment (Perry *et al.,* 2019). This will be discussed further in chapter 6.

Whilst the demands of the NHS and its spending have increased in recent years, there is no matching evidence on effective long-term planning for service improvement or vision for a high-quality service (Mannion & Davies, 2018; Perry *et al.,* 2019). Patient complaints continue to rise and the total number of all reported written complaints in 2017-18 reached 208,626 (National Health Service [NHS] Digital, 2018b). This is the equivalent to 4,012 written formal complaints a week or 573 complaints per day (NHS England, 2019).

In summary, whilst being one of the largest and best health organisations in the world, the NHS has been facing capacity and quality issues. It needs to listen to patient feedback and complaints, adopt new ideas, clinical research, theories, or models of care to improve its quality and capacity to deal with the increasing demand. A holistic cost-effective service that may include primary and secondary prevention measures and patient involvement in decision making is needed for better self-management.

1.5 The dermatology service in the UK

Around 54% of the UK population experience a skin condition in a given twelve-month period (Schofield *et al*., 2009). Almost 69% of patients with skin diseases manage through self-care, while 14% seek primary health care and around 70,000 patients seek private sector care (NHS England, 2019; Kasmi *et al*., 2020). Many patients with skin diseases buy skin care treatments over the counter (OTC). In 2007, the sales of OTC products for skin diseases reached £413.9 million or 18% of the total OTC annual sales in the UK (Edwards & Imison, 2014). The high sales of OTC skin products may reflect the impact of skin disease on the patient's quality of life (Moncrieff *et al*., 2018). It may also reflect the difficulty to access the dermatology service within the NHS (NHS Digital, 2018a, 2018b).

In England and Wales around 13 million people (24% of the population) visit their GP for skin problems each year. Skin diseases account for up to 20% of a GP's workload. Children of less than 14 years of age (who account for 19% of the population) represent around 21% of all consulting with skin disease (Levell *et al.,* 2013). However, only 0.8 million (6.1%) of children and adults with skin diseases are referred to secondary care for dermatologist advice (BAD, 2014).

GPs usually follow the National British Association of Dermatologists guidelines for the management of mild cases of skin diseases with topical therapy (BAD, 2019a; NICE, 2007; NICE, 2012). If the GPs are unable to diagnose or manage certain skin diseases, they usually refer them to a dermatologist at community or secondary care for further assessment, advice, diagnosis or management (BAD, 2014). The latter may include offering systemic therapy which requires regular blood test monitoring and close clinical supervision by a specialist (von Hospenthal, 2013).

The dermatology services in the UK have been under immense pressure mainly because of the increasing number of referrals from primary care and the limited number of dermatologists in secondary care (HoC, 2014). Consequently, the increasing demand on the service has led to a long waiting time to see a dermatologist (Edwards & Imison, 2014).

Furthermore, there is a shortage of a holistic dermatology service and a shortage of combined specialities clinics or multidisciplinary care which can provide a cost-reducing service by limiting inaccurate diagnoses, ineffective treatments, unnecessary referrals and at the same time increased patient satisfaction and improved patient outcomes (Patel & Jafferany, 2000).

Telemedicine or teledermatology was introduced around two decades ago. It involves consultation and management of patients with skin problems by remote health care providers (van de Kerkhof, 2016). Although telemedicine can reduce the number of referrals to a dermatologist, there is a considerable percentage of teledermatological consultations resulting in a diagnosis that needs confirmation through a standard face-to-face consultation (McKoy *et al*., 2021; van de Kerkhof, 2016).

In the last decade and as a result of too many referrals being made from primary to secondary care, the BAD made several commissioning decisions with the CCG, often without appropriate engagement with local clinicians and patients (BAD, 2014). They both agreed to establish a dermatology community service (DCS) or Care Closer to Home (CCH) which would be managed and regulated by private medical agents (The King's Fund, 2014).

The CCG make their commissioning decisions and funding choices according to financial priority, levels of demands on dermatology services in certain geographical areas and in line with the BAD and NICE recommendations (BAD, 2014; NICE, 2012). The DCS was proposed to ease the workloads on secondary care by managing mild and moderate cases of skin diseases referred by GPs from primary care. This has not always been possible, mainly because of resource limitations and a lack of communication or cooperation between the DCS and secondary care providers (BAD, 2014, 2020; Nuffield Trust, 2018).

The DCS is almost disconnected from secondary care, and often lacks the resources to manage complex cases of skin cancers and chronic skin diseases that require systemic therapy, light therapy, specialised investigations or major skin surgery (NICE, 2019). Hence, the DCS is unable to provide holistic services to patients with chronic illnesses. Consequently, the majority of such chronic cases who were referred by their GPs to the DCS would be referred by the CDS to the dermatologists at secondary care. This has led to further delays in patient care and waiting time to see a dermatologist and an increase in patient dissatisfaction and complaints as well as destabilisation of resources and manpower in secondary and tertiary dermatology services, which is often overlooked by commissioners (NHS Digital, 2018b; The King's Fund, 2014). Additionally, the DCS is often delivered by general practitioners with a special interest (GPwSI). Although there is some evidence that GPwSI services are effective they have previously not met accreditation guidance, and they may be more expensive than NHS consultant-led services (Edwards & Imison, 2014; Schofield *et al*., 2009).

The CCG not only have responsibility for planning, funding and procuring health services for their local communities, they have to justify the way in which they commission care for people with long-term or complex health conditions (The King's Fund, 2014, 2020). However, they rarely discuss or involve such patients in their decision-making processes (Nuffield Trust, 2013). Moreover, although the delivery of care for people with chronic skin diseases is the responsibility of a large group of GPs and consultant dermatologists, the majority of GPs and dermatologists focus on treating the skin rash and tend to ignore assessing/managing the metabolic and psychological comorbidities under the skin in such patients (Keyworth *et al*., 2015; Nelson *et al*., 2013, 2014, 2016).

Further, according to NICE recommendations, patients with chronic skin diseases such as psoriasis or eczema should be assessed using specific scoring tools such as the Dermatology Life Quality Index (DLQI), Psoriasis Area and Severity Index (PASI) or the SCORing Atopic Dermatitis (SCORAD) index for eczema patients (Finlay *et al.,* 2017; NICE, 2012). In reality however, these scoring tools are not routinely used in a follow-up consultation and they do not always capture the full picture of the disease including the psychological and the metabolic comorbidities under the patient's skin (Moon *et al*., 2013; Na *et al*., 2019; Noormohammadpour *et al*., 2015).

The increasing demand on the dermatology service coupled with a shortage of consultant dermatologists make holistic treatment untenable. Based on government statistics for new patient referrals in 2009–10, a population of 250,000 generates 4,000 new patients (Levell *et al.,* 2013). A consultant dermatologist is expected to see 1,008 new and 1,344 follow-up patients a year (BAD, 2014). This means that a population of 250,000 requires 4 whole time equivalent dermatologists which equates to one consultant dermatologist per 62,500 patients (Levell *et al*., 2013). However, despite being one of the busiest specialities managing around 5% of all specialist outpatient activity in England the ratio of consultant dermatologists to the general population has always remained low at 1:130,000 (BAD, 2014; The King's Fund, 2019; 2020). The national shortage of consultant dermatologists is coupled with a national shortage of specialist dermatology nurses who can provide a range of services in acute and community settings (BAD, 2014; Edwards & Imison, 2014). At the community level, pharmacies can be the first point of patient contact to control their symptoms (BAD, 2014). However, the training of pharmacists in the management of skin problems has been limited and evidence that they are providing appropriate advice is lacking (Nazar *et al.,* 2019; Schofield, 2009).

Furthermore, dermatology services in the UK have been trivialised and marginalised throughout medical and health professional education and training (Edwards & Imison, 2014). Despite skin disorders being the most common reason that people present to their GP with a new problem, the level of training and knowledge of most GPs and primary care healthcare professionals in dermatology is generally limited (Schofield *et al.,* 2009). There is no compulsory dermatology training in undergraduate medical training or for postgraduate GP training. GPs may misdiagnose or delay the referral of potentially fatal skin conditions such as malignant melanoma and cutaneous lymphomas (Nuffield Trust, 2018). Population based studies indicated that many patients with chronic skin diseases experience a wide spectrum of psychological symptoms and they feel let down by the waiting times, level of knowledge of their GP in skin diseases, lack of patient information and lack of counselling and psychological support (de Vere Hunt *et al.,* 2021; Nash *et al.,* 2015; Nelson *et al.,* 2013, 2015).

There is also poor patient involvement in decision making, commissioning, contracting frameworks, referral options, current and future health care development, and primary prevention (Burt *et al.,* 2017; Elwyn *et al*., 2012; Llewellyn-Thomas, 1995; Mckinstry, 2000). Research is needed to examine many areas of uncertainty in the management of patients with chronic skin diseases and to assess the cost effectiveness of the current services compared with other models of care. Equally, there is a lack of clinical evidence on the effectiveness of many traditional and complementary therapies used by the patients (Monk & Hussain, 2019).

Moreover, safe and efficient patient clinical care relies on high quality data, and it is the responsibility of the healthcare provider to ensure the information used in decision making is accurate by liaising with the clinical coding department and providing clinical guidance (BAD, 2020). To produce a true picture of hospital activity, clinical coding staff are entirely dependent on clear and accurate information about all diagnoses documented by the dermatology staff (White *et al.,* 2022). Currently the reporting of diagnoses is not mandated in all public and private healthcare sectors, hence there is no disaggregated clinical data for all skin diseases in the UK. Consequently, there is no accurate epidemiological data on the natural history of each skin disease that could enable stakeholders to provide preventive strategies or to plan a cost-effective dermatology service (BAD, 2020).

The International Statistical Classification of Diseases (ICD) and Related Health Problems is generated by the World Health Organisation (WHO) and contains codes for diseases, signs and symptoms, social circumstances and external causes of injury or diseases. It provides a medical classification, which can be used globally for epidemiology, clinical service planning, payment systems and health services research (WHO, 2018). Its current revision (ICD-11) is the first revision of the ICD that has had significant input from dermatologists. It provides a global dermatology-specific detailed classification of skin diseases. However, it is vital that the international dermatology community (including the NHS) continues to be involved in refining and enhancing the overall value and relevance of the classifications (White *et al.,* 2022).

1.6 The challenges for patients

There are significant psychological comorbidities associated with psoriasis and eczema, mainly because of their appearance (Changing Faces, 2019; Dalgard *et al.,* 2015; Gieler *et al.,* 2015; Jafferany & Pastolero, 2018). In many cultures patients with visible skin diseases such as eczema and psoriasis feel rejected or unwanted as they do not meet social expectations of “desirable skin” (Magin *et al.,* 2011; Rowland, 2019). Abuse is common against people with disfiguring skin diseases (Balieva *et al*., 2016; Corrigan & Rao, 201; Egeberg *et al*., 2019). van Beugen and colleagues (2017), reported that stigmatisation was experienced by 73% of patients with psoriasis in their studied population and was associated with negative impacts on daily life (van Beugen *et al.,* 2017).

Research indicates that both anxiety and depression are more common in psoriasis patients than in the general population (Clarke *et al.,* 2020; Jafferany & Pastolero, 2018; Jensen *et al*., 2016; Lim, Bewley, & Oon, 2018). Approximately one-third of people with psoriasis experience depression and anxiety (Singh *et al.,* 2017). A similar incidence of depression was a recognised comorbidity in eczema patients (Andersen *et al*., 2017; Egeberg *et al*., 2019; Leung & Bieber, 2003; Pyun, 2015; Silverberg *et al*., 2019; Suarez, 2012; Thyssen *et al.,* 2020). Depression and stress can worsen such patients’ skin disease condition and prolong their morbidity and suffering (de Zoysa, 2013). They have a direct negative impact on the immune system as they can trigger an inflammatory process, which leads to exacerbation or flare of their skin disease (Chen & Lyga, 2014; Lowes *et al.,* 2014). The flare of skin disease can provoke further episodes of stress and depression in such patients (Ranabir & Reetu, 2011).

Ultimately, stress and depression can create a vicious cycle (Barankin & DeKoven, 2002; Cohen *et al.,* 2007).

More details on the social stigma and psychological comorbidity associated with psoriasis and eczema will be discussed in the next chapter supported by international studies and patients' and health professionals' feedback.

1.7 Aims and objectives of the research

Considering the above personal, social and healthcare service barriers and limitations; this research aims to explore the needs, comorbidities and feedback of patients with psoriasis and eczema. It further seeks to identify possible mechanisms to support their involvement in decision making and self-management of their chronic disease by the regular use of a paper questionnaire (study tool). The aims and the objectives of this research project are summarised in Table-1.

Table–1: Aims and objectives of the research

Aim	Objectives	Chapter
1. Explore the personal, medical, social, psychological, and financial impacts of skin diseases, mainly psoriasis and eczema	• Review the literature • Discuss psoriasis and eczema • Study the global burden of skin diseases • Understand NHS resources and limitations • Review dermatology service within the NHS • Investigate patients' challenges	1 and 2
2. Examine and trace the root of the psychosocial symptoms associated with chronic skin diseases (psoriasis and eczema)	• Study the biology of healthy vs diseased skin • Investigate the link between skin and brain • Explore psychological challenges of the patient • Review stigma and self-esteem in skin diseases • Review physicians' and patients' feedback • Consider supportive intervention (study tool)	1 and 2
3. Explore the challenges and the management of the psychological disorders in psoriasis and eczema patients and search for alternative supportive care	• Discuss psychological impact of skin diseases • Compare psychotherapy vs. counselling • Discuss psychotherapy limitations in the NHS • Review motivation/self-management theories • Report dermatology service knowledge gaps • Adopt conceptual framework/proposal	1 and 2
4. Situate the research and provide a robust rationale for the methodological and analytical decisions made	• Describe paradigm and discuss pragmatism • Define pragmatic approach within the research • Explain the rationales for using mixed methods • Design and manage mixed method study • Discuss axiology and cultural diversity • Describe the development of the study tool	2 and 3
5. Measure the needs, comorbidities, views and feedback of patients with psoriasis and eczema	• Conduct a pilot study and a postal survey • Identify patient needs • Measure patient metabolic comorbidities • Report patient psychological comorbidities • Discuss study results and limitations	3 and 4
6. Understand patients' views on the healthcare service and on using an intervention at each consultation to support the self-management of their disease	• Discuss the rationale for conducting interviews • Conduct semi-structured interviews • Thematic analysing of the qualitative study • Establish patients' views and feedback • Report patients' opinion on the service • Discuss study results and limitations	4 and 5
7. Discuss the impact of the research on patients' care, reflect on the research process and how to improve the new tool, and suggest future recommendations	• Synthesis of the findings of the research • Review the results in context of the literature • Obtain health experts' feedback on the tool • Reflect on research strengths and limitations • Adjust research proposal accordingly • Report recommendations and conclusion	6, 7 and 8

1.8 Summary

This Chapter has provided a synopsis of the thesis and highlighted the following issues: -

- The epidemiology and management of psoriasis and eczema
- The national and international burden of skin diseases
- The NHS in the UK; its structure, resources and limitations
- The demands and resources of the dermatology service in the UK
- The social, personal and psychological impact of psoriasis and eczema
- The aims and objectives of this research

The next chapter (Chapter–2) presents a review of the literature around the dimensions and the impact of psoriasis and eczema on skin physiology, pathology and on the central nervous system. The chapter will explore the psychological comorbidities associated with these skin diseases and the limitations of the dermatology service in managing such comorbidities. The chapter ends with reviewing healthcare professionals' and patients' feedback as well as discussing the role of self-management and quality of life in patient care aiming to provide an alternative support for such patients.

2. CHAPTER TWO - LITERATURE REVIEW

2.1 Literature review

This chapter reviews the available literature on chronic skin diseases; mainly psoriasis and eczema, to understand the nature of these diseases, their comorbidities, patients' needs, challenges, feedback and some of the knowledge gaps and barriers to their management, aiming to develop an intervention that can regularly address patients' needs, assess their comorbidities and support their involvement in decision making and self-management.

The method of the literature review included a scoping review, which is a relatively new approach to evidence synthesis (Munn *et al*., 2018). Scoping reviews search for evidence in order to explain the breadth and depth of knowledge in a field or topic area, particularly where research literature is expected to be methodologically or theoretically diverse or limited, or where assessment of quality is not required as in this research (Budhwani *et al*., 2018). The focus of this review was to map the range of evidence on the experience of psoriasis and eczema patients with the diseases and with their health service aiming to improve some of the health service gaps and reduce barriers.

Scoping reviews are like systematic reviews in that they follow a structured process, however they are performed for distinct reasons and have some key methodological differences (Peters *et al.,* 2015). According to the Cochrane handbook, a systematic review uses explicit, systematic methods that are selected with a view to minimising bias, thus providing more reliable findings from which conclusions can be drawn and decisions made (Higgins *et al.,* 2022). There exists little guidance regarding the decision to choose between a systematic review or scoping review approach when synthesising evidence, yet both approaches require rigorous and transparent methods in their conduct to ensure that the results are trustworthy (Peters *et al.,* 2015).

Researchers may conduct scoping reviews instead of systematic reviews where the purpose of the review is to identify knowledge gaps, scope a body of literature, clarify concepts or to investigate research conduct (McColl *et al.,* 2009). This was the case with this research. Scoping reviews do not engage in grading or assessing the quality of evidence but seeking to clarify complex concepts and refine questions to support future systematic reviews (McColl *et al.,* 2009). A scoping review was also ideal for this research as the focus was on comprehensive coverage regardless of the type of evidence, which allows the readers to identify strengths and weaknesses in the literature base (Matter *et al.,* 2017). Further, scoping reviews offer a valid approach in those circumstances where systematic reviews are unable to meet the necessary objectives or requirements (Munn *et al*., 2018). Furthermore, scoping reviews can be helpful precursors to systematic reviews and can be used to confirm the relevance of inclusion criteria and potential questions (Budhwani *et al*., 2018).

A scoping review methodology was deployed in this research because it has a multidimensional research question and is not aimed to answer any single question. Scoping reviews can explore the research landscape, concepts, characteristics and patients' experiences in studies concerning psoriasis and eczema, as well as mapping the literature and explore the following: -

1- The pathological roots of psoriasis and eczema. This includes understanding the structure of “normal” skin in relation to diseased skin in the cases of psoriasis and eczema. The examination reviews the histological, immunological, physiological and neurological changes in psoriasis and eczema and their impact on experience.
2- The comorbidities associated with psoriasis and eczema and health service plan/ guidelines in assessing and managing such comorbidities.
3- Patients’ unmet needs and challenges presented in national and international patients surveys and interviews conducted on psoriasis and eczema patients.
4- Healthcare service and cultural barriers to support patients with psoriasis and eczema and review healthcare professionals’ feedback on the service.
5- Health service and knowledge gaps in the field of psoriasis and eczema.
6- Theories, concepts, or alternative approaches to support such patients including the role of self-management in improving treatment outcome and patient quality of life.

In summary, a scoping review was used to: -

1. Map and synthesise the available evidence in the field of psoriasis and eczema.
2. Clarify key concepts, theories, sources of evidence in the literature in these diseases.
3. Identify key characteristics or factors related to a concept.
4. Examine what, how, and when research is conducted on such skin diseases.
5. Identify and analyse knowledge gaps in managing these chronic diseases.
6. Describe interventions tested in this patient population.

7. Summarise evidence to explain the breadth and depth of available knowledge.
8. Search for alternative support or management approaches.

The methodological framework proposed for scoping reviews involves five key stages in accordance with the Arksey and O'Malley framework notably: -

(1) Identifying the dimensions of research question.

What is the state of knowledge on psoriasis and eczema including their epidemiology, pathology, morbidity, comorbidities, impact of the disease, stigma, cultural values, reactions toward chronic visible skin conditions, patients' needs versus health services resources, limitations and other cultural and institutional barriers?

(2) Identifying relevant studies

The online literature search was performed through multiple platforms including: Pubmed/Medline, Embase, CINAHL, Cochrane Library database, WHO, PsycINFO, and Web of Science-Core Collection. A broad search was also conducted using google.com, scholar.google.com and eric.ed.gov search engines to identify and analyse knowledge gaps, the available key characteristics or factors related to the research concept and objectives. The search included using single or a combination of the following keywords to explore the dimensions of research question; “skin diseases” “psoriasis” “eczema” “needs” “burden” “impact” “prevalence” “aetiology” “feedback” “gaps” “challenges” “epidemiology” “physiology” “histopathology” “neuroimmunology” triggering factors” “comorbidities” “depression” “stress” “self-esteem” “social identity” “quality of life” “quality of life scales” “psychotherapy” “psychodermatology” “patient feedback” “health professionals feedback” “treatment” “guideline” “NHS” “NICE” “BAD” “CCG” “APPGS” “WHO” “primary care” “GP” “secondary care” “alternative therapy” “motivation” “theories” “self-management” “self-care” “theoretical framework” “conceptual framework” “review” “interview” “survey” “randomised controlled trial” “intervention” “questionnaire” “tool”.

(3) Study selection

Studies were selected in accordance with the following Inclusion/exclusion criteria: -

Inclusion criteria

- Research investigating the nature of psoriasis and eczema, their aetiology, histopathology, epidemiology and their psychosocial impact on quality of life.
- Studies addressing different aspects of psoriasis and eczema relating and relevant to the research question including their needs, comorbidities and feedback.
- Document types may include journal articles, books, webpages, commissioner reports, guidelines and policy reviews.
- Non-English studies were included if they included an English abstract.
- Studies were not limited by year of publication, age, gender, culture, country, population, policy, politics, criteria, protocol or methodology.

Exclusion criteria

- Studies that are not related to the multidimensional research question.
- Non-English studies or articles without English abstract or translation.
- Studies with unclear methodology.

(4) Collating, summarising and reporting the results

Although the searching process included broad mapping of national and international articles discussing the burden of skin diseases, it focused on exploring two common chronic skin conditions; psoriasis and eczema and aimed to review the needs and challenges of such patients and what barriers and support they have. The search therefore included exploring patients' experiences with these two diseases, and with their healthcare service provider nationally and globally, to identify any knowledge or service gaps facing such patients, aiming to reach a conceptual or theoretical framework and an intervention that can improve their experience with the diseases and with the health service. Multiple theoretical frameworks were reviewed to guide study objectives and design.

(5) Charting the data

Data charting or extraction was conducted independently by a single reviewer (myself), under supervision of 2 academic supervisors. Main fields of data extracted included the first author, publication year, study design, study population and study subject (Table-2). The results of scoping reviews generated a total of 587 relevant articles used in this thesis including 57 studies that are discussed in this chapter and they are as follows: -

Table-2 Types and numbers of the studies discussed in the literature review

*Ps, psoriasis; **AD, atopic dermatitis; ***&, and; $^{+}$QOL, quality of life; $^{++}$RCT, randomised controlled trial

Author and year of publication	Study design	Study population	Study subject
1. Ahn *et al* 2019	Surveys	*Ps & **AD patients	Psychiatric comorbidities assessment
2. Alpsoy *et al* 2017	Surveys	Ps patients	Internalised stigma assessment
3. Augustin *et al* 2015	Surveys	Ps ***& AD patients	Comorbidity assessment in German children
4. Brihan *et al* 2020	Surveys	Ps patients	Self-esteem & QOL assessment
5. Capozza *et al* 2020	Surveys	AD caregivers	AD impact on caregivers
6. Dubbertret *et al* 2006	Surveys	Ps patients	Impact of Ps
7. Egeberg *et al* 2020	Surveys	Ps & AD patients	Burden of Ps & AD in adults.
8. Grover *et al* 2020	Surveys	Ps patients	Internalised stigma & psychiatric morbidity
9. Grover *et al* 2021	Surveys	Ps caregivers	Ps impact on caregivers
10. Halvorsen *et al* 2014	Surveys	AD patients	Suicidal Ideation in Adolescents with AD
11. Jankowiak *et al* 2020	Surveys	Ps patients	Stigmatisation & $^{+}$QOL
12. Krueger *et al* 2001	Surveys	Ps patients	The impact of Ps on QOL
13. Langan *et al* 2012	Surveys	Ps patients	Prevalence of metabolic syndrome
14. Massoud *et al* 2021	Surveys	Dermatologists	Psychodermatology services in the UK
15. Nash *et al* 2015	Surveys	Ps patients	Impact of Ps on QOL
16. Silverberg, 2015	Surveys	AD patients	Adults patient costs & access to care in US
17. Silverberg *et al* 2018	Surveys	AD patients	AD impact on QOL in US adults
18. Silverberg *et al* 2019	Surveys	AD patients	Psychological impact of AD in US adults
19. Treudler *et al* 2020	Surveys	AD patients	Depression, anxiety & QOL
20. van Beugen *et al* 2017	Surveys	Ps patients	Predictors of perceived stigmatisation
21. van der Kraaij *et al* 2015	Surveys	AD patients	Extent of & need for shared decision
22. Alsaadi *et al* 2019	Systematic reviews	Ps patients	Exploring Ps self-management
23. Andersen *et al* 2017	Systematic reviews	AD patients	Comorbidities of AD
24. Bao *et al* 2018	Systematic reviews	AD patients	Association between AD & risk of depression
25. de Korte *et al* 2002	Systematic reviews	Ps patients	Suitability of quality-of-life questionnaires
26. Dressler *et al* 2019	Systematic reviews	Ps patients	Patient education & self-management
27. Eccleston *et al* 2015 UK	Systematic reviews	Chronic illness	Psychological interventions for parents
28. Rencz *et al* 2021	Systematic reviews	Literature	Questionnaire Modifications of DLQI
29. Ridd *et al* 2017	Systematic reviews	AD patients	Self-management interventions for AD
30. Sijercic *et al* 2020	Systematic reviews	Ps patients	Cognitive & behavioural treatments review
31. Suarez *et al* 2012	Systematic reviews	AD patients	Psychoneuroimmunology of stress
32. Tohid *et al* 2016	Systematic reviews	Ps patients	Relationship between Ps & depression
33. de Vere Hunt et al 2021	Qualitative studies	Ps & AD patients	Adolescents feedback on physicians
34. Esser *et al* 2010	Qualitative studies	Ps patients	Self-management experiences in adults
35. George *et al* 2021	Qualitative studies	Ps patients	Behaviour change tool to improve the care
36. Ghio *et al* 2020	Qualitative studies	AD patients	Implications for self-care in young people
37. Magin *et al* 2009	Qualitative studies	Ps & AD patients	Patients' relationships with their doctor
38. Nelson *et al* 2013	Qualitative studies	Ps patients	GPs' & patients' perspectives
39. Nelson *et al* 2014	Qualitative studies	Ps patients	Clinicians' views of supporting lifestyle change
40. Noormohammadpour, 2015	Qualitative studies	Ps patients	Psychological comorbidity assessment
41. Paudyal *et al* 2020	Qualitative studies	Ps & AD patients	Patient's perceptions of DLQI & Skindex-29
42. Hu *et al* 2020	Cohort studies	AD patients	AD phenotypes from birth until school age
43. Jensen *et al* 2016	Cohort studies	Ps patients	Ps and New-onset Depression
44. Kurd *et al* 2010	Cohort studies	Ps patients	Risk of Depression, Anxiety, & Suicidality
45. Schonmann *et al* 2020	Cohort studies	AD patients	Risk of depression/Anxiety in adults with AD
46. Wong *et al* 2020	Cohort studies	Ps & AD patients	Partner bereavement & risk of Ps and AD
47. Lavda *et al* 2012	Meta-analyses	Adults	Effectiveness of psychological interventions
48. Ascott *et al.,* 2019	Meta-analyses	AD patients	Relationship between AD & vascular diseases

49. Orth *et al* 2018	Meta-analyses	Young and adults	Self-esteem from age 4 to 94 years
50. Singh *et al* 2017	Meta-analyses	Ps patients	Relationship between Ps & suicidality
51. Domogalla *et al* 2021	$^{++}$RCT	Ps patients	Impact of an eHealth Smartphone APP
52. Hedman-Lagerlöf *et al* 2021	RCT	Patients	Patient feedback tool assessment
53. Keyworth *et al* 2015	Observational	Health care centres	Promoting healthy lifestyles for patients
54. Maddock *et al* 2020	Observational	Ps patients	Using Modified Buddhist Psychological Model
55. Nelson *et al* 2016	Mixed method	Physicians	Cardiovascular risk assessment
56. The King’s Fund, 2014	Mixed method	Physicians & patients	Dermatology services assessment in the UK
57. Mavrogiorgou *et al* 2020	Retrospective	Patients	Skin diseases & primary psychiatric disorders

The above 57 international studies investigated different aspects of this research question and provided insight on the social, medical, psychological impact of psoriasis and eczema as well as assessing patient needs, challenges, comorbidities and feedback on living with such chronic diseases. The national studies also identified barriers and knowledge gaps in the management of such chronic diseases. This has helped to search for ideas, theories, interventions or tools to support the management of such patients. Overall, the literature review will explore the following themes: -

- Social and psychological aspects of psoriasis and eczema
- Biological aspects of healthy skin versus psoriasis and eczema
- Similarities and differences between psoriasis and eczema
- Brain-skin link and the impact of stress on the patient
- Psychological comorbidity in psoriasis and eczema
- The challenges in managing psychological disorders in eczema and psoriasis
- Limitations of the psychotherapy service in the UK
- The challenges in assessing and managing psoriasis and eczema in the UK
- Patients’ feedback
- Health professionals’ feedback

- Summary of dermatology service limitations and APPGS quotations
- Health service and self-management
- Self-management/motivation theories
- Self-management theories and the dermatology service
- Knowledge gaps
- Conceptual framework and research proposal (study tool)

2.2 Social and psychological aspects of psoriasis and eczema

Human skin is not only an interface between the environment and the human body, but also the most visible, vulnerable and accessible body organ that is often subject to diverse personal, social-cultural, economic, sexual and political comments, judgement and criticism (Rowland, 2019; Stern, 2000; van Beugen *et al*., 2017). Throughout human history people judge themselves and others by skin age and colour (Maisel *et al*., 2018; World Health Organisation [WHO], 2006). Old, wrinkled skin or skin of colour can be criticised or rejected socially, politically or sexually (Fares *et al*., 2019; Magin *et al.,* 2011; Montes & Santos, 2018).

Even a small visible skin lesion or a scar in the face can evoke social responses, comments, criticism or abuse. Consequently, patients with such a lesion may develop a psychological reaction and symptoms including anxiety, anger, shame, guilt, embarrassment, withdrawal or depression (Gorrigan & Rao, 2012; Jankowiak *et al.,* 2020; Stern, 2000; Waldman *et al*., 2019). It is therefore not difficult to understand the psychological comorbidity in patients having a long-term disfiguring visible skin disease such as psoriasis and eczema. Although these two chronic skin conditions are rarely fatal and they are not progressive in the way that skin cancer may be, they can cause prolonged and severe distress, discomfort and even considerable chronic physical and psychological pain during the day and night (Balieva *et al*., 2016; Bhatti *et al.,* 2009; Na *et al*., 2019). Patients with psoriasis and eczema are often subjected to social rejection, alienation, abuse and stigmatisation (Alpsoy *et al*., 2017; van Beugen *et al*., 2017). Each of which may lead to a deterioration in their quality of life (Barlow, 2014; Vaidya *et al*., 2015).

Furthermore, People with eczema and psoriasis have reported feeling frustrated in the management of their chronic skin condition and in some cases hopeless that a long-term effective treatment or cure will be found (Barry *et al*., 2019; Beattie & Lewis-Jones, 2006; Bhatti *et al*., 2009). Living with hopelessness and negative emotions for years can significantly impair a patient's quality of life, social functioning, confidence, self-esteem, relationships, education, personal performance, career choice or future goals (Balieva *et al*., 2016; Dalgard *et al*., 2015; Jafferany & Pastolero, 2018; Singh *et al*., 2017).

Psoriasis and eczema are not only triggers for personal, physical, social and psychological challenges for affected patients, but also for their partners, caregivers or families (Ferreira *et al*., 2016; Holman & Lorig, 2000). Chronic skin diseases can seriously affect the lives of their family members, sexual partners or care givers (Capozza *et al*., 2020; Eccleston *et al.,* 2015; Manzoni *et al.,* 2013; Sampogna *et al*., 2017; Tekin *et al*., 2018). During the flare of a chronic skin disease, the family or relatives of patients with skin disease may need to change their daily routine or cancel different social or formal occasions to look after their family members or relatives (Sampogna *et al*., 2017; Tekin *et al*., 2018).

In contrast, those not directly affected by skin disease can trivialise patients with disfiguring chronic skin diseases (APPGS, 2013). Their indifference or distaste may be exacerbated by the misplaced assumption that skin diseases are contagious or that they are caused by poor hygiene (Dalgard *et al*., 2015; van Beugen *et al*., 2017). Abuse, stress and depression in patients with chronic skin diseases such as psoriasis and eczema can impair their ability to function at home, or at work and to comply or adhere with their medical treatment or self-management (Barankin & DeKoven, 2002). The latter plays a vital role in the patient's management outcome (Grady & Gough, 2014), and will be discussed later in this chapter.

Across the world, researchers have demonstrated the psychological impact of these two skin diseases on patients QOL (Barankin & DeKoven, 2002; Clarke *et al*., 2020; Dalgard *et al*., 2015; Egeberg, *et al*., 2020; Ferreia *et al*., 2016; Hay *et al*., 2014; Jensen *et al*., 2016, Langan *et al*., 2012). Three large-scale studies have been conducted on patients with psoriasis, which provide some insight on the psychological impact of this disease.

A population-based cohort study was conducted by Kurd and colleagues (2010) to determine the incidence of depression, anxiety and suicidality in patients with psoriasis compared with the general population. They used the UK patients' electronic medical record from 1987 to 2002, which included 146,042 patients with mild psoriasis, 3,956 patients with severe psoriasis, and 766,950 patients without psoriasis. They reported the adjusted hazard ratios (HRs) for receiving a diagnosis of depression, anxiety and suicidality in patients with psoriasis compared with controls were 1.39 (95% CI 1.37-1.41), 1.31 (95% CI 1.29-1.34), and 1.44 (95% CI 1.32-1.57), respectively. The adjusted HR of depression was higher in young patients with severe psoriasis (HR, 1.72; 95% CI 1.57-1.88) compared with those that had mild psoriasis (HR, 1.38; 95% CI 1.35-1.40; Kurd *et al.*, 2010). The limitations of this snapshot population-based study may include the risk of miscoding of the psychiatric outcome leading to misclassification and an inability to assess the mechanism and the degree of severity or the duration of depression in the studied population. It is also possible that the relationship between psoriasis and the above psychiatric outcome could be indirect due to unmeasured confounding.

A further study was conducted on psoriasis patients by Jensen and colleagues (2016) who examined the risk of new-onset depression in patients with psoriasis in a Nationwide Danish cohort. The latter included around 5 million people in the period 2001–2011. A total of 35,001 patients with mild psoriasis and 7,510 with severe psoriasis were identified and investigated. Incidence rates per 1,000 person/years for depression were 20.0 (95% CI 19.9–20.0), 23.9 (23.1–24.7) and 31.6 (29.5–33.8) for the reference population, mild, and severe psoriasis, respectively. After adjustment for comorbidity, age, sex and inclusion year, the incidence rate ratios (IRRs) were significant in psoriasis patients aged under 50 years with severe psoriasis (IRR 1.23 (1.03–1.46); Jensen *et al.*, 2016). This national Danish study included predominately a Caucasian population and its results may not apply to other ethnicities. Other limitations of this study; it included psoriasis patients who were treated with topical vitamin D derivatives and was unable to assess psoriasis patients who received other treatment options or were not captured by its inclusion criteria. It also was unable to adjust for unmeasured confounders that may contribute to depression in psoriasis patients, for example comorbidities, employment status and alcohol intake.

Singh and colleagues (2017) conducted a systematic review and meta-analysis to investigate psychiatric comorbidities in psoriasis patients. They searched literature published between 1946 and 2017 and identified 18 studies with a total of 1,767,583 participants, of whom 330,207 had psoriasis. The pooled OR for suicidal ideation among patients with psoriasis was 2.05 (95% CI 1.54-2.74). Subgroup analysis showed that patients with psoriasis were more likely to attempt suicide (OR, 1.32; 95% CI 1.14-1.54) or commit suicide (OR, 1.20; 95% CI 1.04-1.39) than those without psoriasis. The suicide risk was also higher in young patients with severe psoriasis (Singh *et al.*, 2017). Their meta-analysis however included few studies examining suicidality in conjunction with psoriasis severity.

Equally, five large studies explored the psychological comorbidity in patients with eczema. Halvorsen and colleagues (2014), performed a survey to explore the relationship of suicidal ideation, mental health problems, and social functioning in patients with eczema. A total of 4,744 adolescents (18–19 years) were invited for the study, of whom 3,775 (80%) participated. The overall prevalence of eczema was 9.7%. Among those with eczema, 15.5% reported suicidal ideation compared with 9.1% among those without eczema. In a subgroup analysis, the prevalence of suicidal ideation in those with both eczema and itch was 23.8%, compared with those without eczema. Eczema was associated with mental health problems assessed by the Strength and Difficulties Questionnaire and the Hopkins Symptom Checklist. Boys with eczema were less likely to have had romantic relationships (Halvorsen *et al.,* 2014). This study did not measure other confounders that may contribute to the depression.

Bao and colleagues (2018) conducted a systematic review for a period between 1966 and 2017. They selected ten qualified studies with a total population of 188,495 patients. They found a positive association between eczema and the risk of depression; the pooled RR was 2.02 (95% CI 1.76 to 2.31). Similar results were observed in subgroup analysis by region (Bao *et al.,* 2018).

In 2019, Silverberg and colleagues published their cross-sectional, population-based study on 2,893 participants (602 adults with eczema and 2,291 controls) living in the USA. They used Hospital Anxiety and Depression Scale Anxiety (HADS-A) and Depression (HADS-D) scores for assessing anxiety and depression in their participants, respectively. After multivariable linear and logistic regression models to control sociodemographic variables, their findings showed that adults with eczema had higher mean HADS-A and HADS-D scores and higher odds of abnormal HADS-A and HADS-D scores. Adults with eczema compared to those without eczema had higher prevalence of self-reported healthcare diagnosed anxiety or depression in the past year (400% vs. 175%). They concluded that eczema is associated with significantly undiagnosed increased anxiety and depression (Silverberg *et al*., 2019). The limitations of this online study may include using an internet panel, which may be subject to false answers, answering too fast, giving the same answer repeatedly by the same respondent. The higher rate of anxiety and depression reported in this study may be attributed to the questions used in this study as depression and anxiety disorders can be classified in several ways according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV; Carl, 1994; Guze, 2006).

Treudler and colleagues (2020) conducted a survey on 9,104 adults (57% female, median age 54 years), 372 (4.1%) had a history of eczema, who answered the following questionnaires: Centre of Epidemiologic Studies-Depression scale (CES-D), Generalized Anxiety Disorder

(GAD-7), Lubben Social Network Scale (LSNS), and Short Form Health Survey (SF-8). The authors found higher scores for depressive symptoms (9.3% vs. 6.3%; P < 0.001) and anxiety (8.4% vs. 5.6%, P < 0.001) in patients with eczema. Odds Ratio (OR) was 1.5 for depression, which was comparable to OR in patients with a history of cancer (1.6). QOL scores were lower in eczema patients than in controls (mean 46.9 vs. 48.0, P < 0.001 for physical and 50.6 vs. 52.5, P < 0.001 for mental components). They recommended mental health evaluation for all patients with eczema (Treudler *et al.,* 2020).

Schonmann and colleagues (2020) published a matched cohort study and reported similar findings. They used data from the UK Clinical Practice Research Datalink for the period between 1998 and 2016, to explore the temporal relationship between eczema and new depression and anxiety. After matching 526,808 adults with eczema with 2,569,030 without, they found eczema was associated with increased incidence of new depression (Hazard ratio [HR], 1.14; 99% CI, 1.12-1.16) and anxiety (HR, 1.17; 99% CI, 1.14-1.19). The depression was correlated with the severity of eczema (HR [99% CI]) compared with no eczema, while the new anxiety diagnosis was not correlated with the severity of the eczema (Schonmann *et al.,* 2020). However, this study may overestimate or underestimate the association between eczema severity and anxiety/depression as it excluded untreated eczematous patients or those refused treatment. Further limitation in this study was the possibility of selection bias as it only included eczematous patients with complete data.

Whilst the above studies had a number of limitations, there is a consistent picture emerging and that is the co-occurrence of mental health issues with either a diagnosis of psoriasis or eczema.

Apart from anxiety and depression, the visible rash in patients with psoriasis and eczema can expose such patients to different types of inappropriate reactions, behaviour, comments, emotional, verbal or physical abuse at school (Egeberg *et al*., 2019), work place (Yang & Kourosh, 2018), leisure centres (Griffiths *et al*., 2017; Jankowiak *et al*., 2020) or in public places (Barankin & DeKoven, 2002; Corrigan & Rao, 2012; Ferreira *et al*., 2016; Magin *et al*., 2011; Na *et al*., 2019; Singh *et al*., 2017). Such abuse can have a harmful impact on a patient's mental health, especially in growing children affected by these diseases (Beattie & Lewis-Jones, 2006; Pyun, 2015). Having psoriasis or eczema during early childhood can negatively impact on the psychological development and academic performance of the child (Ahn *et al.,* 2019; Augustin *et al*., 2015; Beattie & Lewis-Jones, 2006).

Hu and colleagues (2020), conducted a prospective population-based cohort study on children with eczema aged between 6 months and 10 years, using the Child Behaviour Checklist from age 1·5 to 10 years. The study included 5,265 participants (1,270 with eczema and 3,995 without). The authors found children who had eczema had more emotional (internalising) and behavioural (externalising) problems at the age of 10 years than children without eczema. All eczema phenotypes were very modestly associated with more somatic symptoms and attention problems at school age. Children with early eczema had more symptoms of aggressive behaviour. (Hu *et al.,* 2020). The limitations of this study include selection bias as they recruited a healthier and more affluent population. Children not included were of non-European ethnicity and never breastfed and had a lower gestational age and birth weight. The study also relied on the reporting of emotional and behavioural problems by parents of children with eczema which might be different from that by parents of children without eczema. Further, not all confounding factors associated with eczema and behavioural problems were measured or included in the analysis, such as the severity of eczema, sleep problems and other atopic comorbidities.

In the same year, Ghio *et al.,* published their qualitative study which included 23 participants with eczema, 17 were females and 6 males. Their ages were ranging from 17 to 25 years. The authors assessed the perceptions of participants about eczema and how these perceptions impact their daily life and self-care. They identified that participants who experienced eczema as long term and episodic had implications for self-care, challenging the process of identifying triggers of eczema flare-ups and evaluating the success of treatment regimens. Participants' experiences of eczema over time also had implications for adaptation and finding a balance between accepting eczema as long term and hoping it would go away (Ghio *et al.,* 2020).

Apart from the impact of eczema on children and young adults, looking after children with chronic skin diseases can significantly affect the quality of life of the parents or caregivers (Eccleston *et al*., 2015; Holman & Lorig, 2000; Manzoni *et al*., 2013; Na *et al*., 2019; Rosland *et al*., 2012; Sampogna *et al*., 2017; Tekin *et al*., 2018).

Capozza *et al*., 2020 assessed the burden of eczema on caregivers looking after children with eczema, using a 72-item anonymous online survey. The survey included the following domains of impact: sleep, social isolation, time requirements, life decisions, family relationship dynamics, energy/fatigue, mental health impacts and unmet treatment needs. The 235 caregivers completed the survey and reported frequent sleep disturbance, exhaustion, worry and social isolation related to their child's eczema (Capozza *et al,* 2020).

Results highlight the need for psychosocial support and respite care for caregivers of children with eczema.

Likewise, Grover and colleagues (2021) evaluated the impact of psoriasis stigma among caregivers of patients with psoriasis. They assessed 49 caregivers of patients with psoriasis by using the adapted version of Caregivers of People with Mental Illness (CPMI) scale to assess internalised stigma, Explanatory Model Interview Catalogue Stigma Scale, Family Burden Inventory (FBI), Multidimensional aspect of Perceived Social Support Scale (PSSS), Cognitive Behavioural Avoidance Scale (CBAS), and Coping checklist. The caregivers were involved in the care of the patients for a mean duration of 6.5(SD; 4.8) years. Presence of higher social support was associated with higher level of stigma as assessed by using CPMI. A higher level of caregiver burden in all the domains of FBI was associated with higher levels of stigma (Grover *et al.,* 2021).

Epidemiologically, although psoriasis and eczema have different aetiological, pathological and immunological pathways, they share many similar psychological symptoms and management strategies (Clarke *et al*., 2020; Frantz *et al*., 2019; Geale *et al*., 2017; Griffiths *et al*., 2017; Hayes & Koo, 2010; Jafferany & Pastolero, 2018; James *et al*, 2006; Kouris *et al.,* 2017; Lesner *et al*., 2017; Lim *et al*., 2018; Moon *et al.,* 2013; Richards *et al.,* 2004; Singh & Silverberg, 2020).

Understanding the cause of the psychological disorders associated with chronic skin diseases can have implications for effective treatment and management outcomes (Connor, 2017; Lavda *et al.,* 2012). However, the relationship between skin diseases and mental health or psychological morbidity is complex, in part because the biological relationships between skin and the central nervous system are often ignored or overlooked (Balieva *et al*., 2016; Clarke *et al*., 2020; Cohen *et al*., 2007; de Zoysa, 2013).

The following sections will examine and investigate the biology of healthy skin in relation to skin affected by psoriasis and eczema and the pathophysiological impact of these skin diseases on the brain and the immune system. In addition, the psychological management available for these two skin conditions will be reviewed as well as health professionals' and patients' feedback on healthcare resources will be explored.

2.3 Biological aspects of healthy skin versus psoriasis and eczema skin

Human skin (or Cutis in Latin) is the largest organ in the body. It accounts for 16 % of a person's total body weight (Chu, 2008). The skin plays an important role in immunity protecting the body against pathogenic microorganisms, foreign objects, extreme weather, water, blood and fluid loss (Kanitakis, 2002). The layers of the skin play a vital role in health and wellbeing (Singh & Munakom, 2000). Examining the layers of the skin and their interconnection and relatedness to the brain may help to understand and appreciate the psychological impact of chronic skin diseases on quality of life (*Lowes* et al*., 2014*).

2.3.1 Histologically

Histologically human skin consists of three main layers; the epidermis, dermis and hypodermis (Kanitakis, 2002). These layers undergo different histopathological changes in psoriasis and eczema as below:

Epidermis is the top layer of the skin. It contains rows of parallel layers of cells named keratinocytes (Chu, 2008). The basal layer of the epidermis (stratum basale) contains the skin stem cells, which divide continually generating new keratinocytes (Jones, 1996). The new forming keratinocytes move up through the layers above, changing their appearance and nature and forming the following parallel layers *or strata;* spinosum, granulosum, lucidum, respectively (Jones, 1996). Before reaching the surface of the skin, the keratinocytes lose their nuclei and form a dead outer skin layer called stratum corneum. This keratinisation process takes around 4 weeks to happen (Jackson *et al*., 1993). In patients with psoriasis however the process is very rapid and may take 4 days instead of 4 weeks, leading to the formation of psoriasis skin rash or plaques (Lowes *et al.,* 2014; Rendon, & Schäkel, 2019).

The layers of the epidermis are connected by bundles of keratin filaments and fibres forming strong barriers between skin cells (Kanitakis, 2002). The skin barriers in patients with eczema are weak due to genetic defects or deficiency in the fibres connecting the epidermis cells; hence patients with eczema lose water from the skin and end up with dry itchy broken skin with poor skin barriers to prevent the invasion of environmental allergens and microorganisms (Cork *et al.,* 2020; Jackson *et al*., 1993).

Dermis is a layer of skin which lies beneath the epidermis and above the hypodermis (Jones, 1996). It contains capillary blood vessels, lymphatic and nerve fibres as well as a large number of cells, mainly white blood cell corpuscles and mast cells. During the flare of psoriasis and eczema the above inflammatory cells in the dermis appear in large amounts secreting inflammatory markers (cytokines) which lead to the formation of the inflamed red or itchy skin rash (Griffiths *et al.,* 2017). Many glands (sweat, sebaceous and apocrine glands) are also present in the dermis and they play a role in controlling body temperature, skin texture and body odour (Jackson *et al*., 1993). In severe cases of psoriasis and eczema, the skin loses its function to control body temperature and water and such patients become liable to hypothermia and dehydration, respectively (Lowes *et al.,* 2014).

Hypodermis is also known as subcutaneous layer or *panniculus* layer. It is the deepest layer of the skin and represents the main body fat storage except in certain areas of the human skin such as the eyelids, ears, clitoris, penis and scrotum (Kanitakis, 2002). The hypodermis consists of groups of fat cells (*Lipocytes)*, which act as endocrine cells to produce leptin, a hormone that regulates body weight by way of the hypothalamus (Chu, 2008). The hypodermis provides a safe space for drugs and hormones that need to be released slowly and gradually such as insulin, adrenaline and many biologic therapies used for treatment of psoriasis and eczema (Griffiths *et al.,* 2020; James *et al*., 2006).

The thickness of the skin varies from less than 0.1 mm in the eyelid to 1.5 mm in the soles of the feet (Kanitakis, 2002). In psoriasis and eczema, the thickness of the skin increases at the site of the rash and becomes red, inflamed, rough, uneven and irregular due to the process of abnormal keratinisation and lichenification, respectively (Jones, 1996; Rendon & Schäkel, 2019). Additionally, the thick skin in both conditions is often associated with dryness, itchiness, soreness, burning sensation or discomfort, and occasional bleeding. These symptoms can create daily physical challenges and distress in such patients (Egeberg *et al*., 2019).

2.3.2 *Physiologically*

Physiologically skin is the interface between the human body and environment. It provides the body with insulation, protection, balance sensation, fluid and temperature regulation and plays a significant role in maintaining body homeostasis (Chu, 2008; Kanitakis, 2002). The latter is mediated by cutaneous nerve endings that have thermo, chemo and mechanic receptors (Jackson *et al*., 1993). These receptors react to heat, cold, touch, pressure, vibration and tissue injury. They also provide different types of sensations during physical, emotional and sexual contact (Murphy, 1997). The inflammatory process in psoriasis and eczema results in defects in skin homeostasis leading to itchy red inflamed bleeding skin rash, which has been reported to discourage many sufferers from having physical and social interaction. It can also interfere with their ability to enjoy tactile or sexual stimulation (Bhatti *et al*., 2009; Changing Faces, 2019; Kanitakis, 2002; Magin *et al*., 2011).

In the most severe cases of psoriasis and eczema (erythroderma), when the red inflamed skin rash covers the entire skin surface area, the inflamed skin loses its defence shield and its homeostasis functions. Subsequently, patients with erythroderma become highly vulnerable to potentially fatal dehydration, hypothermia and microorganism invasion (Egeberg *et al.,* 2019). These complications can lead to rapid circulatory collapse, septicaemia and even death (James *et al*., 2006; Lowes *et al*., 2014; Thyssen *et al*., 2020). Hence, erythroderma is one of the indications for admitting such patients to hospital as it requires urgent hydration and intensive medical care (Griffiths *et al*., 2017, 2021).

2.3.3 *Immunologically*

Immunologically skin is the largest immune organ and is rich in immune cells and immune modulators that provide both innate and adaptive immunity (Matejuk, 2018). The dermis contains most of the immune cells such as Macrophages, Langerhans cells and T lymphocyte cells. The latter play a major role in the pathogenesis of psoriasis and eczema (Kanitakis, 2002).

As a barrier between internal organs and the environment, the skin is exposed and covered by microorganisms including bacteria. They are usually harmless until the skin barrier becomes defective as in patients with severe eczema who develop broken skin rash and become vulnerable to the invasion of many opportunistic microorganisms that normally colonise the skin such as *Staphylococcus*. The latter can cause potentially fatal infections such as Staphylococcal Scalded Skin Syndrome (Fishbein *et al*., 2020).

Patients with severe eczema may therefore require urgent treatment to restore the function of their damaged broken skin. This may involve hospital admission, systemic therapy, regular blood tests monitoring and frequent follow-up consultations after hospitalisation (Barry *et al*., 2019; Fishbein *et al*., 2020; Frantz *et al*., 2019; Suarez *et al*., 2012). The prolonged morbidity of such patients can have a significant impact on a patient's quality of life as well as that of their partners or families (Ahn et al., 2019; Na *et al*., 2019; Schut *et al*., 2014; Silverberg, 2017; van der Kraaij *et al.,* 2020).

2.4 Similarities and differences between psoriasis and eczema

The prevalence of concomitant eczema and psoriasis was found to be 1.5% in a retrospective study (Barry *et al*., 2019). Patients with these two common diseases often share almost similar psychological symptoms (Augustin *et al*., 2015; Egeberg *et al*., 2019; Griffiths *et al*., 2017; Na *et al*., 2019; Psomadakis & Han, 2019; Schmitt *et al*., 2008; Singh & Silverberg, 2020; van der Kaaij *et al*., 2020). Nonetheless, there are clinical and epidemiological differences between these two chronic skin conditions.

Egeberg and colleagues (2020) compared disease characteristics, lifestyle factors and disease burden in adult patients with psoriasis and eczema. They used registry data from the Danish Skin Cohort, which included 3,348 and 3,834 adults with psoriasis and eczema, respectively: as well as 2,946 adults from the general population. They found patients with psoriasis mostly reported disease onset throughout adulthood, but early incidence peaked in those with a positive family history, while eczema predominantly began in childhood. Although the distribution of the rash was generalised and symmetrical in both conditions, each disease affected different anatomical areas. They also found that patients with psoriasis were more overweight or obese and physically inactive and had a positive smoking history, compared with the general population. However, patients reported disease burden was much higher in eczema than in psoriasis, whereas metabolic syndrome was more frequent in psoriasis patients. They concluded that these two chronic skin conditions belong to different pathological entities (Egeberg *et al*., 2020).

In Germany, Augustin and colleagues (2015), conducted data analysis on children with eczema and psoriasis aged 18 years and below. They utilised prevalence data derived from the database of a German statutory health insurance company, which included 1.64 million persons of whom 293,181 were children up to 18 years (150,244 boys, 142,937 girls). Among the investigated children 1,313 (0.45%) had psoriasis and 30,354 (10.35%) had eczema. Their results demonstrated that psoriasis prevalence in children correlated in a linear manner with age. It increased from 0.13% (95% CI 0.10–0.18) at the age of 0–2 years to 0.67% (95% CI 0.62–0.73) at the age of 14–18 years, whereas the prevalence of eczema decreased from 17.13% (95% CI 16.65–17.62) at the age of 0–2 years to 7.3% (95% CI 7.11–7.49) at the age of 14–18 years. Metabolic syndrome disorders were more frequently diagnosed in children with psoriasis, while hay fever and bronchial asthma are common in children with eczema. Obesity was significantly elevated among children with psoriasis (7.08%) compared to children without psoriasis (3.61%) and children with eczema (4.11%). They also concluded that psoriasis and atopic eczema have different pathological entities and comorbidities (Augustin *et al.*, 2015).

In terms of the psychological comorbidity in both diseases, Ahn and colleagues (2019) conducted a large cross-sectional study by using the 2015 Korean National Health Insurance Research Database. Their sample size contained 182,127 children, of whom 42,641 had eczema and 5,323 had psoriasis. They classified their participants by age: infant aged 0–3 years (31,471); early childhood aged 4–8 years (25,227); late childhood aged 9–12 years (14,677); adolescent aged 13–18 years (29,526); adult aged 19–64 years (67,878); and elderly aged above 65 years (13,348). After preforming multiple logistic regression models their data showed that the incidence of depression was not significantly different between eczema and non-eczema patients. Nonetheless, patients with severe eczema had a high Odds Ratio (OR) of depression (OR 3.15; 95% CI 2.83 –3.51). Patients with psoriasis had increased prevalence of anxiety (OR 1.16; 95% CI 1.03 –1.30); sleep disorder (OR 1.29; 95% CI 1.14 –1.47); and depression (OR 1.38; 95% CI 1.23 –1.56). In contrast patients with eczema showed a higher prevalence of attention-deficit/hyperactivity disorder (ADHD; OR 1.25; 95% CI 1.06 –1.48) and conduct disorder (OR 2.74; 95% CI 1.30–5.78; Ahn *et al.*, 2019).

In summary, human skin is the interface shield against many environmental harmful factors. It plays a vital role in protecting the body and the internal organs from extreme weather, foreign bodies and microorganisms invasion. Healthy skin has an essential role in human physiological and psychological homeostasis. It forms a major component of the immune system and for many aspects of an overall system of health. In contrast, diseased skin such as in eczema and psoriasis can subject humans to a wide range of environmental risks as well as immunological and psychological disorders. Managing the latter requires understanding the brain-skin link, which will be discussed next.

2.5 Brain-Skin link and the impact of stress on the patient

In the Embryo, both the brain and the skin originate from the same anatomical layer, named ectoderm, which divides and differentiates into the skin, nails, hair and the neural ectoderm (Chen & Lyga, 2014). The latter gives rise to the brain, spinal cord, and peripheral nerves. Any genetic or environmental defect of the ectodermal layer development in the embryo can lead to disorders in skin, hair, teeth, nails, and brain development including learning disability (Singh & Munakom, 2020).

The brain is the centre of thinking, which influences people’s feelings and behaviour (Nowak & Wong, 2016). Many mental health conditions can result from changes in a person's thinking (Beck, 2011; Guze, 2006; Stern, 2000). Such changes are common in patients with psoriasis and eczema and have been attributed to the impact of the chronic visible, itchy, sore or bleeding skin rash that can interfere with their daily activities at home, school, work, public places or leisure centres (Ahn *et al.,* 2019; Bajorek *et al.,* 2016; Balieva *et al.,* 2016). The chronic uncomfortable skin rash creates different levels of anxiety, stress, anger and/or depression in patients with psoriasis and eczema (Hayes & Koo 2010; Jensen *et al*., 2016; Lesner *et al*., 2017; Noormohammadpour *et al*., 2015; Schmitt, Meurer, Klon, & Frick, 2008 ; Singh *et al*., 2017; Suarez *et al*., 2012; Schut *et al*., 2014).

Stress is one of the most common symptoms in patients with psoriasis and eczema (Ahn *et al.,* 2019; Augustin *et al.,* 2015; Connor, 2017; Geale *et al.,* 2017; Griffiths *et al.,* 2017, 2021; Lesner *et al.,* 2017; Nash *et al.,* 2015). It can trigger the onset of such skin diseases (Wong *et al.,* 2020), and it can also create a neuropathological vicious circle (Cohen *et al*., 2007; Ranabir & Reetu, 2011). During stress, patients with psoriasis and eczema can develop a flare of their skin rash, which can cause more distress and anxiety to the patients. The latter may aggravate the severity of the disease and prolong its morbidity (Chen & Lyga, 2014).

Wong and colleagues (2020) conducted a 3-year cohort study to investigate the association between partner bereavement (extreme life stressor) and psoriasis or atopic eczema, using data from the UK Clinical Practice Research Datalink (1997–2017) and Danish nationwide registries (1997–2016). Their pooled adjusted HR for the association between bereavement and psoriasis was 1·01 (95% CI 0·98–1·04) and atopic eczema was 0·97 (95% CI 0·84–1·12) in the bereaved partners across the entire follow-up. They concluded that acute stress mainly in the first 3 months of bereavement plays a role in triggering the onset of new eczema or relapse of atopic eczema, but they found no evidence for increased long-term risk of psoriasis and atopic eczema following bereavement (Wong *et al.,* 2020). However, partnership status in this cohort may have been misclassified, as direct data on partner relationship status was unavailable. The algorithm they used to define eczema excluded untreated individuals; hence it reduces its sensitivity to detect milder cases. Additionally, this cohort study did not investigate the pathogenesis of the stress in the participants.

To investigate the impact of stress on patients with eczema Suarez and colleagues (2012) reviewed the literature for the years 1965-2010 using keywords such as Atopic Dermatitis (AD), eczema, and stress. They reported that although the mechanism underlying the association of AD with psychological stress has not been fully elucidated, during stress, sensory nerves release neuromediators that regulate inflammatory and immune responses, as well as skin barrier function. Stress was reported to have direct and indirect effects on immune response, cutaneous neuropeptide expression and skin barrier function. The authors speculated a great potential for identifying new neuroimmune-modulating therapeutic targets. Their review also identified stress management programs as a successful psychological intervention that can decrease itching in AD patients (Suarez *et al.,* 2012).

Psychologically, stress has been defined as any situation that disturbs the equilibrium between a living organism and its environment (Nowak & Wong, 2016; Ranabir & Reetu, 2011). It is usually induced when the individual perceives that the mental, physical or emotional pressure exceeds their adaptive power (Barankin & DeKoven, 2002; Beck, 2011). Stressful thinking and rumination can trigger the release of stress hormones including corticotrophin-releasing hormone, glucocorticoids, catecholamines, epinephrine, growth hormone, insulin, thyroid, vasopressin, and prolactin (Chen & Lyga, 2014). These hormonal changes alter body mobilisation of energy sources and adapt the individual to its new circumstance (Ranabir & Reetu, 2011).

In acute stress, the brain drives the body towards a fight or flight reaction (Cohen *et al*., 2007). This is a transient physiological state and is typically associated with skin changes such as excessive sweating, raised body hair or having goose bumps (Kanitakis, 2002). If the stress persists for days or months, a wide range of biological and cognitive changes occur that may help the body to adapt to chronic stress (Chen & Lyga, 2014). Continuous or mounting stress beyond a patient's capacity can disturb cortisol circadian levels and contribute to the activation of the immune system (Suarez *et al*., 2012). The latter activation leads to a shift in the immune cells' response, which may subsequently release inflammatory immune mediators or cytokines (inflammatory particles). These inflammatory responses can trigger the onset or exacerbate the severity of skin illnesses (Cohen *et al*., 2007; Suarez *et al.,* 2012).

Indeed, in the last two decades, international clinical trials have shown that the use of novel biological therapy which acts by inhibiting these inflammatory immune mediators has become a successful and a promising therapy in the management of psoriasis and eczema and in improving the quality of life of such patients (Sbidian *et al.,* 2020; Smith *et al*., 2017). Nevertheless, biological therapy is expensive, does not cure psoriasis or eczema and is associated with side effects including immunosuppression (Light *et al.,* 2019).

Management of psychological comorbidity has also been found to be helpful to improve the symptoms in chronic skin conditions and can be cost saving (Goulding *et al.,* 2017). Lavda and colleagues (2012), conducted a meta-analysis on 22 studies (17 randomised and 5 non-randomised), which included participants on psychological intervention (excluding educational interventions and complementary therapies). The investigated studies included 929 patients with psoriasis, atopic dermatitis, acne, vitiligo and pruritus. The mean age of the participants ranged from 22 to 48 years. The studies assessed and compared the following interventions: habit reversal, cognitive behavioural therapy, arousal reduction, group therapy, psychodynamic therapy, emotional disclosure/therapeutic writing, combined interventions, standard medical care, no treatment or other comparison groups. The duration of the interventions ranged from one session to nine months and were delivered as individual, group or self-help. The authors concluded that when all studies were combined, the effect of psychological interventions on skin conditions was moderate (*g*=0.54 95% CI 0.34 to 0.71). Psychological interventions had a medium-sized effect on outcomes in participants with psoriasis (*g*=0.51; 95% CI 0.25 to 0.77; 8 studies) and atopic dermatitis (*g*=0.55 95% CI 0.24 to 0.86; 9 studies) compared to control (Lavda *et al.,* 2012). However, this meta-analysis did not explore the longer-term benefits of psychological interventions or the cost-effectiveness of these interventions.

Many of the above interventions however are not available or accessible within the NHS (Massoud *et al.,* 2021), and without specialised psychological advice and management, some patients may not cope with long-term negative thoughts (Balieva *et al.,* 2016; Singh *et al.,* 2017). Their failure or inability to cope may lead them to reach a crisis point or suicide (Singh *et al*., 2017), or live many years with psychological comorbidity, which will be discussed next.

2.6 Psychological comorbidity in psoriasis and eczema

The psychological impact of skin diseases reflects the sensitive relationship between human skin and human psychology, which has evolved over time (Balieva *et al*., 2016; Barankin & DeKoven, 2002). Our psychological growth is predominantly influenced by our environment; both family and societal (Bandura, 1997). It is a process of interaction between human genes and external stimuli during the first years of life (Guze, 2006; Parry *et al.,* 2003). The outcome of such a process can significantly influence children's thinking, feeling, reaction, interest and trust level as well as their characteristic conscious and unconscious thoughts, emotions and behaviour (Stern, 2000).

Human skin represents part of human identity and acts as a communication and sensation organ for emotional and sexual stimulation (Balieva *et al*., 2016). We are increasingly living in a physical appearance dominated society. The value individuals place on their appearance is becoming greater and more disproportionate to other aspects of self-concept (Firth *et al*., 2019; Geale *et al*., 2017). Around two-thirds of young people and adults experience significant levels of dissatisfaction or distress in relation to appearance (Rowland, 2019).

Media and advertising suggest that achieving an appearance close to current ideals will improve life and increase happiness (Fares *et al*., 2019; Montes & Santos, 2018). The number of people seeking aesthetic procedures is on the increase and such behaviour has been progressively perceived as normative (Grant, Lust, & Chamberlain, 2019; Kluger *et al.,* 2019; Waldman *et al*., 2019; Wang & Rieder, 2019; Waterloo, 2018).

It is not difficult to understand the psychological strains of modern society on patients with chronic and disfiguring skin diseases such as psoriasis and eczema, particularly due to their visibility (Clarke *et al*., 2020; Ferreira *et al*., 2016; Finlay, 2009). The red scaly visible skin rash can subject people to negative comments, stigma, bullying or generate fear of contagion (Alpsoy *et al.,* 2017; Noormohammadpour *et al*., 2015; van Beugen *et al*., 2017). This can have a harmful impact, particularly on children growing up with an unpleasant visible skin rash without receiving the right support at this critical time of their lives (Beattie & Lewis-Jones, 2006). They may adopt negative coping mechanisms such as avoidance of social situations and limiting their outdoors or academic activities (Augustin *et al*., 2015; Hu *et al.,* 2020; Ghio *et al*., 2010).

In the long term, avoidance and isolation can become a regular habit (Beattie & Lewis-Jones, 2006; Manzoni *et al*., 2013). The visible rash can affect all aspects of their lives including self-esteem (Bedrow & Bulaj, 2018), social interaction (Barankin & Dekoven, 2002), employment (Bajorek, Hind, & Bevan, 2016), education (Ahn *et al.,* 2019), schooling or work performance (Beattie & Lewis-Jones, 2006), productivity (Balieva *et al*., 2016), career choice (Bhatti *et al*., 2009), life goals (Dalgard *et al*., 2015), leisure activities (Changing Faces, 2019), recreation (Dubertret *et al*., 2006), sleep (Egeberg *et al*., 2019), daily washing (Moon, Mizara, & McBride, 2013), facial grooming, dress code (Fares *et al*., 2019), relationship and sexual activity (Ferreira *et al*., 2016).

Patients with psoriasis and eczema often suffer from a wide spectrum of psychological conditions, which can be manifested in one or more of the following disorders:

- Anxiety (e.g., Barankin & DeKoven, 2002; Clarke *et al*., 2020)
- Avoidance (e.g., Dalgard, *et al*., 2015; Singh & Silverberg, 2020)
- Withdrawal (e.g., Ahn *et al.,* 2019; Barankin & DeKoven, 2002)
- Loneliness (e.g., Ferreira *et al*., 2016; Gupta & Gupta, 1998)
- Social isolation (e.g., Balieva *et al*., 2016; Hu *et al.,* 2020)
- Poor self-esteem (e.g., Bedrov & Bulaj, 2018; Ghio *et al.,* 2020)
- Lack of normality (e.g., Monk & Hussain, 2019)
- Poor sense of body image (e.g., Magin *et al*., 2011)
- Feeling unattractive (e.g., Changing Faces, 2019; Krauss *et al*., 2019)
- Feeling undesirable (e.g., Ghio *et al.,* 2020; Lim *et al*., 2018)
- Feeling imperfect (e.g., Ahn *et al.,* 2019; Maisel *et al*., 2018)
- Feeling guilty (e.g., Hu *et al.,* 2020; Noormohammadpour *et al*., 2015)
- Feeling shame (e.g., Alpsoy *et al*., 2017; Changing Faces, 2019)
- Feeling dirty (e.g., Monk & Hussain, 2019; Na *et al*., 2019)
- Feeling unhygienic (e.g., Balieva *et al.,* 2016; Nash *et al*., 2015)
- Uncertainty of the future (e.g., Na *et al*., 2019)
- Fear of rejection (e.g., Moon *et al*., 2013; de Zoysa, 2013)
- Fear of becoming unwell (e.g., Bajorek *et al.,* 2016; Parry *et al*., 2003)
- Fear of the stigma or social acceptance (e.g., Singh *et al*., 2017)
- Fear of not being able to have an intimate relationship (e.g., Andersen *et al*., 2017)
- Fear of being abused for having disfiguring skin (e.g., Changing Faces, 2019)
- Fear of being misjudged for having a “contagious” disease (e.g., Alpsoy *et al.,* 2017)
- Fear of lack of cure or having ineffective treatment (e.g., Seth *et al*., 2017)
- Fear of losing career and income (e.g., Bajorek *et al.,* 2016; Lim *et al*., 2018)
- Fear of having poor medical care (e.g., Lesner *et al*., 2017; Stern, 2000)
- Financial distress due to buying treatment for many years (e.g., Steen *et al*., 2017)
- Hopelessness to be cured (e.g., Lesner *et al.,* 2017; Schut *et al*., 2014)
- Hopelessness to have a partner (e.g., Sampogna *et al*., 2017)
- Fear of transmitting the disease to their own children (e.g., Gupta *et al*., 2014)
- Depression (e.g., Jensen *et al*., 2016; Singh & Gupta, 1998)
- Suicide ideas (e.g., Singh *et al*., 2017; Picarde *et al*., 2013)
- Self-harm (e.g., Jafferany & Pastolero, 2018; Richards *et al*., 2004)
- Addiction to alcohol and narcotics to escape the pain (e.g., Hayes & Koo, 2010)
- Fear of inability to look after family (e.g., Sampogna *et al*., 2017)
- Fear of losing education, career or life goals (e.g., Bajorek *et al.,* 2016; Ferreira *et al*., 2016)

The stigma associated with psoriasis and eczema can have a significant impact on a patient’s self-esteem and social identity. This impact will be discussed next.

2.6.1 Stigma

Stigma is a sign of disgrace, disapproval of, or discrimination against a person based on perceivable social characteristics that serve to distinguish them from other members of a society (Barlow, 2014). Public stigma has received the most research attention, as it represents the prejudice and discrimination directed at a person or a group by the larger population (Corrigan & Rao, 2012). Social stigmas are commonly related to culture, gender, race, intelligence, health and sexuality (Rowland, 2019). In certain cultures, skin disease stigma can be regarded as a shame or a curse (Grover *et al.,* 2020; Jankowiak *et al*., 2020).

van Beugen and colleagues (2017) conducted a cross-sectional study on 514 patients with psoriasis to examine predictor variables for perceived stigmatisation in psoriasis. They found stigmatisation was experienced by almost 73% of the respondents. Their multiple-regression analyses associated stigmatisation with higher impact on daily life, lower education, higher disease visibility, severity and duration, higher levels of social inhibition, having a type D personality and not having a partner. They also reported that cognitive behavioural treatment, including social skills training seems promising as an intervention framework for such patients (van Beugen *et al.,* 2016). Limitations of this study include the cross-sectional design, and self-reported measures were used to assess disease severity, which may not correlate reasonably well with clinician assessed PASI scores.

Alpsoy and colleagues (2017), conducted a larger multicentre cross-sectional study on 1,485 patients with psoriasis and found a significant positive correlation between mean values of Psoriasis Internalised Stigma Scale (PISS) and Psoriasis Area and Severity Index, Body Surface Area, DLQI and General Health Questionnaire-12 ($p < 0.001$ in all). Lower perceived health score ($p = 0.001$), early onset psoriasis ($p = 0.016$), family history of psoriasis ($p = 0.0034$), being illiterate ($p < 0.001$) and lower income level ($p < 0.001$) were determinants of high PISS scores. Mean PISS values were also higher in erythrodermic, generalised pustular psoriasis, involvement of scalp, face, hand, genitalia and fingernails as well as arthropathic and inverse psoriasis ($p = 0.001$). They concluded that internalised stigma may be one of the major factors responsible for psychosocial burden of the disease (Alpsoy *et al.,* 2017).

More recently, Grover and colleagues (2020) conducted another survey to assess the stigma in 104 patients with psoriasis by using multiple assessment tools including the Internalised Stigma of Mental Illness scale (ISMIS), Participation Scale (Pscale-), Patient Health Questionnaire (PHQ-9), Generalised Anxiety Disorder (GAD-7) scale, Dermatology Life Quality Index (DLQI), and Psoriasis Disability Index (PDI). They reported 27.9% of the participants had experienced stigma on ISMIS, 52.9% experienced discrimination followed by stigma resistance (51.9%), social withdrawal (24.1%), and alienation (23.1%). Lower social support was associated with higher stigma in all the domains. All the domains of ISMIS except discrimination and stigma resistance were associated with a higher level of anxiety and depression, poor quality of life and higher disability (Grover *et al.,* 2020).

The common misperception of contagion can further intensify the impact of stigma on self-confidence and self-esteem and can seriously compromise perceived freedom, independence and quality of life as well as it can increase the tendency toward self-isolation and suicidal ideation (Grover *et al.,* 2020; Kouris *et al*., 2017; Singh *et al*., 2017; Zhang *et al.,* 2012). The visible skin rash can be perceived as infectious in public places and can be rejected in the community, even if they volunteer to provide a supportive service:

> “*I think you have ringworm. We can’t accept a donation from you. The entire room went silent as everyone stared at Jennifer, age 34, who has suffered from severe plaque psoriasis*” (Yang & Kourosh, 2018, p. 23).

Equally, eczema shares many similarities in terms of its potential stigma and its impact on a patient’s quality of life and mental health (Chu *et al*., 2017; Suarez *et al*., 2012). Moreover, the onset of eczema usually during early childhood can exacerbate the experience of stigma. At this early stage in development social rejection has the potential to have a major impact on a child’s psychosocial development (Ahn *et al*., 2019; Ghio *et al.,* 2020; Hu *et al.,* 2020; Silverberg, 2017) and impact their families (Capozza *et al*., 2020; Na *et al*., 2019).

Stigmatisation has a direct impact on self-esteem levels in patients with psoriasis and eczema (Alpsoy *et al.,* 2017, 2015; Stern, 2000). Fear of stigmatisation, teasing and bullying can hinder the self-esteem of growing children and teens with psoriasis and eczema and their lower self-esteem can impair their confidence. This will be discussed next.

2.6.2 Self-esteem

Self-esteem is an individual's subjective evaluation of their own worth (Barlow, 2014). It encompasses beliefs about oneself as well as emotional states, such as triumph, despair, pride, and shame (Parry *et al.,* 2003). A meta-analysis of longitudinal studies claimed that levels of self-esteem increase between ages 4 and 11 years, then remain relatively stable between 11 and 15 years, increase strongly up to the age of 30 years and then continue to increase until they peak at 60 years where they remain relatively constant up until age 70 years from when they begin to decline (Orth, Erol, & Luciano, 2018). However, multiple factors in the family environment shape the development of self-esteem during early childhood and adolescence (Barlow, 2014). Self-esteem is also influenced by the level of family and social support available and has been correlated with stigma (Jankowiak *et al.,* 2020).

Self-esteem directly influences self-concept and self-efficacy (Bandura, 1997). Self-concept (also called self-construction, self-structure, self-identity or self-perspective) is a collection of beliefs about oneself, and it generally embodies the answer to the question *"Who am I?"* (Chambers, 2007). Self-concept interacts with self-esteem and if a person has low self-esteem, the self-concept may be skewed in the direction of negative thoughts and expression (Grady & Gough, 2014). Self-efficacy refers to an individual's belief in their capacity to execute behaviours necessary to produce specific tasks (Bandura, 1997). Self-efficacy correlates with self-esteem and affects every area of human endeavour (Barlow, 2014). People with high self-esteem and self-efficacy are often able to recognise their limitations without a judgment attached (Krauss *et al.,* 2019; Stern, 2000). Patients who endorsed the belief that their chronic skin disease will have negative consequences, were found to have low self-esteem, be less active in problem solving and experienced more depressive reactions, poor concentration, interrupted sleep that may affect their performance at work, leading them to miss income or failing to achieve their career or life goals (Bajorek *et al.,* 2016; Jankowiak *et al.,* 2020).

Brihan and colleagues (2020), assessed self-esteem in 110 patients (56 with mild psoriasis and 54 with severe psoriasis and psoriatic arthritis; 41.07% were women and 58.92 were men) using the Rosenberg Self-Esteem Scale, which consists of 10 items (Rosenberg, 1965). They reported that self-esteem of patients with severe cutaneous psoriasis and psoriatic arthritis was lower, compared with that of patients with mild forms of psoriasis. The authors also found in mild forms of psoriasis, the self-esteem of women and men is relatively equal, but below the general population average. Male patients with psoriatic arthritis have a much lower self-esteem compared with that of women. They concluded that psoriasis has a major impact on self-esteem, which correlates with the severity of the disease and with the skin condition that creates a major visual impact in society (Brihan *et al.,* 2020).

Jankowiak and colleagues (2020), also assessed the relationship between self-esteem and stigmatisation in 166 psoriasis patients (their PASI was 10 or less; 55.6% were women and 44.3% were man) using the Polish versions of the 33-item Feelings of Stigmatisation Questionnaire, Dermatology Life Quality Index (DLQI), and a questionnaire developed by the authors of this study that contained questions about sociodemographic characteristics of the participants and information about their disease. Unlike the above study their findings showed that the mean score in the stigmatisation questionnaire for female patients was nearly 2 points lower than the mean score for men. They suggested that lower self-image scores in women in whom the severity of skin lesions is the same as in men may be a cause of the stronger sense of stigmatisation and greater impairment of social functioning which is eventually reflected by the worse quality of life (Jankowiak *et al.,* 2020).

The limitations of the above studies may include relying on cross-sectional assessment and not providing information about the longitudinal course of psychosocial impact of disfiguring skin disease. Some of the sample sizes used are relatively small and they included clinic attending patients, hence their findings may not be generalisable to those in the community and not seeking help from dermatologists. However, although the above two studies used different methodologies, populations and sample sizes, they provided an idea on the impact of psoriasis on self-esteem, which should not be considered merely as a somatic problem, but also as a psychological and social burden that can impair personal interaction and social activities (Hu *et al.,* 2020).

Within modern societies, self-esteem is closely associated with physical appearance and dissatisfaction with body image can produce repetitive negative thoughts and feelings (Shah, 2018). This can create challenges for individuals in terms of their preparedness to visit public places, build relationships with friends or become romantically involved (Barlow, 2014). Negative thoughts and poor self-esteem are a common occurrence among patients with inflammatory skin diseases such as psoriasis and eczema and can lead to an increase in avoidance behaviour, stress, anger or feelings of guilt (van Beugen *et al*., 2017; Yang & Kourosh, 2018). Low self-esteem can also drive such patients to think negatively, engage in harmful behaviour, have a diminished sense of personal worth or a diminished sense of one's ability to influence behavioural outcomes (Bandura, 1997; Beattie & Lewis-Jones, 2006).

Compared with healthy controls, patients with psoriasis and eczema reported significantly higher rates of anxiety, negative emotions, avoidance-oriented coping strategies, lower rates of task-oriented coping strategies and significantly lower levels of self-esteem (Ahn *et al.,* 2019), which in return can impact on a patient’s career, life goals or income:

> “*This struggle to find employment at age 53 has taken a large hit on her self-esteem, and the stress of finding an income to pay off her outstanding student loans has contributed to her diagnoses of depression and anxiety.” ….” She receives support from her mother but finds that most people do not understand her condition because she looks healthy. She feels misunderstood because you see the environment differently from how I see it. I am constantly evaluating my surroundings and anticipating triggers*.” (Yang & Kourosh, 2018 p. 25).

The above psychosocial reaction is not uncommon in modern society where people tend to have a psychological connection to the groups or cultures dominated by specific values and roles (Rowland, 2019). Equally, eczema was found to have significant behavioural effects on children's self-esteem, ultimately resulting in a lack of opportunity to develop proper coping mechanisms to interact with the group's psychological representation or social identity (Nguyen *et al.,* 2016).

2.6.3 Social identity

Social identity is a person's sense of who they are based on their social group or culture (Stern, 2000). Social identity theory introduced the concept of a social identity as a way in which to explain intergroup behaviour, suggesting that cultures or organisations can influence an individual's behaviours (Rogers, 1970). People are usually motivated to engage in in-group bias to create, maintain, and/or protect a positive social status for their in-group and, consequently, a positive social identity (Martiny & Rubin, 2016). People also have a need for positive self-esteem, and this need motivates them to behave in ways that create, maintain, and protect the positivity of their social identity (Stern, 2000). Hence, social identity can be influenced by self-esteem and vice versa (Barlow, 2014). High self-esteem can motivate group members to protect and enhance social identity and the positivity of their group (Martiny & Rubin, 2016). In contrast, having low self-esteem can make them vulnerable to discrimination or abuse (Krauss *et al*., 2019).

Since societies typically value certain physical traits, individuals with chronic skin conditions may struggle to feel accepted in their social world (Jankowiak *et al.,* 2020). It is therefore not difficult to understand the daily challenges of patients with psoriasis and eczema who are struggling with both the physical issues and their low self-esteem (de Vere Hunt, *et al.,* 2021). Patients with skin diseases may require a high level of self-esteem to meet the group norm and to challenge social discrimination and stigma (Clarke *et al*., 2020; Yang & Kourosh, 2018). Affected individuals may modify their behaviour and expectations to mix with peers or with people in their society (Stern, 2000). This may require support from family, friends or counselling services (de Zoysa, 2013). Without a supportive environment, family or culture, psoriasis and eczema sufferers may be affected by negative social stereotypes attributed to their skin rash (Barankin & DeKoven, 2002; Nowak & Wong 2016). Their disease can be regarded as a disability in terms of seeking employment or achieving life goals:

> "*In 1955, I was 14 years old and just diagnosed with psoriasis. I didn't know it then of course, but it would never go away. My general practitioner gave it no name, but said it was common and could just go away. He said I might "grow out of it" and that I should get used to it, learn to live with it. Thus, I grew up with it. Years and life unfolded, offering new opportunities and experiences, but also demanding adjustments. I had long wanted to join the Navy. No one doubted my physical fitness. I spent months competing for officer selection, but I was inevitably rejected on medical grounds and was hugely disappointed. Those who had insisted that psoriasis was not an illness had neglected to tell me that it could still be a handicap*." (Jobling, 2007 p. 953)

In summary, healthy skin is an essential organ for human homeostasis and defence against extreme environmental disorders and cultural stigma, while diseased skin can impose personal, social, medical and psychological burdens on the quality of life of the affected individuals and their families or relatives. Psychological comorbidity, particularly stress has been suggested to induce a harmful vicious cycle by triggering or flaring chronic skin diseases. Evidently, the psychosocial challenges associated with these skin conditions have an important role to play in their treatment and management. Without a family, social or psychological support patients with psoriasis and eczema may endure many years of stigma and low self-esteem that could negatively impact on their personal, social, medical, psychological and professional performance, career and income. Such patients may benefit from regular psychological assessment and support (Connor, 2017; Lavda *et al.,* 2012). However, there are service gaps and challenges in managing psoriasis and eczema and their comorbidities, which will be discussed next.

2.7 The challenges in managing psychological disorders in eczema and psoriasis

The first step in managing any problem is to understand its nature (Connor, 2017). This might seem an easy statement, but quite often psychological problems will have an impact for some time before they are recognised by a clinician (Guze, 2006). Detection of psychological disorders in patients with psoriasis and eczema may be extremely difficult without a high index of suspicion along with regular screening of such patients to assess their psychological comorbidity (Ahn *et al*., 2019). Such patients may underplay or deny their symptoms, mood or they may not even recognise their presence, often so focused on their skin that they do not notice how anxious or depressed they have become (Connor, 2017). It is even possible that patients may grow so habituated to their emotional state that they can no longer detect just how far from normal it is (Stern, 2000).

The unsolved underlying psychiatric distress and mental wounds may gradually deepen and greatly impact on a patient’s ability to work, sleep or preform daily activities (Bajorek *et al*., 2016; Bhatti, 2009; Singh *et al*, 2017). When patients do not raise the concern themselves, it undoubtedly makes it harder to know that the problem exists. Furthermore, studies revealed that GPs and dermatologists are not very good at detecting psychological distress in their patients (Nelson *et al.,* 2013, 2016). Without formal training, and with time constraints and other pressures at play, clinicians are simply not adept at detecting mental health disorders in their patients (Connor, 2017).

Overall, the psychological disorders in patients with psoriasis and eczema can be divided into four categories: primary and secondary psychiatric disorders, psychophysiological disorders and mixed disorders (de Zoysa, 2013).

- Primary psychiatric disorders include patients with pre-morbid psychiatric conditions such as obsessive-compulsive disorder, anxiety, depression, psychosis, self-induced skin lesion, neurotic excoriations, acne excoriée, factitial dermatitis, habit-tic deformity, trichotillomania and delusional infestation (Mavrogiorgou *et al.,* 2020).
- Secondary psychiatric disorders are usually resulting from the emotional distress of living with disfiguring or highly symptomatic skin diseases like eczema and psoriasis. Such patients may develop social anxiety and major depression (Barankin & Dekoven, 2002).

- Psychophysiological disorders in which patients' emotional states fluctuate according to their clinical severity. This category includes patients with eczema and psoriasis, and they usually report flares of their skin disease during stress, anxiety, or depression (Barlow, 2014).
- Mixed disorders. Patients with psoriasis and eczema may develop one or more of the above psychological disorders (de Zoysa, 2013).

A retrospective study, conducted on more than 17,000 patients with primary psychiatric disorders to investigate dermatological comorbidities, the authors found 1.24% (n=212) patients with primary mental disorders also had dermatological disease. Psoriasis (35.4%) and atopic dermatitis (22.6%) were the most frequent dermatological diseases among these 212 patients. The most common mental disorder was a depressive illness (Mavrogiorgou *et al.,* 2020). However, it would be difficult to confirm the type of mental health disorders (e.g., primary or secondary) in such patients without a longitudinal or a cohort study. Interestingly, Tohid and colleagues (2016) conducted a literature review on 88 eligible studies and found the relationship between depression and psoriasis is bidirectional. Depression has been found to increase the concentration of pro-inflammatory cytokines systemically which may migrate towards the epidermis and cause psoriatic lesions in susceptible patients, either increasing psoriasis severity or potentially leading to its outbreak (Tohid *et al.,* 2016).

Depression in patients with psoriasis and eczema can impact differently to their daily challenges with the chronic skin disease and may negatively influence their personal, social, occupational, financial and sexual performance (Barlow, 2014; Bedrov & Bulaj, 2018; Egeberg *et al*., 2019). Their psychological reaction may not correlate with the extent or the severity of their skin rash (Jafferany & Pastolero, 2018). Indeed, Noormohammadpour and colleague

(2015) evaluated the psychological parameters in 200 adult patients with psoriasis (101 females and 99 males with the mean age of 43.2) and found that the extent of the skin rash or Psoriasis Area Severity Index (PASI) score had an insignificant relationship with illness perception, coping strategies or psychological vulnerability score. Their psychological vulnerability was found to be the main predicting factor of illness perception and coping strategies (Noormohammadpour *et al.,* 2015).

Regardless of the methodological limitations of the above studies which might have influenced their results; some of their findings match with findings of the studies discussed earlier in this chapter (Bao *et al.,* 2018; Halvorsen *et al.,* 2014; Jensen *et al.,* 2016; Kurd *et al.,* 2010; Schonmann *et al.,* 2020; Silverberg *et al.,* 2019; Singh *et al.,* 2017; Treudler *et al.,* 2020). They present consistent international observational findings and challenges to offering the level and type of support that has been identified as potentially important for patients with psoriasis and eczema (Bajorek *et al.,* 2016; Schofield *et al.,* 2009). Likewise, there are service challenges reflected in the NHS resource and financial constraints as well as the way resources are allocated and heath conditions prioritised (Massoud *et al.,* 2021; The King's Fund, 2014, 2020).

In addition to resource limitations, evidence suggests that many patients are not motivated to attend psychology-based interventions because they may fail to see their relevance or they may fear the stigma of having mental health issues (Richards *et al*., 2004). Moreover, managing psycho-dermatological cases by GPs or dermatologists with no training in psychology can be challenging and may put both the physician and the patient at clinical risk (Connor, 2017; de Zoysa, 2013). In the absence of a dermatologist with training in psychotherapy, patients with psycho-dermatological disorders should be referred to a psychologist or another mental health professionals (Xiao *et al*., 2019). Nevertheless, access to psycho-dermatology service in the UK is limited (Massoud *et al.,* 2021), so is access to the mental health services, mainly because of shortages in staff and resources to deliver such services (Rimmer, 2021).

Additionally, psychotherapeutic methods that can be used in psychotherapy such as habit reversal training, stimulus control, biofeedback, hypnosis, family therapy and psychodynamic therapy are rarely available or accessible in healthcare settings (Moon *et al*., 2013). In an ideal clinical setting however one psychotherapy intervention can be combined with other medical or non-medical interventions to form an eclectic approach (Lavda *et al.,* 2012). For example, in psoriasis, an eclectic approach of mindfulness therapy and Cognitive Behaviour Therapy (CBT) could be used for patients with certain psychological disorders (Shenefelt, 2018).

The above combined therapies however may not be an effective treatment option for all patients with psoriasis or eczema. Having disfiguring skin diseases in early childhood can carry negative thoughts and beliefs into adulthood (Barankin & DeKoven, 2002). These stored negative memories in certain personality traits can act as a barrier for psychotherapy (Beattie & Lewis-Jones, 2006). Even clinical improvement may not reflect the true psychological impact of these chronic diseases (Enander *et al*., 2019; Vaidya *et al*., 2015). Ideally, such patients may need their clinician to understand the complex nature of their illnesses and the emotional comorbidity associated with their chronic skin diseases (de Zoysa, 2013). A good clinical approach with effective doctor-patient communication skills, within a context of empathy and positive regard as well as providing an effective medical therapy may help most patients with skin diseases (Barlow, 2014; Connor, 2017).

Nevertheless, the restricted consultation time at primary and secondary care can disable health professionals from discussing and assessing patients' concerns, needs and psychological wellbeing. Equally, GPs may lack comprehensive training in assessing chronic skin diseases and their comorbidities (Nash *et al.,* 2015). Nelson and colleague (2013) interviewed 29 patients with psoriasis and 14 GPs and examined GP perspectives about psoriasis management. They reported that patients perceived GPs to be lacking in confidence in the assessment and management of psoriasis and both patients and GPs recognised that psoriasis was not being managed as a complex long-term condition (Nelson *et al*., 2013).

2.8 Limitations of the psychotherapy service in the dermatology service

The main psychotherapy services that could benefit patients with chronic skin diseases including eczema and psoriasis are discussed below together with the challenges and the limitations of providing such services.

2.8.1 Psychodermatology and counselling

Psychodermatology is a psychotherapy service that deals with psychological disorders in patients with skin diseases (Moon *et al.,* 2013). The concept of psychodermatology has been recognised since as early as the 17th century with Richard Burton's book Anatomy of Melancholy, where pruritus was noted to be associated with depression (Shah, 2018). Psychodermatology acknowledges and responds to the association between the "mind" and the "skin" and was found to be constructive and productive for managing the psychological comorbidity associated with chronic skin diseases (Connor, 2017). However, regardless of the psychological disorders affecting patients with chronic skin diseases the first step in psychologically based dermatology practice is the nature of the doctor-patient relationship (Fortune *et al.,* 2002).

For successful counselling, research suggests that the clinician should be relating to the patient with three key attributes: non-judgmental attitude, empathy and positive regard (Capoore *et al.,* 1998). If these attributes are combined with effective communication skills to assist the patient to solve his or her own problems rather than the clinician solving it, counselling can be therapeutic (Lavda *et al*., 2012). Adapting such communication and interpersonal skills are nonetheless not always easy for every physician to acquire without receiving explicit academic training in communication skills (de Zoysa, 2013).

Additionally, effective doctor-patient communication and interpersonal skills may not be enough for patients with primary psychological disorders or whose illness condition is associated with psychological factors as antecedents or as a co-existing condition. At this point, multiple psychological interventions such as counselling, psychotherapy and pharmacological intervention may be needed (Connor, 2017). The decision of which of these types of therapies should be used with a patient often lies in the type and the severity of the patient's psychological history and status (Lavda *et al*., 2012, 2017).

Before providing psychotherapy however, counselling can be a helpful intervention for those with psychological conditions that have not yet met the minimum criteria of a diagnosable mental health condition as stipulated by the International Classification of Diseases or the Diagnostic and Statistical Manual of Mental Disorders (Nowak & Wong, 2016; Guze, 2006). For example, patients who have a disfiguring skin condition and have some difficulty when facing the public or their partner might benefit from counselling (Connor, 2017).

Psychotherapy however may be needed if counselling is ineffective as it addresses deeper psychological issues (Capoore *et al*., 1998). Dermatologists with recognised training, experience, and qualifications in psychotherapy or psychodermatology may be able to provide initial psychological assessment, counselling, psychotherapy to their patients or refer them to appropriate services (de Zoysa, 2013). However, having consultants with dual training and accreditation in dermatology and psychology are rare in the UK, and within the restricted consultation time in primary and secondary settings the majority of physicians are unable to assess or manage their patients' psychological comorbidity (APPGS, 2013; Shah, 2018).

Additionally, psychotherapy may not be a suitable or effective therapy in certain dermatopsychological conditions, such as delusional parasitosis or delusional infestation that are usually best treated by pharmacological interventions (Nowak & Wong, 2016). Nevertheless, the therapies reported below have been found to be beneficial to some groups of patients with psoriasis and eczema (Connor, 2017; Lavda *et al*., 2012).

2.8.2 Cognitive Behaviour Therapy

Cognitive Behaviour Therapy (CBT) suggests that our thoughts determine our feelings and our behaviour (e.g., negative or unrealistic "thoughts" can generate negative "feelings" of distress, depression or anger; Beck, 2011). In return, distress can make the way in which we interpret situations skewed. The latter can have a negative impact on the actions "behaviour" we take. Negative thinking therefore can lead to conflict or negative behaviour towards oneself or toward others (Fortune *et al*., 2002).

In practice, CBT aims to overcome psychological difficulties by helping the patient to identify and change dysfunctional ways of thinking, modifying erroneous thoughts and beliefs about themselves, others and the world and challenging these dysfunctional thoughts and beliefs by using certain methods such as Socratic questioning (Enander *et al*., 2019). Such a change can lead to a consequent change in patients' feelings and behavioural responses (de Zoysa, 2013). Gradually, CBT can make people aware of their negative thoughts, judgments or interpretations (Lavda *et al*., 2012).

CBT was found useful in skin conditions that have been identified to be triggered by a psychological stressor or for those whose skin conditions are exacerbated when exposed to stressful life situations (Connor, 2017). It has been reported that skin diseases can increase the likelihood of 'cognitive errors' taking place and there is evidence to suggest that CBT can be effective for those with psoriasis, eczema and other skin disorders (Lavda *et al*., 2012). By exposing the rationale behind negative perceptions, CBT can empower patients to improve their self-esteem to deal with their chronic skin problem (Lavda *et al*., 2012).

Hedman-Lagerlöf and colleagues (2021), conducted a RCT on 102 adults with atopic dermatitis (mean [SD] age, 37 [11] years; 83 [81%] female). Participants were randomised in a 1:1 ratio to 12 weeks of therapist-guided internet-delivered CBT (n = 51) or a control condition (n = 51) that gave instructions about standard care. Their primary analysis indicated that participants receiving internet-delivered CBT, relative to the controls, had a significantly larger mean weekly reduction in symptoms of atopic dermatitis as measured with the Patient-Oriented Eczema Measure. Their secondary analyses indicated that internet-delivered CBT also produced significantly greater reductions in itch intensity, perceived stress, sleep problems, and depression. Treatment satisfaction was high, and gains were sustained at 12 months of follow-up. The authors recommended internet-delivered CBT as effective adjunct behavioural treatment for patients with this common skin condition (Hedman-Lagerlöf *et al*., 2021).

The findings of this RCT may not be easily generalised as it included a relatively small sample size from one country and excluded children below 18 years who usually have a higher prevalence of eczema (Cork *et al.,* 2020). It also excluded adults above 60 years of age and patients with mild eczema (score 8 or less on the Patient Oriented Eczema Measure; POEM).

CBT that includes parents is also found to be beneficial for reducing the suffering of children with eczema. Eccleston and colleagues (2015), reported an update to the version of the original Cochrane review published in Issue 8, 2012, on psychological interventions for parents of children and adolescents with chronic illness. The update added 13 studies to the original version, giving a total of 47 RCTs. These RCTs, focused on the following paediatric conditions: n = 14 painful conditions, n = 13 diabetes, n =10 cancer, n = 5 asthma, n = 4 traumatic brain injury and n = 1 atopic eczema. They reported that CBT that includes parents was beneficial for reducing children's primary symptoms, and problem-solving therapy (PST) that includes improved parent adaptive behaviour and parent mental health (Eccleston *et al*., 2015).

For psoriasis patients, Sijercic and colleagues (2020), conducted a systematic review to examine the efficacy of treatments that delivered psychotherapy with a major CBT component to patients with psoriasis. After assessing the quality of included studies nine randomised controlled trials met their inclusion criteria. Half of the studies found improved psoriasis severity following treatment and nearly all studies that examined quality of life as an outcome found improvements following CBT (Sijercic *et al.,* 2020).

Nevertheless, CBT is not aimed to improve the skin condition, but to restore normal brain-skin homeostasis by developing coping mechanisms (Beck, 2011). Additionally, CBT is not always accessible, available, or affordable. It requires frequent visits to a CBT specialist, and it can be unsuccessful or ineffective if the patient does not comply with the therapy or if the therapy was delivered by inexperienced or burnt-out staff (Fortune *et al*., 2002).

Further, CBT might not always provide long-term effects and would not be an appropriate intervention if the negative behaviour results from others (Beck, 2011; Fortune *et al*., 2002). In many cases, negative situations are in fact caused by external factors (e.g., stigma, public discrimination, or abuse). Patients with visible skin rash can be subjected to rejection and abuse in public places or leisure centres such as swimming pools (van Beugen *et al*., 2017). CBT aims only to address those circumstances in which patients' perceptions may have been influenced by irrational internal thought processes (Hedman-Lagerlöf et al., 2021).

2.8.3 Mindfulness-based therapies

Mindfulness theory is based on Buddhist practices, particularly that of the Buddhist cultivating mindfulness (Shenefelt, 2018). Mindfulness involves cultivating our ability to pay attention in the present moment without the composite of the Buddhist doctrine and is usually used in a non-spiritual context (Lloyd *et al.,* 2018). There are five main steps needed for mindfulness training; observation of internal and external sensations, awareness of the present moment, ability to label experience, non-judgment of experience and non-reactivity allowing thoughts to come and go without responding with distraction or worry (Kennedy, 2016; Montgomery *et al.,* 2016; Montgomery & Thompson, 2018).

Unlike CBT, mindfulness is self-managed and does not require a commitment to attend regular visits. It aims to ease psychological distress and enhances the psychological well-being in the person, by disengaging individuals from automatic thoughts and facilitates acceptance of the situation in the present moment while taking mindful action toward desired change (Nowak & Wong, 2016).

Mindfulness has been shown to be effective in people with psoriasis and eczema (Kennedy, 2016; Lloyd *et al*., 2018; Montgomery *et al*., 2016). It can reduce stress, anxiety, skin disease symptoms, negative thinking, and judgment toward self or toward others (Lavda *et al*., 2012). It has also been shown to be effective in managing symptoms associated with skin diseases such as compulsive skin picking or the habit of repetitive skin scratching which are common symptoms in eczema and psoriasis patients (Kennedy, 2016; Montgomery *et al*., 2016).

Maddock and colleagues (2020) examined the individual differences in psoriasis patients' wellbeing, anxiety and depression using a clinically modified Buddhist psychological model (CBPM). They recruited 285 psoriasis patients of whom 209 completed measures of each CBPM component. Their analysis found that a direct and mediated effect of the CBPM model was a good fit to the participants' data. They suggested that non-attachment, aversion, acceptance and self-compassion could have a direct effect on the wellbeing, anxiety and depression of psoriasis patients and an indirect effect through reduced worry and rumination. They recommended CBPM as a useful explanatory framework of psoriasis patients' anxiety, depression and wellbeing (Maddock *et al.,* 2020). The limitations of this study include the lack of validity and reliability of the CBPM model over time and across clinical and non-clinical populations in the assessment of mindfulness, mainly due to concerns over interpretation of mindfulness items. The measurement of psychological phenomena using a questionnaire may import some error in measurement into the relevant variable scores. The use of two data collection points (before and after the intervention) within a repeated measures design means that the conclusion regarding causality may not be asserted.

Just like CBT, mindfulness might not be effective in patients with fanatical or fixed belief systems or thoughts that disable them from accepting or adopting non-judgmental thinking (Nowak & Wong, 2016). Additionally, despite the longevity and experience of the NHS, most of the above psychotherapy services are not easily accessible to dermatology patients (APPGS, 2013). A recent survey was distributed by email to the UK membership of the British Association of Dermatologists (BAD) and Psychodermatology UK. The survey contained 13 questions asking about the availability of psychodermatology services. The results showed that less than a quarter of the respondents (24%) have access to a nearby dedicated psycho-dermatology service. Only around 5% of the clinicians have access to a clinic that provides psychology-dermatology-oncology service, and even fewer dermatologists have access to a paediatric psychodermatology service (4.8%). Although psychodermatology in the UK has improved to some extent over the past decade it is still insufficient and unable to fulfil patient demand, especially for vulnerable individuals such as children and dermato-oncology patients (Massoud *et al.,* 2021). The limitations of the survey include a low response rate (21%) and it is unclear if it was well representative as there was no proof that all the dermatology departments in the UK replied. The survey did not include the commissioners to capture their views on the psychodermatology service limitations.

2.9 The challenges in assessing and managing psoriasis and eczema in the UK

Both psoriasis and eczema are currently incurable diseases and the clinical improvement of the skin rash in such diseases is not permanent nor is it always associated with the improvement of psychological comorbidity or quality of life (QOL; Balieva *et al.*, 2016; Barankin & DeKoven, 2002; Beattie & Lewis-Jones, 2006; Noormohammadpour *et al.*, 2015). Given the high prevalence of psychological comorbidity in patients with psoriasis and eczema and in order to aid appropriate referrals and prevent serious mental health disorders, timely and appropriate psychosocial assessment is paramount to ensure quality of care and person-centred practice (de Zoysa, 2013). It is also conducive to apply a bio-psycho-social approach in dermatology practice, which includes assessing patients' morbidity, comorbidities, and needs within their personal and social context (Connor, 2017). Such an approach is essential given the complexity and/or severity of the multidimensional challenges facing patients with chronic skin diseases (Chouliara *et al.,* 2017). It is imperative therefore that appropriate psychological assessment is available to dermatology patients. It is also crucial that dermatology and primary care clinicians are competent in appropriate psychosocial interventions (Connor, 2017). To optimise patient care, there are tools that have been developed nationally and internationally to assess the following aspects in patient's care: -

1- Clinical severity of skin disease
2- Quality of life of the patient
3- Psychological comorbidities and/or stigma

2.9.1—Tools for assessing the severity of skin disease: In 2012, NICE recommended utilising clinical scoring tools such as the Psoriasis Area and Severity Index (PASI) and the Psoriasis Epidemiology Screening Tool (PEST), to assess the severity of psoriasis skin rash and psoriatic arthritis, respectively (NICE, 2012). For eczema patients, Patient-Oriented Eczema Measure (POEM), eczema Area and Severity Index (EASI) and Scoring Atopic Dermatitis (SCORAD) have been used in clinical trials to assess the severity of skin rash in eczema before and after certain treatments (Chopra *et al.,* 2017). In clinical practice however these tools are mainly used in patients who may be placed on systemic therapy (Cork *et al.,* 2020; Light *et al.,* 2019; Powell *et al.,* 2018).

2.9.2—Tools for evaluating QOL in dermatology: There are three main types of tools for assessing QOL; generic, dermatology-specific and disease-specific instruments (Chouliara *et al.,* 2017). These tools will be discussed in the next chapter in relation to the development of the study tool.

2.9.3—Tools for assessing psychological comorbidity and stigma: In their systematic review, Ali and colleagues (2018) reported that the most common psychiatric tools used alongside the DLQI were Beck Depression Inventory (BDI) and Hospital Anxiety and Depression Scale (HADS; Ali *et al.,* 2018). The BDI was published in 1961 and is a 21-item patient reported outcome measure (Score range 0-63; Beck *et al.,* 1961). The HADS was developed in 1983 and was found to be a reliable generic instrument for detecting states of depression and anxiety in the setting of a hospital medical outpatient clinic. It contains 14 items, of which seven correspond to depression (HADS-D) and the remaining seven to anxiety (HADS-A; Zigmond & Snaith, 1983). Other tools used include Patient Health Questionnaire (PHQ-9), the Generalised Anxiety Disorder (GAD-7) scale, the 12-item General Health Questionnaire (GHQ-

12), the SWIFT Tool (Stress/Coping; Work/Home; Illness/ Condition; Family/Friends; Things I like to do), and Distress Thermometer (Chouliara *et al.,* 2017). Tools used to assess stigma include; 6-item Stigmatisation Scale, 33-item Feeing of Stigmatisation Questionnaire, Internalised Stigma of Mental Illness Scale (ISMIS), Participation Scale (P-scale), Feelings of Stigmatisation Questionnaire, Psoriasis Internalised Stigma Scale (PISS) and Questionnaire on Experience with Skin Complaints, (Grover *et al.,* 2020; Kowalewska *et al.,* 2021; Zhang *et al.,* 2021).

In practice, the above assessment tools are not routinely used by GPs or dermatologists in most primary and secondary care settings, mainly because of limited resources in these settings (Edwards & Imison, 2014; Nelson *et al.,* 2013). GPs and dermatologists in the UK are facing increasing workloads and time pressures, which make the use of these tools on a regular basis unlikely, except in patients receiving systemic or biologic therapy (Deleanu & Nedelea, 2019; Sbidian *et al.,* 2020). With the limited consultation time in primary and secondary healthcare services (Irving *et al*., 2017), the shortage of dermatology specialist nurses and dermatology consultants in most district hospitals (Levell *et al.,* 2013), clinicians are under time workload pressure and often unable to screen or assess their patient for psychological distress even by asking simple yet important questions about the impact of chronic disease on their coping mechanism, mood status, sleeping habits, leisure or personal activities, in order to understand each patient's needs to self-manage or self-care (Monk & Hussain, 2019; Nelson *et al*., 2013, 2014, 2016). Further, clinicians in primary or secondary care rarely offer psychological support or refer patients to counselling services to build up patient confidence and self-esteem in order to cope with their chronic illnesses (APPGS, 2013; Changing Faces, 2019; Nash *et al.,* 2015).

Furthermore, mental health services in the UK are under severe pressure and access to different types of psychotherapy are not easily accessible (Chen & Cardinal, 2021; Edbrooke-Childs & Deighton, 2020) . Psychodermatology service in the UK has emerged over the last 2 decades to deal with the psychological or psychiatric elements related to skin disease. Two previous studies in 2004 and 2010 highlighted the deficiency of psychodermatology services in the UK. They have shown significant variability in the national provision of psycho-dermatology services, despite evidence that these services are highly in demand and highly cost-efficient (Massoud *et al.,* 2021). This has left many patients with chronic skin diseases struggling with their psychological symptoms, which in turn can aggravate their skin condition and impair their QOL (Cohen *et al.,* 2007; Ranabir & Reetu, 2011)

In 2013, the All-Party Parliamentary Group on Skin emphasised the importance of assessing patient's quality of life and managing psychological comorbidity associated with skin diseases:

> "*A number of tools designed to assess patients' quality of life* (often in the form of a questionnaire) *have been produced over the years, however the uptake of these is still patchy and there remains confusion as to what to do with the results. Some quality-of-life measures do not ask about distress and thereby minimise the actual measured impact on psychological wellbeing. The psychosocial impact of skin disease should be taken into account by clinicians when considering treatment and management options. Quality of life measures should be used, and the results incorporated into health-service planning when assessing priorities*." (APPGS, 2013 p. 11).

The diagnosis and management of the psychological impact of psoriasis and eczema at an early stage can reduce or prevent negative thoughts from forming and progressing into a mental health condition and is the first step toward improving patient care (Connor, 2017; Ersser *et al.,* 2010; Lavda *et al*., 2012). Research has identified that increasing our understanding of the medical and psychological comorbidities associated with skin diseases can help to provide a biopsychosocial approach to the management of such diseases and facilitate the provision of effective support services for affected patients to improve their quality of life (Barankin & DeKoven, 2002; Chen & Lyga, 2014; Deleanu & Nedelea, 2019; Light *et al.,* 2019). Further, managing psychological disorders can reduce overall costs of treatment of the skin condition, enhance the individual's quality of life, productivity and compliance with medical treatment, and reduce morbidity, and absence through sickness (Bajorek *et al.,* 2016; de Zoysa, 2013; Fortune et al., 2002; Moncrieff *et al.,* 2018).

However, offering a holistic approach to patients with psoriasis and eczema should not be limited to managing psychological comorbidity; international research has shown that such patients are often suffering from other comorbidities (Ascott *et al.,* 2019; Andersen *et al*., 2017; Augustin *et al.,* 2015; Pyun, 2015; Silverberg, 2017).

Andersen and colleagues (2017) conducted a literature review and reported that patients with eczema may have an increased risk of cardiovascular diseases, certain malignancies, autoimmune diseases, and neuropsychiatric diseases. They related these associations to many factors including genetic predispositions, systemic low-grade inflammation, environmental exposures, medication, ethnicity, lifestyle factors and behavioural risk factors. They recommended that early eczema therapy and reduction of risk factors may help prevention of such comorbidities (Andersen *et al.,* 2017).

In 2019, Ascott and colleagues published the first meta-analysis investigating the association between eczema and cardiovascular diseases (CVD) outcomes. They included 19 eligible population-based studies and found that the effects of eczema reported in cross-sectional studies were heterogeneous, with no evidence for pooled associations with CVDs, or stroke. In cohort studies eczema was associated with increased risk of CVDs, ischemic stroke, and heart failure. They reported a dose-response relationship between increasing severity of eczema and CVDs (mean RR increase between severity categories, 1.15; 95% credibility interval, 1.09-1.21; uncertainty interval, 1.04-1.28; Ascott *et al.,* 2019). It is possible however, that this meta-analysis is subjected to misclassification bias as those with severe CVD are often defined by receiving systemic therapies which can protect against CVDs.

Langan and colleagues (2012) assessed metabolic comorbidities (a syndrome which includes 3 or more of the following; diabetes mellitus, hyperlipidaemia, hypertension and obesity), in psoriasis patients using a cross-sectional study. Their study included 44,715 participants (4,065 with psoriasis and 40,650 controls), with age group of 45-65 years. They reported that psoriasis was associated with metabolic syndrome, an adjusted Odds Ratio (adj. OR) of 1.41, 95% CI 1.31-1.51) and the association increases with increasing disease severity. They suggested offering screening for metabolic disease for psoriasis patients, especially when it is severe (Langan *et al*., 2012). In the same year, NICE issued the same recommendations (NICE, 2012).

Nevertheless, despite NICE recommendations research conducted in the UK found prevention and management of metabolic comorbidities in such patients was poor in different healthcare service providers. Nelson and Colleagues (2016) conducted a mixed method study to determine the proportions of cardiovascular disease (CVD) risk factors among patients with psoriasis at risk assessment and to examine patient and practitioner experiences of risk communication. They used audio recordings of consultations of 287 patients with psoriasis and 12 GPs. They reported that despite high levels of risk factors identified in the psoriasis patients, which were above NICE recommendations [very high waist circumference (52%), obesity (35%), raised blood pressure (29%), smoking (18%) and excess alcohol consumption (18%)], opportunities were missed in consultations to support patients with psoriasis to understand CVD risk and to promote risk reduction. They recommended GPs need training in behaviour change techniques to capitalise on teachable moments and increase the effectiveness of risk screening (Nelson *et al.,* 2016).

Earlier Nelson and colleagues (2014) carried out in-depth semi structured interviews with 23 dermatology specialist and general practitioners in English primary and secondary care settings to elicit their views and attitudes about addressing Lifestyle Behaviour Change (LBC) for patients with psoriasis. Their findings showed that clinicians recognised that LBC was important in psoriasis management, but believed it was not their role to facilitate it. Limited knowledge and skills to implement LBC principles and techniques underpinned their beliefs. Clinicians identified a need for training to enable the incorporation of LBC support activity into psoriasis services (Nelson *et al.,* 2014).

There were also poor efforts from the service provider to educate psoriasis patients about their disease by using health promotion leaflets or posters. Keyworth and colleagues (2015) conducted an observational study to record the frequency and quality of educational leaflets and posters in 24 random primary and secondary health centres' waiting areas addressing lifestyle behaviour change that would provide information and support for patients with psoriasis. They measured the frequency, characteristics and standard of the health promotion materials in the above health centres. They found poor information quality in these centres with poorly displayed materials, with no high-quality psoriasis-specific patient materials evident (Keyworth *et al.,* 2015).

Furthermore, some medications used to treat psoriasis and eczema (e.g., Acitretin) and their comorbidities (e.g., beta-blockers) may exacerbate the symptoms of these diseases, worsen or trigger further metabolic or psychological comorbidities (Sbidian *et al.,* 2020; Shi & Lio, 2019; Smith *et al.,* 2017). Clinicians should therefore be aware of such potential associations and the challenges that exist in the recognition and management of drug causes induction or exacerbation of psoriasis and eczema (Balak & Hajdarbegovic, 2017).

In summary, the dermatology service in the NHS has been affected by the increasing demand beyond its capacity. It has also been fragmented into multiple levels of care and settings (primary, secondary and community service), yet most of these services failed to provide a swift or holistic approach to manage skin diseases and their associated comorbidities, mainly because of a shortage of staff and resources, bureaucracy and poor communications between different regional health services providers, limited consultation time, failing to screen patients for comorbidities and severe shortages in specialised psychodermatology clinics. This has led to challenges in managing psychological comorbidity in psoriasis and eczema.

However, before making a judgement on the NHS and for a better understanding of the challenges facing such patients, feedback from the service users (patients with eczema and psoriasis) and service providers (health professionals) is needed. This will be reported next.

2.10 Patient feedback

The limitations in managing psoriasis and eczema patients are not restricted to the NHS in the UK; below are three large postal surveys conducted on adult members of psoriasis associations in the UK (Nash *et al*., 2015), Europe (Dubertret *et al*., 2006) and the USA (Krueger *et al*., 2001) as well as a survey carried out simultaneously in the USA and European countries (Lebwohl *et al.,* 2014). Equally, two surveys were conducted on patients with eczema (Silverberg, 2015; Silverberg *et al*., 2018) and many of the findings of these surveys share similarities regarding patients' unmet personal, medical and psychological needs. This was also the case in qualitative studies conducted on psoriasis and eczema patients (de Vere Hunt *et al.,* 2021; Ersser *et al.,* 2010; George *et al.,* 2021; Magin *et al*., 2009).

British psoriasis survey

Nash and colleagues (2015) from the UK conducted a large postal survey on all members of the British Psoriasis Association. They posted 2,830 questionnaires in reply-paid envelopes and 1,619 of them were returned. However, 55 of the returned questionnaires were not included in the survey as they contained insufficient data to merit inclusion. Hence, the final sample size was 1,564. Their questionnaire was designed to gather information on members' management experiences, quality of care, and feedback on treatment and healthcare professionals. A coping and quality of life section was included, which drew on issues covered in the DLQI. The questionnaire included two open ended questions for participants' comments. The findings of the survey identified that:

- Participants were dissatisfied with their treatment regimes.

- They felt that they were under-informed, and their skin disease treatment was not targeted to their needs.
- 30% of respondents did not trust their GP’s diagnosis and requested referral to a dermatologist.
- 19% of them were given an incorrect initial diagnosis of the psoriasis by their GPs.
- 54% were not offered adequate information about their skin disease.
- 56% were not provided with sufficient information about their disease treatments.
- 74% reported that they were not offered different treatment options.
- 54% did not feel they were included in the decision-making process about their treatment.
- 47% requested more time, support, and the opportunity to ask questions during the consultation.
- The majority of the participants acknowledged that stress was a trigger for flare-ups of their skin disease.
- Lack of available support for those experiencing emotional distress.
- 54% of the participants experienced emotional distress, but only 13% of them received professional help for it.
- Only 10% of participants were given contact details of support organisations.
- Topical therapy was the most commonly prescribed and patients found them difficult to apply frequently, unpleasant, time-consuming to manage, and ineffective. This type of treatment was deemed sticky, messy, and impractical.
- Biological therapy was the favoured treatment for the respondents.

Although a high proportion of respondents rated their relationships with their GP and dermatologist as either satisfactory or excellent, the findings of the survey highlighted the lack of formal social and psychological support mechanisms for those with psoriasis and suggested there was scope for improving the training of the GPs in skin diseases. They indicated that GPs should be better informed, and they wanted faster and easier access to the dermatologist as well as greater innovation by the NHS with regard to effective and manageable treatment regimens that target general well-being and greater support for emotional distress and psychosocial functioning. The survey also recognised the evidence that some patients may resist or would not accept psychological help or referral (Nash *et al.,* 2015).

The high response rate in their survey (57%) could be related to self-selection bias, as participants were members of the Psoriasis Association and prepared to complete the questionnaire. The survey however provided evidence on the impact of psychosocial symptoms associated with psoriasis and the need for support to improve patients' ability to cope with stress and the daily hurdles imposed by chronic skin disease.

European psoriasis survey

The European Federation of Psoriasis Patient Associations (EUROPSO) conducted a Europe-wide postal survey on 50,500 members of psoriasis patient associations in Belgium, the Czech Republic, Finland, France, Germany, Italy and the Netherlands (Dubertret *et al*., 2006). The objectives of the survey were to explore patient perspectives of psoriasis and to gain insight into the effectiveness of and satisfaction with the currently available therapies for psoriasis.

In total, 18,386 members responded making the response rate of 36%. Over 58% of the respondents were managed by a dermatologist and 34% were treated by a GP, while 21% of the participants had not consulted a healthcare professional in the past year. The results of the survey matched many of the findings in the UK survey. The majority (77%) of the respondents stated that psoriasis forms a significant problem in their daily activities, especially clothing choice, bathing routine and sporting activities. In addition, psoriasis affected their sleep, relationships with friends, partners, sexual relationships, work or school performance, careers and restricted their smoking and drinking behaviour. The impact of the disease was most noticeably in those with moderate to severe psoriasis and around 11% of the participants were diagnosed with clinical depression. Although participants were generally satisfied with their doctor, they were dissatisfied with psoriasis treatments. Approximately, 72% of the respondents expressed low or only moderate satisfaction with prescribed treatment hence a large percentage of patients sought over the counter (OTC) and alternative therapies (Dubertret *et al.*, 2006).

As in the UK survey, the European survey reported that patients with psoriasis suffer significant impairment of their quality of life. However, it is important to acknowledge that the results reported here are from a large population and that the various factors shown to influence disability associated with psoriasis will be different for each individual patient and country. Additionally, as in Nash *et al*. (2015), this survey was subject to selection bias as its population was based on membership of psoriasis support associations and does not represent a random sample of patients with psoriasis. Nevertheless, this large survey disclosed the impact of psoriasis on patient quality of life in the investigated European countries and are considered to be of value to dermatologists in Europe in terms of patient–clinician communication factors that may previously not have been reported or may have been underestimated.

US psoriasis survey

In July 1998, a self-administered questionnaire was posted to 40,350 adult members of the National Psoriasis Foundation in the USA (Krueger *et al*., 2001). As in the above surveys, the objectives of the American survey were to obtain patient perspectives on the psychosocial impact of psoriasis and the effectiveness of the management of their disease. The response rate of the survey was 43% and the results showed similarities with the British (Nash *et al.,* 2015) and the European (Dubertret *et al*., 2006) psoriasis surveys. The disease has a profound emotional, social and physical impact on patients' quality of life including difficulty in workplace or preforming daily duties, socialisation with family members and friends, getting jobs, using hands for manual tasks, walking, sleeping and having sexual relationships.

Many patients with psoriasis, particularly those with severe disease, were dissatisfied with the management of their disease and with their physician's communication. Interestingly, after the postal survey a total of 6,194 patients with severe psoriasis were offered a telephone survey. Of these, 79% reported that psoriasis had a negative impact on their lives, 40% felt frustrated with the ineffectiveness of their current therapies, and 32% reported that treatment was not aggressive enough to clear their psoriasis or its associated symptoms (Krueger *et al*., 2001). As in the UK survey (Nash *et al*., 2015), topical therapy was regarded as time consuming, expensive and/or ineffective. Just like in the European survey (Dubertret *et al*., 2006) a high rate of psoriasis patients in the USA sought over the counter and alternative therapies due to suboptimal management of the disease which was often associated with high relapse rates of the skin rash and symptoms (Krueger *et al*., 2001).

North America and European psoriasis survey

To understand the unmet needs of psoriasis and psoriatic arthritis (PsA) patients, a large, multinational, population-based survey of psoriasis and/or PsA patients in North America and Europe was conducted. Patients were selected randomly and did not have to currently be under the care of a health care provider. A total of 139,948 households were screened and 3426 patients completed the survey. The prevalence of psoriasis ranged from 1.4% to 3.3%; 79% had psoriasis alone and 21% had PsA. When rating disease severity at its worst, 27% (psoriasis) and 53% (PsA ± psoriasis) of patients rated it as severe.

Several participants identified unmet needs which warranted additional attention and action, including improved severity assessment, PsA screening, patient awareness, and treatment options. Psoriasis patients indicated that their most bothersome signs or symptoms were itching (43%), scales (23%), and flaking (20%). Of psoriasis patients, 45% had not seen a physician in a year; >80% of psoriasis patients and 59% of PsA patients were receiving no treatment or topical treatment only. Of patients who had received oral or biologic therapy, 57% and 45%, respectively, discontinued therapy, most often for safety/tolerability reasons and a lack/loss of efficacy (Lebwohl *et al.,* 2014). Limitations of the survey include lack of a control group, did not account for ethnic and health care system differences across countries and was limited by factors associated with accurate recall and interpretation of questions.

Psoriasis qualitative studies

In the UK Ersser and colleagues (2010), conducted a qualitative interview-based study on 22 psoriasis patients to assess how adults with mild to moderate psoriasis manage their skin condition and to identify strategies that can support people to self-manage effectively. The findings of their study share some similarity with the findings presented in the above surveys. Patients with psoriasis do not always achieve what they perceive to be optimal self-management. They usually do not use topical therapy and frequently abandon such a therapy if rapid improvements are not achieved. Factors, which participants identified as likely to improve self-management, included the provision of individualised education directed towards improving effective adherence techniques by medical and nonmedical personnel who have practical experience in topical application of psoriatic therapies. The authors highlighted the need to incorporate these strategies to support individuals to self-manage as effectively as possible to help improve their skin condition and quality of life (Ersser *et al*., 2010). This however might not be feasible in resource-limited services.

More recently, in the UK George and colleagues (2021), interviewed 21 psoriasis patients individually. Three key themes were identified: comparison with cancer, misalignment of response with need, and fear of social exclusion. Cancer comparison subthemes included poorer services, lack of awareness and trivialisation of psoriasis compared with cancer. Misalignment subthemes related to lack of knowledge and inappropriate response of healthcare professionals (HCPs) and society towards psoriasis. Fear of social exclusion subthemes included erroneous belief of psoriasis being contagious and the expectation of rejection. Consequent emotions of fear, shame and anxiety resulted in avoidant behaviours, which perpetuated social exclusion. Participants valued active listening, shared decision-making and communication of hope regarding treatment by HCPs. The authors concluded that despite extensive research into psoriasis and the availability of effective treatment, many patients with psoriasis live unnecessarily impaired lives and have unsatisfactory healthcare experiences (George *et al.,* 2021).

Psoriasis and eczema qualitative studies

In Australia, Magin and colleagues (2009) reported the findings of their semi-structured interviews on 62 patients with psoriasis, eczema and acne. The participants reported negative experiences with the physician treating their skin conditions. Both general practitioners and dermatologists were reported as having poor comprehension of the psychological implications of skin diseases, being insensitive to their patients' emotional suffering, and trivialising participants' diseases. Participants acknowledged that time considerations and other pressures may explain these apparent deficiencies. Some participants perceived their doctors as medical technicians only managing the skin rash and not the emotional or social aspects under the skin. Given these perceptions, patients may even become more reluctant to present psychological symptoms to their GP. The authors recommend education for GPs about the psychological effects of skin diseases, and education for dermatologists and GPs on how to elicit and manage or appropriately refer these problems (Magin *et al.,* 2009).

Recently de Vere Hunt and colleagues (2021) published a thematic analysis of interviews with adolescents with eczema or psoriasis to explore their experiences with healthcare professionals. A total of 41 text transcripts of interviews with young people were analysed; 23 had eczema, and 18 psoriasis. Participants were living in the UK at the time of interview and aged 15–24 years old. The authors reported the following key messages from young people with eczema and psoriasis for healthcare providers: address the emotional impact, give more information, appreciate patient research, offer choice in treatment, lack of structure/conflicting advice, feeling dehumanised/treat me as a person, think about how treatments will affect daily life (de Vere Hunt *et al.,* 2021). This data highlights the need for greater recognition of the emotional impact of skin disease in adolescence and for more comprehensive provision of information about the conditions.

Eczema survey

In the US, two population-based studies, the 2010 and 2012 National Health Interview Surveys, surveyed 27,157 and 34,613 adults (ages 18-85 years). The surveys were administered in-person to select households by the US Census Bureau using approximately 400 trained interviewers with computer-assisted personal interviewing. One adult per household was randomly selected for the sample adult questionnaires. Interviews were conducted in English and Spanish. The findings showed that adults with eczema had significantly limited access to care with inability to afford prescription medications (OR, 2.36; 95% CI, 1.92-2.81), were unable to get an appointment soon enough (OR, 2.04; 95% CI, 1.73-2.41), had to wait too long to see a physician (OR, 1.59; 95% CI, 1.28-1.97), had delayed care (OR, 1.73; 95% CI, 1.49-2.01), and were not able to get care (OR, 1.66; 95% CI, 1.40-1.97) because of worry about the related costs (Silverberg, 2015).

Another US survey was published in 2018 by Silverberg and colleagues on 602 adults with eczema. Quality of life was assessed in the survey by using the DLQI and the short-form (SF-12) mental and physical health scores. The participants provided higher DLQI scores, which reflect their poor quality of life status. Adults with eczema reported higher proportions of having only fair/poor overall health (25.8% vs. 15.8%) and being somewhat/very dissatisfied with life (16.7% vs 11.4%). The authors reported that having eczema commonly limited patients' lifestyle (51.3%), led to avoidance of social interaction (39.1%), and reduced their daily activities (43.3%). Compared with other chronic illnesses the authors identified that having eczema was associated with worse quality of life than having heart disease, diabetes mellitus and high blood pressure. Moderate and severe eczema were particularly associated with dramatically lower QOL than all the above chronic diseases examined. The authors recommend that clinicians should incorporate QOL assessments in clinical practice to determine disease burden, identify patients requiring step-up treatment (providing more effective treatment) of their skin disease, and potentially screen for patients with mental health disorders (Silverberg *et al.*, 2018). The limitations in this survey include all exposures and outcomes in this study were assessed by self-report, and not verified by physical examination; hence may be subjected to misclassification. Also, the effects of past and present treatment were not examined so was the mediating effect of medication on QOL.

2.11 Health professionals' feedback

2.11.1 UK health professionals' feedback

A major review of health professionals working in dermatology services in the UK was performed between July and December 2013 by the British Association of Dermatologists and The King's Fund (The King's Fund, 2014). Their review was aimed to hear, review, assess, understand, identify and report the gaps in the dermatology service from health professionals' and stakeholders' perspectives. The review included conducting the following inquiries:

- A survey was sent to all members of the British Association of Dermatologists, as well as GPs. A total of 60 survey responses were received, 94% of them from senior dermatology consultants.
- Interviewing 20 stakeholders including consultants at all levels, dermatology specialty doctors, specialist dermatology nurses, GPs, GPwSIs, patients, patient organisations, the independent sector and commissioners.
- Visits to specialist dermatology services.
- Three stakeholder workshops invited more than 80 stakeholders to discuss emerging issues, areas of consensus, challenges, divergence, and the future of the dermatology service.
- Analysis of literature and documents on dermatology services made available from the British Association of Dermatologists.

This national review highlighted the challenges facing the dermatology services at primary and secondary care levels, and identified the followings findings: -

- It was highlighted throughout many of the themes that included patients with psoriasis and eczema that their needs have not been fulfilled in primary and secondary healthcare.
- There was a lack of supporting services and patient involvement in decision-making.
- The outcome of the psoriasis patients survey, which was conducted by the national Psoriasis Association members, found that one third of respondents had requested referral to a dermatologist through their GP. This reflects a lack of

confidence of the patients in primary care capacity, mainly due to the lack of GP training in dermatology.

- Despite this, there are 13 million GP consultations for skin conditions each year and GPs still have poor experience in skin diseases diagnosis and management.
- GPs were unable to assess and support the psychological impact associated with chronic skin diseases.
- The review however did acknowledge that GPs were facing increasing demands from an ageing population with multiple chronic diseases and complex issues and their role has expanded over the past decade including non-clinical duties, with increasing demands and competing tensions.
- Around 50% of all dermatology service activities at secondary care were related to the diagnosis and management of skin cancers, which has an impact on the waiting time to see patients with chronic skin diseases such as psoriasis and eczema.
- The increasing elderly population is likely to increase the prevalence of skin cancers workloads as well as the demand for dermatology services.
- The measured financial impact of skin diseases on the NHS was reported to be around £1,820 million a year in England and Wales. Considering almost 4 million working days are lost each year due to chronic skin diseases and the long-term morbidity, medical follow ups and psychological problems, this NHS budget is relatively low compared to many other chronic diseases such as coronary heart disease (CHD), which costs the NHS approximately £3.2 billion a year.
- Many newly qualified dermatologists are choosing to become locums in areas with high consultant vacancies as a lucrative career option rather working in a low paid

NHS post. Equally, many NHS consultants are seeking early retirement or part-time posts in order to take up highly paid locum or private posts.

- The investigating team agreed that the vision of the Department of Health in 2007 regarding moving the dermatology “Care Closer to Home” or “community dermatology clinic” was short sighted and has led to destabilisation of the dermatology service manpower and further shortages in the dermatology workforce. It also has led to a shortfall of dermatology specialist nurses as well as consultants across England. Additionally, the Care Close to Home service has limited resources to manage common chronic skin diseases such as psoriasis and eczema that require long-term follow-ups and care by a consultant dermatologist. While the patients prefer the concept of less travel, they soon found the disadvantages of the community dermatology services and they were more than happy to travel to far away hospitals in order to get a full package of treatment that community clinics can rarely provide (The King’s Fund, 2014).

2.11.2 North America and European health professionals’ feedback

A Multinational Assessment of Psoriasis and Psoriatic Arthritis (MAPP) surveyed dermatologists (n = 391) and rheumatologists (n = 390) in North America (Canada and the United States) and Europe (France, Germany, Italy, Spain and United Kingdom). The aim of the survey was to obtain real-world physician perspectives on the impact of psoriasis and PsA and its treatment on patients’ daily lives, including satisfaction with current therapies. The dermatologists classified 20.3% and 25.7% of their patients as having severe psoriasis and severe PsA, respectively. Rheumatologists indicated that 48.4% of their PsA patients had active disease. Of the psoriasis patients complaining of joint pain, only 33.0% had a diagnosis of PsA. An impact on daily activities or social/emotional well-being was recognised by 57.2% to 79.3% of physicians. In patients with moderate-to-severe psoriasis, dermatologists reported 74.9% were receiving topical therapy, 19.5% conventional oral therapy and 19.6% biologics. Dermatologists and rheumatologists reported similar rates of topical (45%) and biologic (30%) therapy utilisation for their PsA patients; conventional oral therapy was more often prescribed by rheumatologists (63.4%) compared with dermatologists (35.2%). Reasons for not initiating or maintaining systemic therapies were related to concerns about long-term safety, tolerability, efficacy and costs (biologics). Both surveyed dermatologists and rheumatologists acknowledged unmet treatment needs, largely concerning long-term safety/tolerability and efficacy of currently available therapies. This evidence suggests undertreatment of PsA and psoriasis among dermatologists (van der Kraaij *et al.,* 2015). The survey may be limited by factors such as accurate recall and interpretation of its questionnaire. The survey was blinded; hence physicians could not be re-contacted to clarify answers. The survey also lacked a control group and was not designed to capture differences in use of or attitudes towards various agents within a class of drugs or the impact of healthcare system requirements on decision-making.

2.12 Summary of the dermatology service limitations and APPGS quotes

From the above the limitations of the dermatology service can be summarised by the following: -

1. National and international studies showed that patients with psoriasis and eczema are suffering chronic distressing symptoms, stigma and mental health disorders. This may reflect patient under-treatment, presence of gaps in the dermatology service or failure of offering effective treatment.

2. Assessment of the psychological comorbidity and quality of life is rarely conducted within the limited consultation time at primary or secondary care settings.

3. Stress management therapy, counselling, CBT and psychotherapy are not routinely available or easily accessible in the NHS and the healthcare system is not presently set up to do this.

4. Skin diseases are regarded as non-priority and patients with psoriasis and eczema may have to wait for many months and up to a year to see a dermatologist.

5. The majority of GPs have limited dermatology training and limited resources to manage patients with chronic skin diseases and therefore they refer such cases and skin cancer cases to the dermatologists.

6. Studies showed that GPs and dermatologists may not provide patients with adequate opportunities to discuss their concerns and such consultations may recursively discourage patients to present their psychological symptoms to their physician with adverse consequences for self-care, and self-management including adherence to prescribed medications.
7. Around 50% of all dermatology service activities at secondary care level were related to the diagnosis and management of skin cancers, which has an impact on the waiting time to see patients with chronic skin diseases such as psoriasis and eczema.

8. There is a plethora of evidence to suggest that dermatology services in the UK are stretched to a point that makes providing basic services challenging.

9. The national shortage of dermatologists and the mounting pressure of NHS referrals led to a long waiting time and poor access to healthcare service when needed.

10. There is a lack of a holistic dermatology service and shortage of combined specialities clinic or multidisciplinary care which can provide a cost-reducing service by limiting inaccurate diagnoses, ineffective treatments, unnecessary referrals and at the same time increased patient satisfaction and improved patient outcomes (Patel & Jafferany, 2000).

11. There is also a national shortage of dermatology nurse specialists to support the service.

12. The community dermatology clinic “Care Closer to Home” project was short sighted and has led to destabilisation of the dermatology service manpower and further shortages in the dermatology workforce.

13. There is no long-term plan for a primary/secondary preventive strategy to reduce the risk of comorbidities associated with chronic skin diseases nor are there motivating healthy lifestyle measures that have been implemented to reduce the incidence of such comorbidities.

14. Although tele-dermatology may reduce the number of referrals to the dermatology service, there was a considerable percentage of tele-dermatological consultations resulted in a different diagnosis that needed a confirmation through a standard face-to-face consultation.

15. There are limitations and knowledge gaps in understanding psoriasis and eczema patients' needs, coping status and mechanisms, patient health assessment and involvement in decision-making, and self-management, as well as patient education and motivation for self-care.

The APPGS report stated:

> "*The need for a more tailored set of measurement tools is crucial if the psychological needs of patients are to be assessed efficiently within a very short period of time. From the affected person's point of view, the score for a predetermined set of questions may not reflect what is of importance to that individual person. Methods that take account of individual variation in importance are therefore desirable, provided they remain simple*." (APPGS, 2013 p. 38).

> "*Although research into this area has developed in recent years, there remains a lack of dedicated services to tackle the psychological needs of patients with skin disease. Investment should continue with the aim of developing evidence based psychological interventions capable of addressing differing levels of need. There is a need for further access to self-help/management tools as well as to psychological therapy*." (APPGS, 2013 p. 39).

From the above APPGS' quotes, healthcare service limitations and knowledge gaps, there is a need to develop a system for regularly assessing and managing psoriasis and eczema patients' morbidity and comorbidities, involving them in decision making and support self-management. The latter can play a vital role in improving patient care and treatment outcome (Grady & Gough, 2014; Lorig *et al.*, 1999). This will be discussed next.

2.13 Healthcare system and self-management

The healthcare system contains a level of complexity qualitatively different to other systems due to the social nature of health, and therefore requires a different set of research methods (Kernick, 2006). The system has proved a challenging environment for innovation, especially in the area of health services management and research. This is often attributed to the complexity of the healthcare sector, characterised by intersecting personal, social and political systems spread across geographical areas (Mannion & Davies, 2018). There is a need for turning towards new methods and frameworks, including simulation modelling, using theories, implementing and evaluating health services innovations (Lorig *et al.,* 2013).

The traditional medical model, which historically has focused on managing a specific disease condition, as opposed to managing the patient, has proven to be both expensive and ineffective in the treatment of chronic diseases mainly because most adults have more than one chronic condition and competing life circumstances that impair patients' capacity to self-manage their conditions (Wagner, 2001). The limitations of the medical model have resulted in a new and evolving chronic disease treatment paradigm that requires a patient-provider partnership involving collaborative care and education in chronic disease self-management to ensure the best possible health outcomes for the patient (Bodenheimer *et al.,* 2002).

A significant proportion of the unnecessary health care utilisation costs and poor health outcomes associated with the treatment of chronic diseases result mainly from the failure of patients to effectively self-manage their condition in response to recommended medical therapy (Holman & Lorig, 2000). If the management of chronic diseases is to be advanced, health care providers and systems of care need to organise patient self-management into an integrated system of chronic illness care that can increase the capacity of patients by providing knowledge, resources and skills necessary to perform the multiple tasks necessary to self-manage their conditions better (Bandura, 2004). These topics will be discussed next.

2.14 Self-management

Thomas Creer first described self-management in the mid-1960s and proposed that patients are active participants in their own treatments (Lorig & Holman, 2003). Grady and Gough defined self-management as the day-to-day management of chronic conditions by individuals over the course of an illness (Grady & Gough, 2014), while Lorig and Holman patient, claimed that self-management involves three separate but related sets of tasks: medical or behavioural management of the disease, role management and emotional management (Lorig & Holman, 2003). Bandura proposed that self-management operates through a set of psychological sub functions. People have to learn to monitor their health behaviour and the circumstances under which it occurs, and how to use proximal goals to motivate themselves and guide their behaviour (Bandura, 2004).

Self-management however is often used interchangeably with terms such as self-care, self-regulation, patient education, and patient counselling. Indeed, self-management may include all the above practices and may be also viewed as the unifying force behind the three processes; primary, secondary, and tertiary prevention, that span efforts to maintain wellness and control symptoms and illness progression (Holman & Lorig, 2000). Therefore, self-management can include dealing with symptoms, disability, monitoring physical indicators, managing complex medication regimens, maintaining proper levels of nutrition, diet, exercise and healthy lifestyle, adjusting to the psychological and social demands, including difficult lifestyle adjustments, and engaging in effective interactions with health care providers (Wagner *et al*., 2001).

Self-management has become a paradigm in which individuals with chronic conditions play a key role in guiding their care, in partnership with health care providers in order to maintain patient independence and quality of life over longer periods of time (Budhwani *et al.,* 2018). It requires building on and tailoring what is already known to be effective and disseminating evidence-based programs and practices beyond the clinical setting to enable and support people in the context of their homes and diverse communities (Jauhar *et al.,* 2019). Patient self-management of chronic diseases is increasingly essential to improve health behaviours, health outcomes, and quality of life and in some cases, has demonstrated effectiveness for reducing health care utilisation and the societal cost burden of chronic conditions (Allegrante *et al.,* 2019).

Research to develop and evaluate disease self-management programs dates back over four decades and the initial efforts to develop such programs were designed to provide disease-specific information and improve compliance with prescribed medication (Jauhar *et al.,* 2019). Since then, chronic disease self-management has evolved to enable patients with chronic diseases to develop a broad range of behavioural skills, competence, self-efficacy or capacities to adopt and navigate a variety of disease-management tasks across a range of chronic conditions (Barlow *et al*., 2002).

In 2010, the Department of Health and Human Services included self-management as one of four goals in a strategic framework for improving the health status of individuals with multiple chronic conditions (Parekh, Goodman, Gordon, & Koh, 2011). In 2012 the Institute of Medicine published the "Living Well with Chronic Illness" report, which included self-management as one of several models of living well interventions and offered tools for patients to use in caring for their chronic illness (Institute of Medicine, 2015). Hence, self-management has become a promising direction for addressing chronic conditions that are a major health and economic concern in many countries and it has proven successful at improving health behaviours and health status, resulting in fewer hospitalisations or fewer days spent in the hospital; an added benefit of reduced health care costs (Lorig *et al*., 1999).

Self-management can play an important role in primary, secondary and tertiary prevention of morbidity and comorbidities in psoriasis and eczema. Educating individuals with a family history of psoriasis and eczema including avoiding environmental triggering factors for these chronic diseases may arguably be effective in primary prevention or delaying the onset of such diseases and a spectrum of comorbidities associated with such diseases (Barry *et al*., 2019; Millar, 1997; Schmitt *et al.,* 2008). Equally, self-management can help in secondary and tertiary prevention by providing strategies for mitigating illness and managing it in later life (Andersen *et al*., 2017; Chu *et al*., 2017; Fishbein *et al*., 2020; Lorig *et al*., 1999).

Nevertheless, the ability to self-manage chronic conditions is found to be directly affected by factors related to the patients' personalities, their own community, home environment, quality of the health service and available resources; hence demographic disparities contribute to the formation of certain social barriers for self-managing chronic conditions (Manzoni *et al*., 2013; Martiny & Rubin, 2016; McKinstry, 2000; Sox, 2003).

Although innovation in biomedical research has produced clinical medical treatments such as biologic therapy, which can significantly improve the QOL of patients with psoriasis and eczema, the management of these conditions increasingly involves partnering with patients to support efforts to undertake long-term adherence to a preventive or therapeutic regimen that can improve functional status and health outcomes (Sbidian *et al.,* 2020). This may include patients adopting and maintaining multiple lifestyle behavioural changes in dietary practices, exercise, and the use of prescribed medications, as well as managing complex communications with family and health care providers and systems (Allegrante, 2018). Therefore, managing a chronic condition constitutes a problem-based endeavour, which may require multiple self-management skills including problem solving, decision making, resource utilisation, the formation and long-term maintenance of a patient provider partnership, action planning and self-tailoring are central to the successful self-management of chronic conditions (Lorig & Holman, 2003; Wagner *et al.,* 2001).

Overall, three main methods of intervention delivery characterise chronic disease self-management programs: small-group meetings, Internet-based technologies and printed materials (Lorig *et al.,* 2013): -

Small-group meetings comprise the basic intervention method of chronic disease self-management programs and have been used successfully across a wide spectrum of chronic conditions (Lorig & Holman, 2003). This format provides face-to-face engagement between and among participants and it facilitates peer interaction, discussion and social support. However, attendance rates and completion may suffer owing to the need for patients to attend scheduled group sessions (Barlow *et al*., 2002).

Internet-based technologies and communication technologies can reach large numbers of the population with disease self-management programs and permit standardising and tailoring of health-related messages. In addition, technology, offers privacy, anonymity, autonomy, and usability can be made graphically engaging (Oldenburg *et al.,* 2015). Internet-based self-management has been implemented and evaluated in chronic conditions (Lorig *et al.,* 2013). However, not all patients are able or willing to participate in small-group meetings or internet-based chronic disease self-management programs (Allegrante *et al.,* 2019).

Printed materials that are distributed either through mail or in person, present a feasible alternative intervention method. It provides the necessary printed information about patient disease and the available treatment options (Bodenheimer *et al.,* 2002).

Participation in the above 3 self-management programs can be influenced by factors related to patient and to service provider (Wagner, 2001).

Facilitating home and community based services is one of the objectives outlined by the Department of Health and Human Services' strategic framework for optimising health and the quality of life for individuals with chronic conditions (Parekh *et al.,* 2011). There are however limitations in studies conducted to assess self-management on patients with psoriasis and eczema.

In 2016, a systematic review was published aimed to assess the effects of patients' education that specifically addresses QOL among people with chronic inflammatory skin conditions including psoriasis and eczema. Seven RCTs met the reviewers' inclusion criteria. Two RCTs showed that for psoriasis in adults, group-based and text message education as adjuncts to usual care, resulted in better QOL and disease severity outcomes than comparators, respectively. One RCT found that group-based education for children with eczema and their parents resulted in greater improvements in parents' QOL and in the children's disease severity than no education at 12 months. The authors however found that none of these RCTs found statistically significant effects on QOL or disease severity compared with usual care (Pickett *et al.,* 2016).

In 2017, Ridd and colleagues, published their systematic review of self-management interventions for people with eczema and found twenty studies (3028 participants) conducted in 11 different countries. The majority of these studies (*n* = 18) were based in secondary care and most (*n* = 16) targeted children with eczema. Thirteen studies were face-to-face educational interventions, five were delivered online and two were studies of written action plans. The review identified a general absence of well-conducted and well-reported RCTs with a strong theoretical basis. The authors recommended that future studies should seek to evaluate interventions that are pragmatic and tailored to the context and needs of the patients (Ridd *et al.,* 2017).

In 2019, Alsaadi and colleagues, published their literature review on interventions designed to promote self-management in adults with psoriasis in order to better conceptualise self-management and to identify its barriers. A total of 29 eligible articles were included in the review and revealed a broad view of self-management which focuses on patients tailoring treatment around their everyday lives. They reported that autonomy may pose significant challenges to patients in situations where their knowledge is limited, treatment is ineffective or psychosocial support is inadequate. This can lead to non-adherence, inappropriate self-medication and disengagement from healthcare appointments. The evidence reinforces that the benefits of patient autonomy are optimised when care is individualised. To achieve this, physicians should provide guidance that enables patients to have an active role in decision making, whilst offering continuity of care. Given limited consultation times, the published evidence suggests that web-based technology and education delivered by allied healthcare professionals can be beneficial if patients are to develop self-management skills (Alsaadi *et al.,* 2019).

In the same year Dressler and colleagues (2019) published a systematic review to identify studies evaluating educational interventions for psoriasis patients. The review evaluated 16 eligible studies; two RCTs assessed patient-practitioner or patient-nurse one-to-one interventions, one RCT assessed a web-based intervention and three RCTs reported group interventions taking place frequently; one RCT reported one-off group sessions. The remaining RCTs compared the healthcare professionals involved. The authors concluded that interventions that included an individual (one-to-one) session appeared to be successful for self-management (Dressler *et al.,* 2019).

The above systematic reviews may suffer from publication, selection bias or inadequate blinding, and a range of methodological limitations. More recently, Domogalla and colleagues (2021) published a RCT on 107 patients with psoriasis. They randomised them into the control group (49.5%) or intervention group (50.5%) who received an educational program with a disease management smartphone app on the mental health of patients with psoriasis. Approximately, 71.9% of the patients completed the study. A significant reduction in HADS-Depression (HADS-D) in the intervention group was found at weeks 12 (*P*-.04) and 24 (*P*-.005) but not at weeks 36 (*P*-.12) and 60 (*P*-.32). Patient stratification according to app use frequency showed a significant improvement in HADS-D score at weeks 36 (*P*-.004) and 60 (*P*-.04) and in HADS-Anxiety (HADS-A) score at weeks 36 (*P*-.04) and 60 (*P*-.05) in the group using the app less than once every five weeks. All findings were independent of sex, age, and disease duration. The authors supported the use of a disease management smartphone app as a valid tool to achieve long-term improvement in the mental health of patients with psoriasis if it is not used too frequently (Domogalla *et al.,* 2021).

Although this RCT was small and of monocentric design, which may limit generalisability of its results, digital health technology for people with psoriasis seems to be a promising additional component in disease self-management (Bedrov & Bulaj, 2018; Dendere *et al.,* 2019; Hazara *et al.,* 2020). Furthermore, considering the COVID-19 pandemic, many healthcare services are being rapidly redesigned, and this seems an opportune time to include patient voices in this process. Although young peoples' comfort with technology may well make them ideally placed to embrace a service with a greater emphasis on online support and consultations, older patients may prefer paper information or direct consultation (de Vere Hunt *et al.,* 2021).

Therefore, research and new interventions are needed to support patients' self-management from all age groups (Allegrante *et al.,* 2019). RCTs with economic evaluation are required to rigorously test self-management modalities. Psoriasis and eczema's self-management has not been given the attention it deserves by health care providers (Alsaadi *et al.,* 2019; Flanagan *et al.,* 2017).

Improved self-management can lead to better patient outcomes, less need for outpatient follow-up, and possible savings in cash-strapped health service (Allegrante *et al*., 2019; Goodman *et al*., 2022). However, self-management requires multiple needs and support. It should be based on a sound understanding of the core skills required for effective self-management and theoretical and conceptual frameworks (Budhwani *et al.,* 2017).

Self-management theories could be used as a working tool for developing a new intervention supporting self-care and behaviour changes (Alderson, 1998). Although such an approach's success depends on a huge range of factors, systematic review and meta-analysis suggested that theory-based interventions can have a significant impact on patient's management outcomes (Conn et al., 2016; Guevara *et al.,* 2003; Roter *et al.,* 1998).

2.15 Self-management/motivation theories

This research will discuss three theories that are relevant to patients' motivation for self-management and provide evidence to justify using these theories in this research aiming to reach a theoretical or conceptual framework to support the management of patients with psoriasis and eczema:

- **Self-determination theory**
- **Self-efficacy theory**
- **Self-regulation theory**

2.15.1 Self-determination theory

In the 1970s, SDT emerged and defined motivation as psychological energy directed at a particular goal (Deci & Ryan, 1985). This theory was first applied toward understanding the process of education (Flink *et al*., 1990). Thereafter, SDT evolved assessing motivation within health contexts including the healthcare environment, health behaviour changes and interventions (Patrick & Williams, 2012). SDT hypothesised that people, regardless of culture or developmental level had three innate psychological needs:

- Autonomy (feel choiceful, self-determinate and volitional while taking decisions)
- Competence (to gain mastery of a task and feel capable of achieving desired outcome)
- Relatedness (feel close to, supported and understood by important others)

Self-determined motivation behaviour will be promoted when these three psychological needs are satisfied which in turn can enhance mental health. In contrast, threats or deprivation of these psychological needs appears to be the principal source of human distress and mental health issues. Ryan and Deci (2000) suggested two types of social motivations: intrinsic and extrinsic motivation.

Intrinsic motivation is based on inherited interests, values and curiosity. It is considered a relatively autonomous or self-determined form of motivation, reflecting an inherited sense of volition and personal causation with respect to a behaviour (Gagne & Deci, 2005; Pinder, 2008).

Extrinsic motivation is an attempt to engage, adapt or foster a new behaviour to gain approval, rewards or to avoid punishment or risk. Many health promotion campaigns are likely extrinsic in nature (Patric & Williams, 2012). SDT uses the term “internalisation” to describe the process by which behaviour becomes relatively more autonomously regulated by taking in value and regulation of a new behaviour or “integration” (transfer of the value into habit or behaviour (Gagne & Deci, 2005).

However, not all extrinsic motivations are equivalent, and its continuum includes:

- *Introjected regulation* (engaging in behaviour out of some sense of guilt or obligation)
- *Identified regulation* (engaging in behaviour because it is important to them)
- *Integrated regulation* (engaging in behaviour as it is consistent with one’s goals/values)

Different forms of regulations may coexist for the same behaviour and across contexts (Patrick & Williams, 2012). Hence, SDT is conceptualised as multidimensional where different qualities of motivation are the key focus (Fortier *et al*., 2012).

In a health care setting, SDT argues that motivated patients have better physical and psychological health, become more creative, better problem solvers when they encounter obstacles or challenges, have better performance and positive emotions. However, patients' autonomous motivation requires supportive environments, which may include:

- Understanding their perspective
- Offering choice
- Allow patients to engage in the decision-making process
- Support their exploration
- Encourage them to be self-initiating
- Provide them with a meaningful rationale which can help them to understand and internalise it and make it part of their value system (Gagne & Deci, 2005; 2012; Ryan & Deci, 2000).

Many studies targeting health behaviour change have supported the SDT within the context of health and autonomous motivation and demonstrated its positive influence on behavioural engagement including self-management (Borghi *et al*., 2018; Flink *et al.,* 1990; Frotier *et al*., 2012; Hagger & Chatzisaranits, 2008; Lindwall *et al*., 2017; Lloyd *et al*., 2018; Lock *et al.,* 2018; Patrick & Williams, 2012; Sounders, 2020; Teixeira *et al*., 2012). Below are three meta-analyses on the impact of SDT in the health domain.

Ng and colleagues (2012) published the first large meta-analysis of applications of SDT in the health domain. They identified 184 independent datasets, primarily non-experimental studies examining the relations between the SDT based constructs and health behaviours (e.g., smoking abstinence, physical activity) and indices of health (e.g., quality of life, depression). The authors found positive relations of psychological need satisfaction and autonomous motivation were beneficial toward health outcomes. They identified that competence was the major predictor of motivation and health outcomes and had a better effect on physical and psychological health than autonomous motivation (Ng *et al*., 2012). This meta-analysis included many non-experimental studies and combined indices of physical health with health behaviours. This may impose difficulty in assessing the mechanisms by which such interventions work and difficulty in generalising the findings to other areas of treatment or health promotion.

Gillison and colleagues (2017) analysed 74 intervention studies that met their inclusion criteria in promoting motivation and need satisfaction for health behaviour change. The authors coded studies in terms of the use of 18 SDT–based techniques to promote need satisfaction. Their meta-regression analysis did not identify particular strategies that induced meaningful changes in need satisfaction. They concluded that a combination of such strategies might be necessary to promote need satisfaction (Gillison *et al*., 2017). This meta-analysis was limited by the comparability of studies and the intensity of interventions varied widely. They included studies from sport in which the emphasis was on physical performance and not on health and did not identify the extent to which changes in SDT–based constructs were associated with changes in physical, or psychological health outcomes.

A more recent meta-analysis by Ntoumains and colleagues (2020), found that SDT-informed interventions in the health domain were associated with modest, but significant improvements in autonomous motivation, competence, need satisfaction and need support. These effects were stronger at the end of the interventions than at follow up. SDT interventions had modest effects on changing health behaviours both at the end of the interventions and at follow-up. They had positive effects on physical health at the follow up, but not at the end of the interventions, and they had positive effects on psychological health at the end of the interventions, only (Ntoumanis *et al.*, 2020). These effects however were heterogeneous partially due to increases in self-determined motivation and support from social agents. They admitted that more work is needed to manage lack of motivation, which can be a challenging task to be achieved within the healthcare context. Other limitations include relying mainly on studies focused primarily on physical activity promotion, risk of small-study bias and their coding process was not performed by the same assessors.

Considering the above limitations this research reviewed two more theories that support patients' engagement, motivation, empowerment or involvement in self-management.

2.15.2 Self-efficacy theory

Self-efficacy theory (SET), social leaning theory (SLT) and social cognitive theory (SCT) were founded by a Canadian psychologist, Albert Bandura, and were followed by a circle of related research that has emerged from Bandura's original work. SCT started as SLT in the 1960s by Bandura then developed into SCT in 1986.

Self-efficacy refers to an individual’s belief in their capacity to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control, and willingness to take on and persist with new and difficult tasks. The process towards adequate self-management requires an increase in knowledge, skills and confidence, which is defined as the level of activation for self-management. Higher levels of activation reflect better capacity to self-manage an illness.

In the early 1960s, Bandura proposed “reciprocal determinism theory” for human behaviour, which states that a person's behaviour is influenced both by personal factors and the social environment. It can be conditioned through the use of consequences (outcome) and can be positively and negatively influenced by the interaction of human cognitive factors (internal factors) with the social environment (external factors). He claimed that that people learn by observing other people whom they believe are credible (models), and the learned behaviour that is reinforced or rewarded tends to be repeated and adopted by the observer. He also claimed that the learning process has four stages (attention, retention, reproduction and motivation) and is influenced by individuals’ self-efficacy (Bandura, 1991).

Most people want to achieve certain goals in their life but based on their belief system, confidence, and self-efficacy they only tend to try things that they believe that they will be successful in. To build-up their self-efficacy they need motivation and support (Chambers, 2007). Self-efficacy can be influenced by how people feel, think, react, and behave. Their personal beliefs produce diverse effects through four major processes: cognitive, motivational, affective and selective processes. These processes can influence individuals' assessment of their own ability, self-esteem, and emotional evaluation of their own values to achieve a goal (Bandura, 1997).

Self-efficacy, therefore, can be a strong and consistent predictor of physical activity and can play a major role in how one can achieve goals, tasks, and challenges (Morano *et al*., 2019). If self-efficacy is strong people develop a deeper interest in the activities and form a stronger sense of commitment to achieve their goals. They can visualise their success positively regardless of the challenges they might face. In contrast, if self-efficacy is lacking, people tend to behave ineffectually or avoid tasks even though they know what to do. They may also focus on personal failings and negative outcomes and lose confidence in their personal ability.

Bandura stated that self-efficacy can be influenced by four factors: -

- *Mastery experiences* (how successful a person has been with a task in the past)
- *Vicarious experiences* (phenomenon of observing others and feeling what they feel)
- *Verbal persuasion* (impact of other on the learner by making them aware of their skills)
- *Physiological states* (the levels of emotional arousal the learners experienced and how they identify with that arousal)

Later, Lorig and Holman provided a conceptualisation of SET for self-managing those with chronic disease, stating, “only the patient can be responsible for his or her day-to-day care over the length of the illness,” (Lorig & Holman, 2003, p.1). Changing peoples’ behaviour (e.g., successful self-management), adopting a new behaviour and maintaining practising the new behaviour require an approach that is over and above the incorporation of teaching of essential knowledge and skills alone, but also includes cognitive processes to change behaviour in people with chronic disease. The following steps can enhance patients’ self-efficacy to self-manage their chronic illness:

- Encourage patients to create small achievable health goals to improve their lifestyle experience.
- Offer patients training, workshops or mentors to increase their observational learning.
- Ensure that they have social or family support systems for encouragement.
- Decrease stressors by teaching coping skills or counselling.
- Offer information on self-management; explain the negative impact of bad habits.
- Offer feedback, reflection, reinforcement for their positive healthy behaviour (Ebrahimi Belil *et al*., 2018; Gruber-Baldini *et al*., 2017; Lorig, 1996)

At least, four reviews (Hoffman, 2014; Gruber-Baldini *et al*., 2017; Nafradi *et al*., 2017; Williams & Rhodes, 2017), two cross-sectional studies (Peters *et al*., 2019; Tharek *et al*., 2018), a qualitative study (Ebrahimi Belil *et al*., 2018) and a case control study (Jauhar *et al*., 2019) reported that SET could empower and motivate patients to self-manage their chronic illness. Self-efficacy motivation can be achieved even when using digital health technologies

(Bedrov & Bulaj, 2018). It can also improve individuals' academic performance (Yokoyama, 2019) and physical activity or fitness (Caireny *et al*., 2012; Morano *et al*., 2019).

Both SDT and SET theories are based on the ideology that humans are agents of their actions and they significantly correlated with the empowerment of self-esteem. However, the role of competence in SDT is a more distal factor and has a direct relationship with self-determined motivation rather than behaviour, while competence in SET has a direct and proximal influence on behaviour (Sweet *et al.,* 2012). Additionally, SDT is reported to be more amenable to health contexts (Beauchamp & Childress, 2001; Woolf *et al*., 2005), and overlap with motivational interviewing (MI). The latter is a set of clinical techniques, which have been used in a health behaviour intervention context. MI is almost similar to the empowerment concept of SET and was theoretically supported by SDT (Patrick & Williams, 2012). Both SDT and SET have been used in physical activity literature but not in dermatology (Ebrahimi Belil *et al.,* 2018, Ntoumanis *et al*., 2020; Peters *et al.,* 2019; Sweet *et al.,* 2012).

2.15.3 Self-regulation theory

Self-regulation theory (SRT) claims that a person is motivated to self-regulate their thoughts and emotions by a desired goal or behavioural endpoint (Baumeister *et al.,* 1994). It is a process of anchoring and adjusting our performance, both mental and physical in nature, in response to corrective feedback within social and physical environment. SRT requires that we expend effort in control of what we think, say and do, trying to be the person we want to be, both in particular situations and in the longer-term (Bandura, 1991).

Roy Baumeister an American social psychologist described four components of self-regulation:

- Standards of desirable behaviour
- Motivation to meet standards
- Monitoring of situations and thoughts that precede breaking standards
- Willpower, or the internal strength to control urges

He described the ability to self-regulate can be limited in capacity and through this he coined the term ego depletion (Baumeister *et al*., 2007).

In health domain, self-regulation includes stopping ourselves from doing things we know we should not do and adopting positive behaviour. For example, if a physician suggests we should avoid eating high fat food, we know this is good advice, then we need to have the self-discipline to implement such recommendations (Kliemann *et al.,* 2016). Self-regulation includes impulse control, the management of short-term desires. It is typically needed when there is a conflict of motivations, for example to run away from a fire as opposed to helping to rescue victims of the fire (Clark *et al.,* 2014).

Self-regulation is influenced by the power of the goal associated with a value that the goal represents for the individual. The more important the goal is, the more the person will engage in self-regulation behaviour. In terms of self-management, engaging in any disease management action is influenced by both internal and external factors (Allegrante *et al.,* 2019). SRT views individual self-regulation of health-related behaviour as central to achieving the desired outcomes of treatment. It is the process of taking control and evaluating one's own learning and behaviour (Bodenheimer *et al.,* 2002).

Illness behaviour in self-regulation deals with issues of tension that arise between holding on and letting go of important values and goals as those are threatened by disease processes (Lorig, 1996). People who have poor self-regulatory skills may not succeed in self-management (Grady & Gough, 2014). Their failures can have two categories: under regulation and misregulation. Under regulation is when people fail to control oneself whereas misregualtion deals with having control but does not bring up the desired goal (Sayette, 2004).

The behavioural and cognitive components of SRT may overlap with SET. They both proposed that motivation can be driven by rewarding outcomes or goals (Bandura, 1997; Baumeister *et al*., 2007). Albert Bandura claimed that humans are able to control their behaviour through a process known as self-regulation that includes self-observation, judgment and self-response.

- Self-observation (also known as introspection) is a process involving assessing one's own thoughts and feelings in order to inform and motivate the individual to work towards goal setting and become influenced by behavioural changes.
- Judgement involves an individual comparing his or her performance to their personal or created standards.
- Self-response is applied, in which an individual may reward or punish his or herself for success or failure in meeting standards (Bandura, 1997).

Arguably, SDT, SET and SRT overlap in the concepts of self-management. They all require multiple needs, consist of several stages of patients' education and support to contributor to their own motivation, behaviour and self-development within a network of reciprocally interacting influences. These theories may however differ in nature of their tasks. In SET however, patients should deliberately monitor their own behaviour and evaluate how this behaviour affects their health. If the desired effect is not realised, the patient changes personal behaviour. If the desired effect is realised the patient reinforces the effect by continuing the behaviour (Lorig *et al.,* 1999)

Patients need to realise a personal health issue and understand the factors involved in that issue. They must decide upon an action plan for resolving the health issue. They also need to monitor the results in order to appraise the effects, checking for any necessary changes in the action plan. A further factor that can help the patients to reach their own personal health goal is health professionals' support to relate to the patients in the following: Help them figure out the personal/community views of the illness, appraise the risks involved and give them potential problem-solving/coping skills (Bodenheimer *et al.,* 2002; Muth *et al*., 2019)

One of the challenges of SRT is patients' will power which can undermine their motivation (Spring *et al.,* 2021). Obesity is a global health problem and although many people are self-managing their weight reduction, others are not able to control their thought (desire) to eat their desired food. Their "motivation" to eat is driven by their desire and not needs (Spring *et al.,* 2021; Teixeira *et al*., 2012). Another challenge of SRT is that researchers often struggle with conceptualising and operationalising self-regulation (Wagner *et al*., 2001; Warsi *et al.,* 2004). There is also lack of rigor in the literature, especially when examining how often even lower quality published reviews are cited (Hennessy *et al.,* 2020). A recent meta-review of 66 meta-analyses between 2006 and 2017 examined the link between self-regulation and health behaviour change. The review found that although some self-regulation intervention components are successful in some health behaviours and with particular populations, other interventions might be ineffective for certain health behaviours, and require further empirical examination to assess whether they are indeed worth resource expenditure, especially with some of the high levels of heterogeneity presented in this meta-review (Hennessy *et al.,* 2020).

2.16 Self-management theories and the dermatology service

The determinants of engagement/motivation of the patients are related to multiple factors including their personalities, belief, age, physical, psychosocial status, professionals' behaviour, persona and healthcare resources as well as family and social factors (Borghi *et al*., 2018). Patient's personality may or may not fall in a spectrum of motivation. Increasing age was found to correlate with low motivation, while patient's families could reduce motivation by pushing the patient too hard to make changes or being overprotective (Lindwall *et al*., 2017). Central among the social factors were aspects of the health professionals' own behaviour, which might have diverse implications for patient motivation and care (Maclean *et al*., 2002).

For successful engagement, involvement or motivation of the patients in self-management, clinicians need to build up a trusting rapport with patients (Hoffman, 2014; Jauhar & Nursasi, 2019; Patrick & Williams, 2012). This task can also help the clinicians to assess their patient's lifestyle and treatment plans to determine if the patient needs motivation or not. The checklist includes if their management plan indicates specific wellness goals, their prescription is appropriate and manageable for the patient and does not interfere with a patient's lifestyle (Lindwall *et al*., 2017; Lock *et al.,* 2018). Physicians should also recognise the warning signs of a patient who begins to disengage, such as a history of poor compliance or depression, limited patient support network, lack of trust between patient and provider or an unstable lifestyle. Patients with no specific treatment plan or individual end goals and patients who do not have regular face-to-face encounters with clinicians are also less likely to be compliant (Lock *et al*., 2018; Maclean *et al*., 2002).

Building trust with patients is an essential step for engagement/motivation and to stimulate a patient’s desire to change and give them the confidence to do so (Lindwall *et al*., 2017). However, with the shortage of the dermatology staffing and limited consultation time physicians are unable to guide patients through the process of self-management such as setting goals and engage them in a two-way conversation focusing on education and goal setting and to believe that behaviour change is possible (Teixeira *et al*., 2012). In a busy dermatology clinic physicians may have no time to engage patients in motivational interviewing, using open-ended questioning, affirmations, or feedback during different parts of the wellness journey, reflective listening, or helping patients arrive at answers instead of prescribing a need for motivation, summaries or repeating back to patients, observations that patients have made themselves (Maclean *et al*., 2002, Patrick & Williams, 2012).

Incentive-based models may be used for modifying patient extrinsic motivation, such as offering cash incentives to obtain an outcome separable from the activity *per se*. People can be motivated by a variety of incentives, but such motivation is regarded as a relatively controlled motivation, whereby patient behaviour is governed by external pressure or acts (Ryan & Deci, 2000). It can impose financial and clinical risks to the patient and to the service resources (Lindwall *et al*., 2017). Patients may be engaged in an activity to gain a tangible or social reward or to avoid disapproval and not necessarily to maintain a healthy lifestyle or to improve their own health (Fortier *et al*., 2012).

There are limited resources and restricted consultation time within most of the NHS services (Edwards & Imison, 2014; Irving *et al*., 2017). Clinicians rarely have enough time and resources to motivate and empower their patients during the face-to-face consultation. They tend to focus on skin treatment and often miss or ignore managing the patient's needs and comorbidities under the skin (Nelson *et al.,* 2013, 2014, 2016; de Vere Hunt *et al.,* 2021). The lack of assessment of patient needs and comorbidities means that little is known about them, and this can leave the management of the psychological symptoms unsuccessful as a result (de Zoysa, 2013).

The lack of success may also be related to a lack of patient understanding of their psychosocial condition and its link to their behaviour, belief or lifestyle and a subsequent lack of value placed on psychological referral (Barankin & DeKoven, 2002). This research proposed providing an intervention or a tool to engage/involve the patients to play an active role in decision making and the self-management of their chronic skin diseases as well as assess their needs, comorbidities and feedback on a regular basis. However, there are many assessment tools available for assisting patient care such as the following: -

The Person-Centred Dermatology Self-care Index (PeDeSI) is a self-efficacy theory-based questionnaire tool to measure education and support needs of adults with long-term skin conditions. The objective of the use of PeDeSI is to help patients, physicians, and nurses work collaboratively to assess the education and support required to enhance self-management (Cowdell *et al.,* 2012). Although the tool can act as a vehicle for engaging patients in the process to improve adherence with treatment and provides a basis for evaluating the effectiveness of measures to support self-management, the use of this tool is limited by logistical factors that prohibited the collection of data from each patient with skin diseases.

Additionally, the tool does not assess comorbidities and offer limited autonomy to the patient to be involved in decision making of their management.

Patient Benefit Index (PBI) was developed in Germany to measure patient-defined treatment objectives and benefits, claiming that patient benefits in dermatology can only be defined by the patient him/herself, and not by the physician's perspective (PBI, 2020). The PBI is a tick box tool which showed good feasibility, reliability, and construct validity, high responsiveness and discrimination between subgroups in dermatological treatment (Augustin *et al.,* 2009). However, this tool is not routinely used in the UK's dermatology service and not recommended by NICE (NICE, 2012). It focuses on patient's response to the treatment and offers limited autonomy to patient feedback to understand patient perspective or assess their needs and comorbidities that may influence their self-management or QOL.

Other assessment tools discussed earlier in this chapter (please see page 99-100) can be used in the dermatology service. However, they have limitations and were unable to regularly assess patients' needs, comorbidities and feedback as well as support patient involvement in decision making and self-management.

2.17 Knowledge gaps

National and international studies discussed in this review explored psoriasis and eczema patients' experience with these diseases and with the health services. The review also identified the following knowledge gaps: -

1- Lack of studies offering a tool, method or intervention that can regularly screen patients with psoriasis and eczema for both metabolic and psychological comorbidities.

2- Lack of studies offering innovation that can involve psoriasis and eczema patients in decision making and support their self-management on a regular basis.

3- Lack of research aiming to offer comprehensive/holistic service to patients with psoriasis and eczema to improve their treatment effectiveness and enhance their QOL.

2.18 Conceptual framework and research proposal

The knowledge gaps in the literature review led me to look for an intervention or a tool that can fill these gaps and support psoriasis and eczema patients' unmet needs on a regular basis. However, for the patients to use a new tool on a regular basis, it should provide comprehensive services relevant to their needs, wishes, desires or feedback (Allegrante *et al.,* 2017; Ryan & Deci, 2000). Reviewing self-management/motivation theories helped me to identify some of the possible relationships between QOL, needs, wishes and desires. Patients may have a desire to end their life when they have poor QOL or terminal illness (Robinson *et al.,* 2017). In contrast, QOL and patients' motivation can be enhanced if their needs and desires are fulfilled (Bandura, 1997; Costanza *et al.,* 2007; Maslow, 1943; Ryan & Deci, 2000).

The above relationships guided me to develop a conceptual framework adopted from the above theories (SDT, SET and SRT). These theories claim that motivation can be driven by human needs, rewarding outcomes or goals. However, their motivation requires a complex set of cognitive functions, including controlling thoughts, emotions or behaviour to reach a goal, problem solving, decision making, and having supportive environments. The latter may include having a supportive family and healthcare systems, understanding a patient's perspectives, offering the patients choices, allow them to engage in the decision-making process, supporting their exploration, encourage them to be self-initiating, provide them with a meaningful rationale which can help them to understand and internalise it and make it part of their value system, and self-esteem, strengthening their social relationships and boosting their caring performance (Bandura, 1997; Baumeister *et al.,* 1994; Ryan & Deci, 2000). Nonetheless, not every patient has supportive or a close family and with the limited resources of the dermatology service, a shortage of dermatologists and dermatology specialist nurses, achieving the above multiple needs for self-management is not always feasible (The King's Fund, 2014).

The above theories however, helped me to reach a conceptual framework of "**patient engagement, involvement or motivation can be driven by their needs to improve their QOL or to satisfy their desires**".

According to Abraham Maslow, humans may require both “essential needs” and “non-essential needs or desires”. He proposed that people have a hierarchy of psychological needs in the form of a pyramid, with basic physiological needs which are essential for human living such as air, food, water, and safety (Maslow, 1943). Other types of needs are “not essential” for survival such as aesthetic needs, self-actualisation and transcendence; but they represent “desires” for self-development towards happiness and satisfaction within certain cultures (Maslow, 1962; Ventegodt *et al.,* 2003).

I also proposed that my conceptual framework can be achieved by using an assessment tool on a regular basis. I developed an unstructured paper questionnaire (study tool) for clinical use and not for research purposes. It contains seven open-ended questions, one Likert question and a DLQI scale. I proposed that the study tool can engage patients with psoriasis and eczema to use it on a regular basis at each consultation if it is able to offer comprehensive services that can satisfy their unmet needs and improve their QOL. The tool aims to regularly screen psoriasis and eczema patients for new/hidden comorbidities and address their needs and feedback as well as engaging them in decision making and self-management. The latter can play a vital role in improving patient management outcome and health service resources (Lorig & Holman, 2003; Newman *et al.,* 2004; Ridd *et al*., 2017).

Engagement, involvement or motivation of patients with chronic skin diseases might not always include satisfying human essential needs but fulfilling their psychological desires such as making their own choices, having education and autonomy to make their own decisions, exerting control over their own lives (competence/self-efficacy) and be related to caring health services, or a caring medical team (Bandura, 1997; Baumeister *et al.,* 1994; Ryan & Deci, 2000). Whilst some patients may be intrinsically motivated to improve their health, others may require external motivation, support and affirmation from their clinicians (Lock, Post, Dollman, & Parfitt, 2018).

In medical practice, autonomy is often expressed as the right of competent adults to make informed decisions about their own medical care and is a cornerstone of medical law (BMA, 2018). Likewise, if the patients are the main drivers of health behaviour change, care management activities, and medication adherence, it is important for the proposed study tool to offer the patient the autonomy and the opportunity (e.g., a questionnaire with open ended questions) to be active participants in their own wellness journey (Maisel *et al*., 2018).

However, to engage the patients to use the proposed study tool regularly, it should have the potential to provide comprehensive services relevant to their needs and QOL (Bandura, 1997; Ryan & Deci, 2000). Assessment of the latter is added in the study tool, as the current evidence suggests that chronic disease self-management can not only yield important benefits to patients, and reductions in utilisation of health care resources but can also lead to improvements in quality of life (Allegrante *et al.,* 2019; Goodman *et al.,* 2022; Hodkinson *et al.,* 2020). Including a QOL score in this research can also provide a wide range of potential benefits to the patients and to the service including determining disease burden, identifying patients requiring step-up treatment (providing more effective treatment such as biologic therapy), potentially screening patients for mental health disorders, monitoring patient management progress and outcome (Devins, 2010; Finlay *et al.,* 2017). This will be discussed further in the next chapter, which will present the methodology required for developing and assessing the potential of the proposed study tool.

2.19 Conclusion

This chapter reviewed the literature and explored the challenges facing patients with psoriasis and eczema in themes. The themes included presenting the psychosocial and biological evidence on the association between such diseases and psychological and metabolic comorbidities. While the national guidelines for these diseases encourage GPs and dermatologists to screen and treat patient comorbidities, the chapter reviewed the limitations of the dermatology service and the barriers between the service provider and the service user, which impair the development of effective care for such patients. The chapter disclosed unsolved national and international problems in psoriasis and eczema patients' care, presented by patients' and health professionals' feedback through surveys and interviews.

Quality of care and patient safety are central to the successful implementation of a dermatology service. However, based on the above reviewed evidence it is clear that patients with psoriasis and eczema have unmet, unidentified, unscreened or underreported needs as well as psychological and metabolic comorbidities. The chapter highlighted knowledge gaps and health service limitations, reviewed self-management theories and proposed a conceptual framework and a tool to assess patient needs and comorbidities as well as to enhance their involvement in decision making and self-management.

The following chapters will discuss the methodology for assessing the acceptability and the potential of the new study tool by conducting a mixed method study to answer the questions raised from the literature review including: -

1. What needs do patients feel they have?
2. Do they feel that these needs are currently met by their services?
3. How do they think these needs could be met?
4. How do patients experience the service they receive?
5. What is the impact of the chronic disease on patient quality of life?
6. Does offering eczema and psoriasis patients an assessment tool help to support their needs?
7. Do psoriasis and eczema patients accept to use the tool on a regular basis to support their needs?

3. CHAPTER THREE - METHODOLOGY

This chapter presents the methodology and methods related to this research project and discusses why they were used to achieve the stated aims and objectives. After explaining the pragmatic philosophy, which underpinned this research, the chapter specifically focuses on discussing the rationale for choosing mixed methods research to undertake this project and describes the challenges involved in conducting such research. The chapter describes the process of developing the study tool and it ends with a discussion of the values, merits and limitations of the quantitative and qualitative studies within the context of this research. The details of the individual conducted studies in this research and their findings are discussed in the following chapters.

3.1 Introduction

Research methods are procedures or tools for doing research, while research methodology is more closely linked to philosophical issues within the research process (Smith, 1989). Research methodology or strategy includes using specific study designs, who and how to recruit specific participants, ethical strategies, funding status, type and details of the inquiry, the way of data collection and why particular methods are chosen (O’Cathain, Murphy, & Nicholl, 2008).

According to Denzin and Lincoln (2005), a research methodology is determined by the nature of the research question and the subject being investigated. As a result, the research format used in an investigation should be seen as a tool to answer the research question. This research aimed to explore and understand the needs and the challenges of patients with psoriasis and eczema. The overarching goal being to offer patients long-term support and to engage them in decision-making and self-management of their chronic skin diseases. In particular, to help patients identify opportunities to voice the challenges they face in their daily lives and seek or develop coping strategies.

This research sought to engage patients with psoriasis and eczema by providing them with a platform to address their needs and feedback at each healthcare consultation through the use of a tool in the form of a paper questionnaire (study tool). The long-term objective being to involve patients in decision making of their management and offering them an opportunity to develop a sense of autonomy and self-efficacy to structure their needs with respect to the self-management of their chronic condition and relatedness with their healthcare provider.

The research questions have been developed from reviewing the literature including national and international studies conducted on patients with psoriasis and eczema (Dubertret *et al*., 2006; Ersser *et al*., 2010; Krueger *et al*., 2001; Nash *et al*., 2015; Silverberg *et al*., 2018). The compelling narrative from the studies reviewed was that psoriasis and eczema patients have unmet needs and their psychological and metabolic comorbidities were not always assessed or managed (Ahn *et al.,* 2019; Augustin *et al*., 2015; Balieva *et al*., 2016; Barankin & DeKoven, 2002; Dalgard *et al*., 2015; Egeberg *et al*., 2019; Griffiths *et al*., 2017; Hay *et al*., 2014; Langan *et al*., 2012; Na *et al*., 2019; Nash *et al.,* 2015; Nelson *et al*., 2013; 2016; Schmitt *et al*., 2008).

To provide an effective and durable management plan for such patients, first there is a need to understand their views and challenges in coping with their chronic diseases, the impact of the disease on their daily life, their psychological, metabolic and other associated comorbidities and their feedback on the services they have received (Andrew & Halcomb, & 2009; Bhatti *et al.*, 2009; Denzin & Lincoln, 2005). Further, as these chronic skin diseases require long-term health care for a number of years, an assessment tool, intervention or method is needed to assess and monitor the progress and the outcome of their health condition as well as the quality of their healthcare over the follow-up period with their service provider (APPGS, 2013; Monk & Hussain, 2019).

Hence, the proposed intervention or tool needs to be designed and refined in order to engage/involve patients as well as be systematically and extensively utilised for developing improvement initiatives (Boylan, Williams & Powell, 2019). It should reflect the main goals of patient needs, review the various elements of patient feedback ranging from its measurement, predictors for improvement and the impact of collecting patient information to build up strategic, quality improvement plans and/or initiatives to shed light on the magnitude of the subject (Al-Abri & Al-Balushi, 2013; Reeves & Seccombe, 2008).

In the long term the tool is envisaged to provide autonomy and self-efficacy for patients to structure their needs and feedback. At the same time, the tool will provide the opportunity for the organisation managers and policy makers to obtain a better understanding of patient views and perceptions of the quality of the healthcare service that can enhance the extent of their involvement in improving the quality of services such as implementing effective change, replacing old behaviours and/or introducing new ones for better healthcare (Boylan *et al.,* 2019; Burt *et al*., 2017).

Research questions that need to be assessed by the new tool are:

- What are the challenges facing patients with psoriasis and eczema?
- What is the psychological impact of the diseases on their quality of life?
- Are they coping with their chronic incurable skin disease?
- What types of barriers and comorbidities do they have to deal with, if any?
- What are their needs to self-manage their chronic skin illness?
- How do they feel about their healthcare system?
- Would the new intervention or tool be beneficial for supporting their management?

3.2 Aims of the research

The aims and the objectives of this research are summarised in Table-1 (Chapter-1).

3.3 Research philosophy (paradigm and pragmatism):

3.3.1 Paradigm

A paradigm is defined as a set of beliefs and practices that guide a field of research and/or summarise the beliefs of researchers (Morgan, 2007). A paradigm is also defined by a set of distinct elements including epistemology (how we know what we know), ontology (nature of reality), axiology (values) and methodology (the process of research; Hanson *et al.,* 2005).

Researchers are urged to locate their research in a selected paradigm as paradigm differences can influence how we know our interpretation of reality, our values, research questions and methodology or the method we use to answer our research questions (Creswell & Plano Clark, 2011; Doyle *et al.,* 2009).

Historically, research in health care was nearly exclusively of the quantitative (positivist) tradition which was asserted to be objective, unbiased and considered to be the 'gold standard' (Bryant, 2009; Elmousalami, 2019; Fanelli, 2019; Howe, 1985). Positivism claims that there is a single reality and therefore seeks to identify causal relationships through objective measurement in a relatively large sample size and through statistical analysis (Firestone, 1987). Constructivism or qualitative research has emerged as an alternative to the positivist form of inquiry as researchers sought to examine the context of human experience in smaller sample sizes (Schwandt, 2000). Constructivism proposes that there are multiple realities and different interpretations may result from any research endeavour (Appleton & King, 2002).

The difference between the quantitative (positivism) and qualitative (constructivism) paradigm can be summarised in that the former is regarded as an objective process of deduction whereas the latter research is a subjective process of induction that can only be viewed in context (Morgan, 2007). Although, constructivists' approaches can be subjective, their focus is directed at a deeper understanding of what is happening with a smaller sample, and they seek to illuminate the reality of others through the process of detailed descriptions of their experiences (Appleton & King, 2002). In recent years, the qualitative paradigm has received greater attention and has been described as naturalistic inquiry, post-positive, constructivist or interpretative approach (Braun & Clarke, 2019).

The current research sought to utilise both quantitative and qualitative studies to assess patient needs and to understand their views, respectively. However, traditionalists argue that these paradigms quantitative (positivism) and qualitative (constructivism) are not compatible and cannot be mixed as it is not possible to combine the ontological and epistemological stances (Sandelowski, 2001). Nevertheless, it was proposed that mixed methods might represent a third paradigm, which is able to close the gap between quantitative (positivism) and qualitative (constructivism) positions (Johnson & Onwuegbuzie, 2004). This mixing is compatible with the philosophy of pragmatism which advanced the notion that the consequences are more important than the process and the end justifies the means (Dewey, 1931; James, 1907). It advocates eclecticism and a needs-based or contingency approach to research methods and concept selection, so that researchers are free to determine what works to answer the research questions (Johnson & Onwuegbuzie, 2004).

3.3.2 Pragmatism

The word pragmatism comes from the Greek word, meaning “action” from which the English words “practice” and “practical” were derived. Pragmatism is a philosophical movement began in the United States in the 1870s and its origins are attributed to the philosophers Charles Sanders Peirce, William James, and John Dewey (Bryant, 2009; Dewey, 1931). They suggested that there are many different realities and that reality is in a constant state of flux (Stuhr, 1999). They gave more credence to actions than ideas (Thayer, 1982).

They judged something to be good if it has achieved what it set out to do or getting things done (Talisse & Aikin, 2011). Their approach to knowledge construction emphasised practical solutions to answer applied research questions (Giacobbi *et al*., 2005). In his book, *Pragmatism: A New Name for Some Old Ways of Thinking*, William James asked“ *What difference would it practically make to any one if this notion rather than that notion were true? If no practical difference whatever can be traced, then the alternatives mean practically the same thing* ” (James, 1907, p. 45).

As knowledge construction is contextual in nature and influenced by personal, social, cultural, political and historical factors; pragmatists deny there is a single reality and they see no way for scientists to determine whether their theories are closer to the truth than are their colleagues (Dewey, 1931). They claim that the search for some ultimate truth or complete objectivity is irrelevant to our needs and our practices and they prefer to avoid debate about whether constructivistic (qualitative) or positivistic (quantitative) conceptions of truth are more accurate (Giacobbi *et al.,* 2005; Maxcy, 2003).

Instead, pragmatists try to offer practical solutions to contemporary problems experienced by people and society and they test the veracity of facts through dialogue or inquiry (interview), reflection and analysis (Giacobbi *et al*., 2005). They prefer using one or more research methods to answer the specific research question while simultaneously considering the consequences of such inquiry (Dewey, 1931; Firestone, 1987; Glogowska, 2011). At times it is best to use a qualitative method and at other times a quantitative approach. As both methods have strengths and limitations, sometimes it may also be advisable to combine the two approaches (Hardy *et al.,* 1996).

Accordingly, there are many ways of interpreting the truth and undertaking research, including combining both positivist and interpretivist studies within the scope of a single research project (Creswell & Plano Clark, 2011; Saunders, Lewis & Thornhill, 2012). In other words, there is no single point of view that can ever give the entire picture and that there may be multiple and often competing realities (Haack, 2006).

The current research is not aimed to provide a single objective truth about the research topic, but rather to investigate a particular way of looking at and deriving meaning of the phenomenon under investigation. This research deployed two studies on the same population to assess participants' views and challenges from different perspectives and to compare the similarity and dissimilarity of their views (realities) in both studies. The final stage in this research involved presenting the revised model, based on the participants' feedback to a group of specialists in patient care and psychological theory and asking the questions, to what extent does this model address the expressed needs of the patients and from your perspectives whether the model aligned to the aims of the research.

The current research project adopted a pragmatic philosophy because its questions have multiple dimensions that need to be explored, discussed and assessed using different inquires. The pragmatic approach offers practical, moral and ethical consequences of knowledge construction to conduct research (Howe, 1988). As the "objectives justify the means" the pragmatic philosophy focuses on recognising the usefulness of both quantitative study (positivism) and qualitative study (constructivism) and allows these paradigms to be used together on the same population to maximise the strengths and minimise the weaknesses of both studies (Giacobbi *et al.,* 2005). The research also obtained healthcare professionals' feedback on the impact of the proposed online version of the study tool on patient care. Therefore, a mixed method approach can offer greater possibilities than a single method approach for responding to a multidimensional research question (Greene, 2005).

Additionally, the current research aims to make a difference to the patient experience by assessing and identifying the unmet needs of psoriasis and eczema patients and by developing a method or a tool to address and monitor their needs in a way that builds up a patient's sense of self-determination and self-efficacy (Bandura, 1997; Ryan & Deci, 2000). The pragmatic approach to research is informed by the belief that the practicalities of research cannot be driven by theory or data exclusively and a process of abduction is recommended which enables one to move back and forth between induction and deduction through a process of mixed method inquiry (Morgan, 2007).

The research recognises that patient experience within the NHS is time and context specific, which could be influenced by many factors. Given the current context and timeframe, the first objective is to explore the patient experience and ultimately seek to improve it. This research is therefore not seeking the objective truth from the patients but their subjective views on living with chronic skin diseases and on how their perception of the healthcare they have received. The analysis and synthesis of the findings will be discussed in Chapter-6, in relation to the national and international research on similar diseases. This is because the practical truths are those findings that may prove useful within specific contexts and the consequences of inquiry and this is perhaps more important than debating which version of the truth is better (James, 1907).

It is important however, to continue pragmatic and epistemological discussion while using multiple method forms of knowledge construction (Giacobbi *et al*., 2005). As a consequence of the epistemological continuum, the pragmatist often uses multiple or mixed method designs within a single investigation and in an iterative programmatic manner over several investigations (Bryant, 2009). If agreement within a community were established that a specific intervention was improving patient quality of life, then pragmatists would consider such agreement or research findings to approach an objective position (Dewey, 1931). This research obtained the views from independent patient care specialists using a discussion group format (see Chapter-6). Furthermore, if the findings in the current research mirrored the findings reported in the national and international studies, then these conclusions may be deemed objective (Hardy, Jones, & Gould, 1996). Chapter-6 will explore the extent to which the findings concur with those presented in previous national and international research conducted on patients having similar chronic skin conditions.

Mixed-method research involves a combination of procedures where two or more data collection techniques and forms of analyses are used and both contribute to the final results (Tashakkori & Teddlie, 1998). In the current research a sequential mixed method approach was chosen and the results of phase one inform phase two and then phase three, yet neither phase is privileged over the other and each stage of data collection provides useful information to help in identifying the characteristics and experiences of patients' needs and their psycho-social challenges with their skin disease (Talisse, & Aikin, 2011).

There were three phases to this research; the first was a pilot study and subsequent postal survey of the study tool (a paper questionnaire), the second a series of semi-structured patient interviews, and the final stage involved sharing the findings of the research and a proposal of the online version of the study tool with experts in patient care. Each stage was predicated on the findings of its predecessor. The interviews in the current study were conducted after the survey-based study to enhance understanding of participants' emotional responses to failure in the survey and to obtain their opinions on using the study tool (the questionnaire used in the survey) or any other intervention or idea to support their needs (Appleton & King, 2002).

Nevertheless, while mixing methods from different paradigms is possible, desirable, and often productive, the underlying assumptions of various paradigms (i.e., constructivists versus positivism) may contradict one another (Guba & Lincoln, 1994). For instance, a constructivist may use quantitative data but will adopt a subjective epistemology, whilst a positivist who uses a post-experiment interview will do so under an objective epistemology (Creswell, 1994). Additionally, the approach for mixed method research could include using different designs such as multilevel design, which involves collecting quantitative data on one level and qualitative data on another; or dominant-less dominant design, which involves the use of one dominant method while a relatively smaller part of the study uses an alternative method (Doyle *et al*., 2009). Regardless of the design of mixed method, the results should be presented and discussed in a complimentary manner as data collected in stage one can inform data collected in stage two and so on and all elements of the design can make powerful contributions to the literature (Creswell & Plano Clark, 2011).

Within the context of this research project, the pragmatic approach began with a critical literature review, in order to:

- Understand the relationships between the patients and their chronic skin diseases
- Understand the relationships between the patients and their healthcare system
- Provide insight on the proposed research project, away from personal perceptions judgment or philosophy
- Find out what works well for similar studies in order to answer the research question by valuing both the subjective and objective data
- Keeping in mind that academic stance taken is not a personal matter but an intellectual imperative
- Searching online for similar studies to avoid duplication of the same research or facts

(Andrew & Halcomb, 2006; Feilzer, 2010; Maudsley, 2011)

A mixed method approach was designed to respond to identify questions and to triangulate the findings from both quantitative and qualitative data with a view to present robust and credible evidence to the key stakeholders (Saunders *et al.,* 2012). However, because of the Covid-19 pandemic and the changes in NHS policy, including staff redeployment and enforcing national safety measures, a deliberative inquiry could not be conducted with the stakeholders. Such an inquiry would involve presenting and discussing the findings of this research in a meeting with health professionals, patient's representative and commissioners/stakeholders, aiming to reach a decision; whether to pilot the proposed portal system or not. Instead, of the deliberative inquiry the results of the research were presented and discussed with a group of independent healthcare experts, through online inquiry to obtain their views on the proposed patient portal system (chapter 6, study-3).

In short, the current research process followed a serial design where each stage informed the next, Figure 1 below illustrates the process.

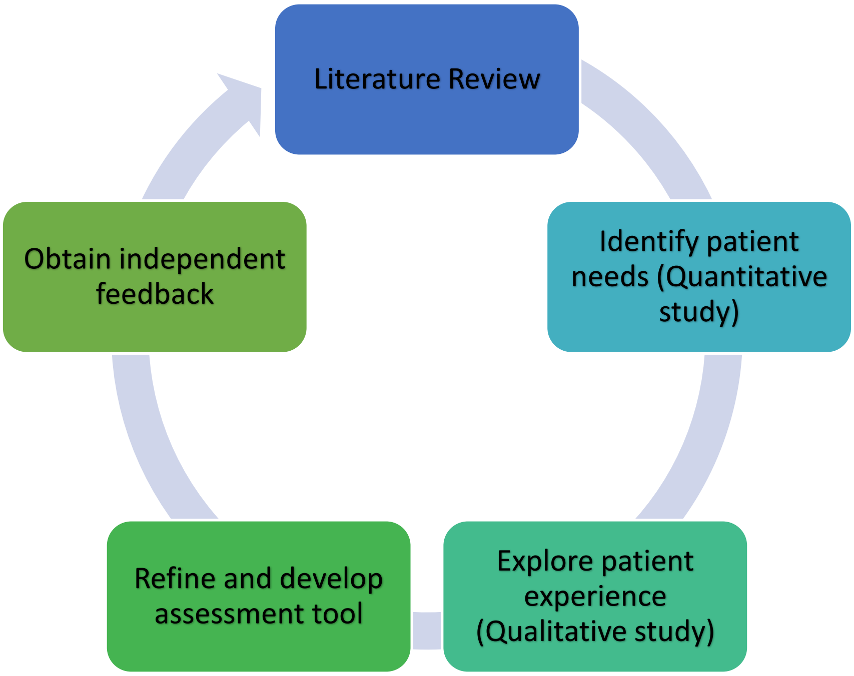


Figure 1: Pragmatic pathway of the research project

This said, a pragmatic research approach could be a demanding task to achieve. It requires time, effort, insights, academic and managerial networking, funding and a broader range of research skills to understand worldwide, cultural diversity and axiology relevant to the research project (Crawford, Candlin, & Roger, 2017; Saunders *et al*., 2012). These challenges will be discussed next.

3.3.3 Axiology

Axiology is the philosophical study of value, which came to be regarded as a tool for the effective processing of ideas and concepts (Ameson, 2009). Axiology is often thought to provide grounds for the study of ethics and aesthetics (Johannesen *et al.,* 2008; Hill, 1984). Aesthetics studies are based on concepts of "beauty" and "harmony", while ethics is the branch of axiology that attempts to understand the nature of morality and investigates the concepts of "right" and "good" in individual and social conduct (Rescher, 2005). Ethical issues arise whenever behaviour could significantly impact another person or be judged by standards of right or wrong (Johannesen *et al.,* 2008). In order to develop ethical practices, axiology was deployed in this research to inform choices in all aspects of conducting communication research (Ameson, 2009).

The ethical questions which need to be considered before conducting this research were: -

(a) What questions are being addressed and are these questions relevant to the individuals being examined and/or society as a whole?

(b) Is the research sample diverse in terms of race, age, ethnicity, socioeconomic status, and sexual orientation?

(c) What implications do the study findings have for diverse groups of individuals? If the findings do not generalise to diverse groups, do the study authors address these limitations?

(d) Are attempts made to disseminate the study findings to people who might benefit from this knowledge (e.g., patients, their family, health professionals) (Whaley, 2001)?

(e) Have the patients, hosting hospital, sponsoring university and the national health research authority’s ethical approval been obtained?

The answers to the above questions will be highlighted in the discussion of the findings of the survey and interview studies in chapters 4 and 5, respectively.

As part of the pragmatic approach in this research, axiology was not only applied to deal with the nature and the types of patients, but with the healthcare provider's values, morals, aesthetics and metaphysics. For the patients, the study patient information sheet (Appendix-I) addressed patient confidentiality and in the questionnaire (Appendix-II) the identity of the participants was removed and replaced by their study number and open-ended questions were provided for the participants to express their views and feedback without restrictions. The open-ended questions are intended to offer the participants the freedom and the autonomy to address their aesthetic and ethical values as well as their challenges incurred by their illness and by the healthcare service (Chapple, 2003; O'Cathain *et al.,* 2004).

Notably, research design decision making was not restricted to situating the research within a research paradigm or approach, it also involved the researchers engaging with their own values and ethics and considering the research from the perspective of others (Goodman, 1995). As a health care professional adopting a dual role of practitioner and researcher several complexities may be introduced to the research process, particularly those around power and knowledge (Bishop, 2007). Although the participation in the research was voluntary, most of the participants were under my care. Even if I take the utmost precautions to minimise sampling bias, I still cannot avoid other types of bias related to the responses of the participants (Mays & Pope, 2000). Response or acquiescence bias could occur as I might use my own judgement, belief, perception, expectation, and values, to make my own prediction and I could influence the response of the participants, especially in a face-to-face interview (Babbie & Mouton, 2001). The participants may perceive that my position and knowledge are more accurate or scientific than their own knowledge or they may feel under pressure to provide a positive response. They may feel uncomfortable challenging my personal approach and providing honest responses (Britten, 1995). Extreme responding bias could occur as they might choose only the most extreme options on the scale-type of a questionnaire (question-7, Likert type in Appendix-II). Nonresponse bias might occur as large groups of patients who were invited to participate in the survey did not participate. Their responses might significantly and systematically differ from those who did (Chew-Graham *et al.,* 2001). Information bias could occur from any misrepresentation of truthfulness that occurs during the collection, handling, or analysis of data in a research study, survey, or an experiment. Some of the most common forms of information bias include misclassification bias, recall bias, observer bias, and reporting bias (Wisdom *et al*., 2012).

To minimise such biases, a patient information sheet highlighting the confidentiality process was used in the survey (Appendix–I). Appendix-II (study tool), contains open-ended questions to offer the participants the freedom of expression away from the researchers' values and judgement. Two academic supervisors continuously assessed the research. All the phases of the research process were reported in detail in the following two chapters, for the readers to assess the quality of the research methodology (Leedy & Ormrod, 2015).

3.3.4 Cultural Diversity

Cultural diversity represents appreciating that society is made up of many different groups with different interests, skills, talents, and needs (Crawford, Candlin, & Roger, 2017). It also means that we recognise that people in society can have differing ethnic backgrounds, religious, personal beliefs, age, gender, and sexualities (UNESCO, 2002). Reflecting on issues pertaining to equality and diversity may be of particular importance in health research, while ignorance of key cultural differences may have the potential to cause harm and distress to the investigated population (Atkins, 2016).

As chronic skin diseases such as psoriasis and eczema are globally prevalent and can affect all cultures, this mixed methods study included adult patients from diverse backgrounds living in northeast London. The diversity can provide wider and less biased views from patients with different backgrounds, but having similar diseases, on their challenges with their illnesses and their feedback on the healthcare service they received (Crawford *et al*., 2017)**.**

Adopting a pragmatic approach has also helped to recognise different realities, cultural differences, and injustices in each background throughout the research process (Creswell & Plano Clark, 2011). Deploying quantitative and qualitative methods with patients with chronic skin diseases with different variables of age groups, genders, beliefs and ethnic backgrounds has underpinned multiple aspects of the social world and provide deeper levels of exploration and understanding of the wider view from different groups (UNESCO, 2002). However, mixed methods can also create various tensions and oppositions that reflect the various ways of understanding the world (Maudsley, 2011; McEvoy & Richards, 2006).

Nevertheless, the implications of not considering cultural diversity or a culturally informed approach can impact on the study questions, objectives, design, validity and the generalisability of the survey and interviews. It can also impose limitations on the quality of the data collected, and on the feasibility and practicality of translating research findings into practice (Denscombe, 2008; Denzin & Lincoln, 2005; Elmousalami, 2019).

In order to minimise selection bias, the recruitment process of the participants in the postal survey and in the interviews included enrolling consecutive male and female adult patients with psoriasis and eczema managed by a dermatology department in a district hospital. Regarding the backgrounds of the participants in the survey, only age and gender were used as the tool is designed for clinical purposes and not for research and asking more personal or demographic questions may deter the patients from participating in the survey (Edwards *et al.,* 2002; Iglesias & Torgerson, 2000; Sahlqvist *et al.,* 2011). Demographic data however can be obtained from the patient NHS digital profile (Boynton & Greenhalgh, 2005).

3.4 Mixed Methods Research – benefits and challenges

3.4.1 The rationale for choosing mixed methods research

Mixed methods research is a methodology for conducting research that involves collecting, analysing and combining quantitative and qualitative data within a single study aiming to have a better understanding of the research problem (Creswell & Plano Clark, 2011). A mixed method study can offer detailed exploration of a complex research problem better than that generally expected from using either type alone (Denscombe, 2008; Wisdom *et al.,* 2012; Zhang & Creswell, 2013). The strengths of one method in a mixed methods study can be used to overcome the weaknesses of another method and can add insights and understanding and increases the generalisability of the results that may otherwise be missed in using a single method (Wisdom *et al*., 2012).

Mixed method studies can be useful in both theoretical and applied research. In theoretical research, scholars can conduct an inquiry to expand what we know about human communication, while in applied research, scholars seek to solve human problems (Glogowska, 2011; Hayes, Bonner, & Douglas, 2013; Rescher, 2005).

As pragmatic philosophy underpinned this research, using both qualitative and quantitative methods can offer a more robust data and outcome than using a single method in answering the research question (Bryman, 2006; Creswell & Plano Clark, 2011). The goal of this research is to understand psoriasis and eczema patients' experiences with the disease, assess and support their needs by offering them the study tool (a paper questionnaire with open-ended questions; Appendix-II) to address their feedback, needs and comorbidities. However, before implementing such interventions, the acceptability and the potential of using such a tool needs to be put to the test (Al-Abri & Al-Balushi, 2014).

To achieve such a goal a postal survey was first conducted using a paper questionnaire (the study tool) which contains seven open-ended questions and the DLQI (Appendix-VI). The objective of adding the open-ended questions was to offer the patients a platform and the autonomy to be involved in the decision making of their management and to write freely their experiences with the disease and with the health service including their comments, complaints, comorbidities and feedback to explore the depth of their daily challenges with their chronic skin diseases as well as to express their individual needs that may not be discussed in the routine dermatology outpatient consultation. The open-ended questions were reported to be better in gaining more understanding than could be offered from closed-ended questions, which may fail to investigate the factors that impact on individuals accessing the service (Andrew & Halcomb, 2009; Jenn, 2006; O'Cathain & Thomas, 2004).

Further, conducting interviews with psoriasis and eczema patients who participated in the survey offered a deeper understanding of patients' needs and challenges with their chronic diseases and revealed their personal view on using the study tool or using any alternative method at each consultation to address and support their unmet needs. Without the interview this information may not be clearly obtained/confirmed in the survey. Furthermore, the interview helped to discuss patients' specific wishes e.g., the majority of the interviewees wished having an online version of the study tool or a patient portal system. Indeed, after the interview my supervisors and I designed a proposal of a portal system, which was presented to an independent group of healthcare experts for their review, advice and comments (chapter 6, study 3).

The rationale for choosing a mixed method study can be summarised by the following points:

- To expand the breadth, depth, and range of the research on patients with chronic skin diseases from diverse backgrounds by using different methods and different ways of inquiries to obtain more comprehensive results.
- To converge, corroborate, validate, and triangulate results from quantitative and qualitative methods to minimise the risk of bias.
- To enhance and clarify the results of both studies in a complementary manner rather than judging each study separately.

- To look for contradictions and new perspectives. The results of one method may be used to examine and change the questions for the other method or to obtain divergent information.
- To provide different prospective and tangible evidence from more than one inquiry.
- To assess the potential of the new tool by using it through different inquires.
- To inform any necessary amendment in the study tool based on the findings of both studies.

3.4.2 Mixed methodology versus other methodologies

A mixed method approach was preferred to using other types of research methods such as cohort study and case control studies. The latter studies are usually deployed to identify the cause or the aetiology of a disorder (Song & Chung, 2010). They may not be appropriate to explore the views and challenges of patients with chronic diseases on managing their illnesses or to motivate them to adopt a new behaviour or to obtain their opinion on using a new intervention to support their needs on a regular basis (Sacristán, 2015).

Similarly, a clinical trial may not provide answers to the current research questions and is not feasible to be conducted in this setting as the literature review showed that the study tool has not been utilised or implemented before within a dermatology service in the UK. However, a clinical trial may be appropriate to be conducted after approving and implementing the new tool in clinical practice to compare the effectiveness of using the novel study tool with the current standards of care (Feilzer, 2010; Wisdom *et al.*, 2012).

A mixed method study was also preferred in this research to using “multi-method” research as the latter involves data collection using two or more methods (e.g., interviews and focus groups, surveys and medical record audits). The latter may not answer the same research questions and triangulate the findings on the same population (Andrew & Halcomb, 2009; Bryman, 2006; Feilzer, 2010). In contrast, this research combined qualitative and quantitative characteristics across the research process to answer the same research questions on the same population, from the philosophical underpinnings to the data collection, analysis and interpretation phases (Mays & Pope, 2000). Nonetheless, as in the pragmatic philosophy, reality might change and can be influenced by many variables, hence a mixed study might need to be repeated at different times and in different settings to assess the validity and the reliability of its findings (Denscombe, 2008; Mays & Pope, 2000).

3.4.3 Mixed method data collection

Data collection methods in a mixed method study can include various forms of surveys (online surveys, paper surveys, mobile surveys or kiosk surveys), interview (face-to-face, telephone or online), longitudinal studies, website interceptors, online polls and systematic observations of other defined variables (Britten, 1995; Opdenakker, 2006; Sturges & Hanrahan, 2004). However, although data from several studies can provide a more comprehensive outcome than using either quantitative or qualitative research alone, it can be subjected to criticism (Denscome, 2008; Creswell & Plano Clark, 2012). The power of quantitative data often correlates with the sample size of the participants yet recruiting a large number of participants may not always be feasible (Lavelle *et al*., 2013; Wisdom *et al*., 2012). Equally, the data in a qualitative study is often considered as subjective, unreliable, cannot be generalised or replicated and is ambiguous or has contradicted views which may reflect social reality and diversity (Andrew & Halcomb, 2009; Feilzer, 2010). Indeed, there were a number of challenges to consider and to resolve while planning and undertaking this mixed method research.

3.4.4 The feasibility and skills of undertaking a mixed methods study

Conducting a mixed method research project within the NHS setting may face many barriers such as time, space, place, privacy within the working environment, staffing, service approval (including hospital's research departments and local ethical committee approval), lack of funding or resources (Doyle *et al.,* 2006). Consideration should therefore be taken in terms of balancing the benefits of the research design against the limited resources and skills required (Andrew & Halcom, 2009). Nonetheless, the benefits of mixed methods design in this research project provided a more detailed understanding than could be gleaned from a single perspective and helped to provide a novel and practical health assessment intervention for patients with chronic skin diseases that can support them remotely, especially within the current COVID-19 pandemic.

Apart from the cross-sectional survey, the addition of qualitative data in this research acted as a complementary approach to explore and confirm patients' experiences of the health service and added significant depth to the understanding of patient perspectives. This said, time, skills, and knowledge were needed to organise and conduct face-to-face interviews with the patients and conduct an online inquiry with healthcare experts (Andrew & Halcom, 2009; Maudsley, 2011). These activities may require networking and linking with the participants and the medical staff, spending extra hours reading, searching, writing and travelling to different sites, incurring additional time and expenses (Bryman, 2006; Maudsley, 2011; McEvoy & Richards, 2006; Wisdom *et al*., 2012).

3.4.5 Designs for mixed methods

Mixed method designs can vary at the point at which the qualitative and quantitative are integrated (Bryman, 2006; Glogowska, 2011). Exploratory studies usually privilege qualitative data, while explanatory studies often prioritise quantitative data (Andrew & Halcomb, 2009). However, various approaches can be used to brace the research questions and mix both qualitative (why?) and quantitative (how often?) questions. (Maudsley, 2011). Though it is vital to understand the implications of the different designs and the extent to which the qualitative and quantitative data interact with each other or are to be kept independent (Creswell & Plano Clark, 2011). Establishing the relative priority of each type of data prior to commencing the study is particularly important if contradictory results are found (Bryman, 2006).

Additionally, choosing a data collection design to combine narrative and numerical data can be a challenging task without the used design being consistent in its criteria (Bryman, 2006; Creswell & Plano Clark, 2012). For example, in simultaneous (concurrent) design, both qualitative and quantitative data are collected at the same time. This can reduce the duration of the data collection, but equally it can be resource intensive and may not allow either data collection to inform the other (Andrew & Halcomb, 2009). In contrast, a sequential design in this study involved qualitative and quantitative data being collected separately. The findings from one type of data collection can provide a basis for the collection of a second set of data (Hayes *et al*., 2013). The disadvantage of such designs however is that they take longer for data collection to be completed (Doyle *et al.,* 2006). Indeed, this research followed the sequential approach and the whole duration of preparing and conducting a sequential design in this research took almost one and half years to be completed.

The sequential design in the current research looked at the research problem from different perspectives aiming to offer collaborative evidence and a clearer picture to answer the research question when analysing results. Additionally, one of the objectives of the research is to assess the potential of a new tool in supporting patients' needs. Hence, the survey was conducted first to assess the ability of the new tool in measuring the dimensions of the problems facing people with chronic skin diseases, their explicit views and perspectives. This was followed by an interview study to obtain a direct and deep understanding of the participants' needs and feedback and their opinion on using the new tool at each consultation to address their needs or whether they would prefer using any alternative method to support the management of their chronic illness. The sequential design offered the participants more time to think and reflect on the advantages and disadvantages of the new tool (Johnson & Onwuegbuzie, 2004).

3.4.6 Project development and management

The quality of any research will in part depend on effective and pragmatic management of the research project by the investigators (Creswell & Plano Clark, 2012). Developing a mixed methods project requires careful planning and management of the chosen design (Bryman, 2006). The research project began with a survey to investigate the research proposal "can the study tool help to assess and address patients' needs?" The survey generated both numerical and narrative data of investigated phenomena. It quantified the problem by generating numerical data that can support or deny the research hypotheses (Fanelli, 2019). The survey was followed by interview research, which provided a systematic inquiry into the social phenomena that included but was not limited to how patients experienced aspects of their lives and how interactions with their healthcare provider shaped their relationships (Teherani *et al*., 2015). The interview provided an interpretative, naturalistic approach to the subject matter that helped to understand the meaning of people's experience in order to develop a holistic picture of the phenomenon in question and making predictions about the investigated setting (Denzin & Lincoln, 2005).

The main key practical implications for project management were resources, time and data management (Simon & Lathlean, 2010). The collection of two datasets rather than one has implications on the time to manage the research project (Doyle *et al*., 2006). The allocation of sufficient time was essential to the successful conduct of the project, particularly in this sequential research, as it required incorporating sufficient time for the collection and analysis of one data set before commencing the second data collection. Failure to allocate this time may result in the second data collection not addressing key issues that arose from the first data set (Creswell & Plano Clark, 2011). In contrast, collecting both qualitative and quantitative data will lead to a larger and more complex dataset than that collected in a purely qualitative or quantitative project (Andrew & Halcomb, 2009). The complexity is also increased when qualitative and quantitative data were being integrated within the analysis phase as this has implications for the time required in data analysis, the range of skills required to manage the data and the resources required for data storage (Bryman, 2006;

Maudsley, 2011). In this research, the study data was managed and stored as e-files within the NHS computer drive of the researcher, which is exclusive to the researcher and is password protected. All the materials used in this research are to be kept in a secure place at Barking, Havering and Redbridge University Hospitals (BHRUH) for 5 years and in line with the Data Protection Act 1998 (Ford, 1999; please also see ethical approval page 228).

3.4.7 Strategy for mixing quantitative and qualitative studies

Despite the importance of mixing data within mixed methods research, the strategies used for mixing should be clearly articulated within research reports and publications (Bryman, 2006; Maudsley, 2011). A key consideration in planning mixed methods research is evaluating which model is appropriate for investigation and building this into the research design prior to commencing the study (Bryman, 2006; Feilzer, 2010).

In their review of how mixing occurs in health services research, Zhang and Creswell (2013) identified three distinct procedures for mixing within the mixed methods literature, namely, integration, connection or embedding. These approaches are not mutually exclusive, and some projects may combine methods of mixing within the design (Creswell & Plano Clark, 2011). The integration of quantitative and qualitative research can occur at any stage of the research process and often depends on the research question. In the convergent research question, both data are collected together to triangulate the findings and to answer the research question (Bryman, 2006; Maudsley, 2011).

Nonetheless, whilst the use of mixed methods can enhance validity, it is necessary to demonstrate rigour using the same criteria as would be used in a quantitative and qualitative investigation, as well as specific mixed methods criteria (Bryman, 2006). This can provide a clear audit trail and a well justified rationale for the decisions made throughout the research process (Lavelle *et al*., 2013). In this research, both studies used the same inclusion and exclusion criteria and the same eligible participants to answer the research question. This helped to reduce the ambiguity of the findings during the synthesis process (Zhang & Creswell, 2013).

Incorporating the findings of both studies, showed that the survey demonstrated the benefits of using the study tool in addressing participants' views, needs and comorbidities associated with their chronic skin diseases, whilst the interviews explored and confirmed the dimensions of the unmet needs and provided patients' personal views on using the study tool on a regular basis. The interviews helped to determine areas of agreement and areas of divergence in participants' views and increased the confidence in the research data and in understanding an investigated phenomenon (Lavelle *et al*., 2013; Thurmond, 2001).

3.5 Study tool (paper questionnaire) development

A questionnaire is a list of questions or items used to gather data from respondents about their attitudes, needs, experiences, views, or opinions (Kishore *et al*., 2021). When data is gathered from a representative sample of a defined population, it may allow the inference of results to the wider population (Ogden *et al.,* 2008).

Since the early 1920s, applied methods of questionnaire construction have been subject to influences from both within and outside psychology (Oosterveld, 1996). Later, the development of statistical techniques contributed to the development of more complex construction approaches, that take into account the relationship between measurement and behaviour (Likert, 1932). The emergence of a formal test theory encouraged the development of methods combining theory development and scale construction (Thurstone, 1929; Guttman, 1944). The increase in psychological knowledge, and the shift from behaviourism to cognitive psychology, contributed to the development of construction methods that are based on content analysis and empirical research into relations between concepts (Cronbach & Meehl, 1955).

Questionnaire construction is usually defined in terms of item selection, or scale construction (Hase & Goldberg, 1967). There are however a range of scales and response styles that may be used when developing a questionnaire (Ogden *et al.,* 2008), though they have their advantages and disadvantages (Zamanzadeh *et al.,* 2015). The item wording can be based on typologies or global descriptions. The material collected by means of interviews may provide suggestions for item content. A separate review phase may be incorporated in the process of item construction such as expert judges provide the preliminary item pool, to assure the face validity. The relevance of the item to the measurement should be reviewed and assessed in order to delete poorly rewritten items (Rattray & Jones, 2007).

3.5.1 Process of developing a paper questionnaire

In this research the process of developing and designing the paper questionnaire (study tool) included the following steps: -

1. Defining the studied population (e.g., patients with psoriasis and eczema).
2. Define the problems to be addressed (e.g., assess psoriasis and eczema patients unmet need, comorbidities and feedback and offering them the opportunity to be involved in decision making and self-management).
3. Decide what will the questionnaire measure? (e.g., comorbidities, needs, feedback, coping status, treatment detail).
4. Decide what types of scale can be used? (e.g., Frequency, Thurstone, Rasch, Guttman, Mokken, Likert, Multiple choice or self-developed questionnaire). This research adapted one item from Likert scale (Appendix II, item 7).
5. Decide how to generate items for the questionnaire (e.g. relevance of items to research question, short items if possible, clear simple language, wording issues, simple response format, free text options, consider recall bias, avoid double negative, word the question as naturally as possible, check questions if accurately address/measure research objectives, anonymity, avoid leading question as it can guide respondents towards answering in specific ways, avoid sensitive or unclear questions, avoid double-barrelled questions as they can be harder to understand (Kishore *et al.,* 2021).
6. Any question beyond the scope of the research should be excluded, otherwise the information gathered would build on ambiguous or biased questions.
7. Decide using open-ended and closed-ended questions. Closed-ended questions are easy to complete but may limit or restrict the depth of participant responses. Open-ended

questions were preferred as the answer options can be multiple or unknown. Open-ended questions can motivate the patients to express their needs and offer choice and autonomy to the respondents to express their challenges and barriers in managing their chronic disease (O'Cathain & Thomas, 2004; Riiskjaer *et al.,* 2012; Takemura *et al.,* 2005).

8. Decide using self-administered paper questionnaire, online questionnaire or both.
9. Valid questionnaire (should ask what it intends to ask and phrased in such a way that the respondent understands the objective of the question; Ogden *et al.,* 2008).
10. Reliable questionnaire (should yield the same answer if the same question is posed to the respondent repeatedly in a short span of time; Boynton & Greenhalgh, 2005).
11. Proofreading to correct grammar and spelling mistakes. Avoid unclear questions, redundant words, overly complex language, jargon, ambiguous or awkward phrasing (Kishore *et al.,* 2021).
12. Questionnaire layout e.g., placing questions in a useful order or in a logical sequence (Takemura *et al.,* 2005).
13. Desk check to assess question quality, coding the responses and further proofreading (Rattray & Jones, 2005).
14. Identify the number of questionnaires that need to be distributed in the survey by choosing an appropriate sampling method to (e.g., Solvin's formula). Using large sampling size may enable researcher to generalise results and reduce sampling bias, but it may require more time and funding (Rattray & Jones, 2007).
15. Ethical approval required before using the questionnaire (Kishore *et al.,* 2021).
16. Assess administration (cost, time to perform and data analysis).
17. Pretesting the questionnaire (e.g., by colleagues, supervisors) can help you catch any errors or points of confusion before performing the survey (Rencz *et al*., 2021).

18. Pilot study; although statistically underpowered, it can help testing the acceptability of the questionnaire by the participants, and whether it requires further assessment and amendment (Boynton & Greenhalgh, 2005).

(Kishore *et al.,* 2021; Jenn, 2006; Ogden *et al.,* 2008; Rattray & Jones, 2007).

3.5.2 Selecting the items for the questionnaire

Item bank was created based on the literature review, which showed that patients with psoriasis and eczema in the UK have unmet needs, and their psychological and metabolic comorbidities are not routinely screened or managed (APPGS, 2013; de Vere Hunt *et al.,* 2021; Nash *et al.,* 2015; Nelson *et al.,* 203,2016; The King's Fund, 2014).

The patients' feedback in the national survey (Nash *et al.,* 2015), and in qualitative studies (de Vere Hunt *et al.,* 2021; Ersser *et al.,* 2010; George *et al*., 2021) showed gaps in the management of psoriasis and eczema patients and unsolved problems including:

- Participants were dissatisfied with their treatment regimes.
- They felt that they were under-informed, and their skin disease treatment was not targeted to their needs.
- The respondents did not trust their GP's diagnosis and requested referral to a dermatologist.
- They were given an incorrect initial diagnosis of psoriasis by their GPs.
- They were not offered adequate information about their skin disease.
- They were not provided with sufficient information about their disease treatments.

- They reported that they were not offered different treatment options.
- They did not feel they were included in the decision-making process about their treatment.
- They requested more time, support and the opportunity to ask questions during the consultation.
- The majority of the participants acknowledged that stress was a trigger for flare-ups of their skin disease, but there was lack of available support for those experiencing emotional distress.
- Topical therapy was the most commonly prescribed and yet patients found them difficult, unpleasant, time-consuming to manage and ineffective. This type of treatment was deemed sticky, messy and impractical.
- Biological therapy was the favoured treatment for the respondents but cannot be offered as a first line therapy (Nash *et al.,* 2015)

- Adult patients with psoriasis in the UK perceived GPs to be lacking in confidence in the assessment and management of psoriasis and both patients and GPs recognised that psoriasis was not being managed as a complex long-term condition. Opportunities were missed in consultations to support patients with psoriasis to understand comorbidities such as CVD and to promote risk reduction. Lifestyle Behaviour Change (LBC) was important in psoriasis management, but clinicians felt that it was not their role to facilitate LBC. Clinicians identified a need for training to enable the incorporation of LBC support activity into psoriasis services (Nelson *et al.,* 2013, 2016).

- Young patients (aged 15–24 years old) with eczema and psoriasis living in the UK felt that clinicians need to address the emotional impact of psoriasis and eczema, give more information, appreciate patient research and offer choice in treatment. They felt lack of consultation structure and conflicting advice. They also felt dehumanised and asked to be treated as a person and for GPs to think about how treatments will affect their daily lives (de Vere Hunt *et al.,* 2021).

The selection of the questionnaire items was based on the above service gaps and problem statements, which reflect patients' unmet needs, undertreatment or dissatisfaction with their healthcare service. It was also based on NICE guidelines, which recommended assessing patients' comorbidities in addition to managing their skin disease (NICE, 2007, 2012).

However, without understanding patients' needs, it may be impossible to support their care or offer them a successful management or self-management plan (Alsaadi *et al.,* 2019; Bodenheimer *et al.,* 2002; Barlow *et al.,* 2002). Hence, the items selection process was not exclusively based on specific theory or was adapted from previous assessment scales, but it was self-developed and focuses on understanding patients' needs, comorbidities, coping status and challenges with their chronic diseases and with their health service. The study tool is also aimed to regularly engage/involve patients in decision making and self-management.

Apart from item 7 in the study tool, which is adapted from the Likert scale, all the other items in the questionnaire were open-ended. The use of open-ended questions is preferred in a questionnaire if the answers to its items are multiple or unknown (Barnett *et al.,* 2008). They can offer the patients the autonomy and the choice to be actively involved in their management and provide their feedback freely (Riiskjær *et al*., 2012). They were found to be positively related to the amount of information elicited from the patients (Takemura *et al.,* 2005), and they also facilitate and inform any further necessary amendment of the questionnaire items (Kishore *et al*., 2021; Jenn, 2006; Ogden *et al.,* 2008; Rattray & Jones, 2007). Equally, they can enable the service provider to gather data on different aspects and domains of the service users that should be addressed and/or managed such as patients' treatment preference, comorbidities, service gaps, psychological support and self-management barriers (Ozuru *et al.,* 2013).

Within each open-ended question there are categorical items for the patients to select. The responses to these items will be pre-coded and analysed using a spreadsheet to generate quantitative data on patients preferred topical therapy, comorbidities, self-medication, alternative therapy, coping status, coping mechanisms, disease triggering factors and patients' needs. Question seven adapted the Likert scale to measure patients' views of their GPs or dermatologists (Appendix-II). The questionnaire included the following items: -

1- The first item in the questionnaire was inquiring patient's response to topical medication. This is the first line treatment offered to patients with psoriasis and eczema (NICE, 2007, 2012). Nash and colleagues reported that topical therapy was the most prescribed in the UK for psoriasis patients, but patients found such therapy was difficult, unpleasant, sticky, messy, impractical, time-consuming to manage and ineffective (Nash *et al.,* 2015). The response to this item can be cost-effective as it can assist the physician to check patient's adherence and treatment preference and decide whether topical therapy needs to be replaced by more effective treatment for self-management (Clark *et al.,* 1991; Jauhar *et al.,* 2019; Woolf *et al.,* 2005).

2- The second item was to assess patient physical, psychological and metabolic comorbidities. Screening and management of early comorbidities is not routinely preformed in all dermatology clinics (Nelson *et al.,* 2013, 2016), yet early treatment of certain comorbidities (e.g., psoriatic arthritis) can prevent lasting damage and/or reduce disabilities (Lorig, 1982, 1996). Equally managing comorbidities can support patient's self-management (Hodkinson *et al.,* 2020; Holman & Lorig, 2000).

3- The third item was to assess the types of alternative treatments used by the patients including antidepressant. This information can assess the efficacy or failure of the current treatment in controlling patients' symptoms or their personal efforts to self-manage their disease. It can also reveal the types of patient's preferred self-management, which may not routinely be discussed in the clinical consultation (Goodman *et al.,* 2022; Muth *et al.,* 2019)

4- The fourth item investigates the triggers for patient's skin disease flare, which need to be discussed and eliminated when possible. Nash and colleagues' survey reported that most of the participants acknowledged that stress was a trigger for flare-ups of their skin disease yet there was a lack of available support for those experiencing emotional distress (Nash *et al.,* 2015). Controlling/managing triggering factors of the disease can improve the management and self-management outcome (Jauhar *et al.,* 2019)

5- The fifth item investigates the coping mechanism of the patient with the stress. This item can also reflect the failure of the current treatment or the efforts of patients to self-manage the symptoms related to their chronic condition (Rosland *et al.,* 2012). It can inform the physician to review the patient’s current treatment and discuss, assess or manage the psychological comorbidity of the disease (Muth *et al.,* 2019).

6- The sixth question inquires about coping status with the chronic disease. Inability to cope with the chronic disease can affect patient’s productivity, personal and social life (Rid *et al.,* 2017). The response to this item can assist the physician to identify and discuss the type of support/needs necessary for the patient to deal with the chronic disease and its self-management (Allegrante *et al.,* 2019).

7- The seventh item is adapted from the Likert scale and it assesses patient feedback of their GP and dermatologist. Such feedback can assist the service provider to review the quality of their service aiming to address and improve patient care and patient-physician relationship. Productive patient-professional interactions based on autonomy, shared goals, education, communal knowledge, choice and mutual respect (de Zoysa, 2013), can play a role in patient self-management (Bodenheimer *et al.,* 2002; Newman *et al.,* 2004; Woolf *et al.,* 2005).

8- The eighth item assesses patients’ unmet needs at home, work or within the health service. These needs can support patient’s self-management and should be discussed/managed before prescribing medication to the patients. Failing to support patients’ needs can impact on their adherence to the treatment, self-management and/or treatment outcome (Clark *et al.,* 1991; Warsi *et al.,* 2004).

The final question was followed with a free text field allowing the patients to write any comment or idea that could support the management of their skin condition. This was then followed by the DLQI scale to assess QOL at each consultation (van de Kerkhof, 2006).

The use of open-ended questions was proposed to offer a platform and autonomy to the patients to express their needs and views and to engage/involve them in decision making and self-management of their chronic skin disease (Boynton & Greenhalgh, 2005; Chapple, 2003; Kishore *et al.,* 2021; O'Cathain & Thomas, 2004; Ogden *et al.,* 2008).

As discussed in the last chapter, there are multiple tools available in the dermatology service to assess patients with psoriasis and eczema such as DLQI, PEST, PASI, SCORAD (please see chapter 2.9). In reality however, these tools are rarely used, except for patients who require or having systemic medications. These tools also have limitations. They do not assess all aspects of patient's emotions, comorbidities, coping status, challenges, feedback and needs (Edwards & Imison, 2014). Equally other tools were developed for dermatology assessment, such as the Person-Centred Dermatology Self-care Index (PeDeSI; Cowdell *et al.,* 2012) and the Patient Benefit Index (PBI, 2000). These tools focus on assessing patient knowledge and management but are not designed to assess patients' comorbidities and needs. Their uptake remains limited so as quality of life tools.

> "*A number of tools designed to assess patients' quality of life* (often in the form of a questionnaire) *have been produced over the years, however uptake of these is still patchy and there remains confusion as to what to do with the results. Some quality-of-life measures do not ask about distress and thereby minimise the actual measured impact on psychological wellbeing. The psychosocial impact of skin disease should be taken into account by clinicians and when considering treatment and management options."* (APPGS, 2013 p. 11).

However, adding the QOL scale to the study tool can complement and enhance the potential of the tool in assessing different aspects of patients medical and psychological status, care, rehabilitation and outcome.

> "*Quality of life measures should be used, and the results incorporated into health-service planning when assessing priorities*." (APPGS, 2013 p. 11).

Indeed, thirteen members of the EADV Task Force on Quality of Life, eight dermatologists, three health psychologists, one epidemiologist and one pharmacoepidemiologist, independently listed all of the ways they thought QOL assessment may be advantageous. A total of 108 different ways of using QOL information in clinical practice were suggested and were classified into 20 descriptive groups. These were sorted into the following five categories: inform clinical decisions, clinician–patient communication, awareness of skin disease burden, informing the consultation and clinical service administration. The wide range of potential benefits identified may not only encourage clinicians to use these measures but also highlights many areas requiring evidence to establish the true value of routine use of QOL measures (Finlay *et al.,* 2017).

Problems revealed by patients' self-reported QOL may lead to modifications and improvement in treatment and care or may show that some therapies offer little benefit (Both *et al.,* 2017). QOL is also used to identify the range of problems that can affect patients. This kind of information can be communicated to future patients to help them anticipate and understand the consequences of their illness and its treatment (Haraldstad *et al.,* 2019). Patients with a long-term condition such as psoriasis or eczema may have continuing problems long after their treatment is completed. These late problems may be overlooked without QOL assessment (Staquet *et al.,* 1996). QOL is also important for medical decision-making as it can be a predictor of treatment success and is therefore of prognostic importance. For instance, QOL has been shown to be a strong predictor of survival. This prognostic ability may reflect the benefits of using QOL assessment in clinical trials (Fayers, P. M., & Machin, 2016). More information on QOL will be discussed next.

3.5.3 Quality of Life

Defining “quality of life” (QOL) and measuring progress toward meeting this goal have been elusive as the term QOL contains multi-scale and multi-dimensional interacting objective and subjective elements (Costanza *et al*., 2007).

The concept of QOL may go back to 1947, when WHO defined QOL as “a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity”. (WHO, 1947 p13). In 1949, Karnofsky outlined that the evaluation of new chemotherapeutic agents in cancer patients should include not only performance status, length of remission, and prolongation of life, but also the patient’s subjective improvement in terms of mood and attitude; general feelings of wellbeing; and activity, appetite, and the alleviation of distressing symptoms, such as pain, weakness, and dyspnoea (Karnofsky & Burchenal, 1949). These subjective improvement criteria can be recognised as QOL considerations (Aaronson, 1988).

Prior to the WHO definition of QOL, in 1943 Abraham Maslow published his paper a "A theory of human motivation" and proposed that people have a hierarchy of psychological needs in the form of a pyramid, with basic physiological needs (e.g., air, food, water, sex, sleep, excretion), at the base of the pyramid followed upward by safety, love/belonging, esteem, cognitive needs, aesthetic needs, self-actualisation, and transcendence at the top of his pyramid of needs (Maslow, 1943). Later, in 1962, Maslow established a theory of quality of life, which based his theory for human motivation and development towards happiness and true being on the concept of human needs (Ventegodt *et al.,* 2003).

QOL may represent the extent to which objective human needs are fulfilled in relation to personal or group perceptions of subjective well-being (Costanza *et al*., 2007). An individual's needs can represent the costs of being human within a society and if a person who does not have his needs fulfilled may function poorly in society (Gough, 1994). Doyal and Gough point to twelve broad categories of "intermediate needs" that define how the needs for physical health and personal autonomy are fulfilled (Doyal, & Gough, 1991). Similarly, Ryan and Deci, claimed that humans have 3 essential psychological needs (autonomy, competence and relatedness) missing one or more of these needs may affect mental health/QOL (Ryan & Deci, 2000).

In 1999, Sprangers & Schwartz proposed a theoretical model to predict changes in QOL “response shift” as a result of: (a) changes in the respondent's health status; (b) individual’s personality; (c) mechanisms, encompassing behavioural, cognitive, or affective processes to accommodate the changes in health status; and (d) changes in the meaning of one's self-evaluation of QOL resulting from changes in internal standards, values or conceptualisation.

They recommended testing QOL hypotheses domains and the clinical and psychosocial conditions would potentiate or prevent response shift effects (Sprangers & Schwartz, 1999).

In 2003, Ventegodt and colleagues claimed that their integrative quality-of-life (IQOL) theory, is a meta-theory encompassing eight more factual theories in a subjective-existential-objective spectrum. IQOL consists of eight different quality-of-life concepts, ranging from the superficially subjective via the deeply existential to the superficially objective (wellbeing, satisfaction with life, happiness, meaning in life, biological order, realising life potential, fulfilment of needs and objective factors [ability of functioning and fulfilling societal norms]; Ventegodt *et al.,* 2003). However, QOL appraisal processes are necessary to improve our ability to interpret IQOL in the traditional sense, and to yield a deeper understanding of the appraisal process in the attribution of and divergence in meaning (Rapkin & Schwartz, 2004).

Despite the importance of QOL in health and medicine, there is a continuing conceptual and methodological debate about the meaning of QOL and about what should be measured and there is no uniform definition of the concept (Post, 2014). In 1995, WHO provided another definition of QOL, stating that QOL represents an individual's perception of their position in life in the context of the culture in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL Group, 1995).

Patient self-report is the most desirable, and often the only way to obtain this critical information (Monk & Hussain, 2019). Thus, accurate and meaningful measures of the various dimensions of QOL are crucial (Andersen & Meyers, 2000). Understanding QOL is important for improving symptoms, care, and rehabilitation of patients (Coons *et al.,* 2000). Problems revealed by patients' self-reported QOL may lead to modifications and improvement in treatment and care or may show that some therapies offer little benefit (Finlay *et al.,* 2017).

QOL data can assess a range of problems that can affect patients and help to anticipate and understand the consequences of their illness and its treatment (Haraldstad *et al.,* 2019). Cured patients and long-term survivors may have continuing problems long after their treatment is completed. These late problems may be overlooked without QOL assessment (Staquet *et al*., 1996). QOL is also important for medical decision-making because it is a predictor of treatment success and is therefore of prognostic importance. For instance, QOL has been shown to be a strong predictor of survival, hence prognostic ability suggests that there is a need for routine assessment of QOL in clinical trials (Fayers & Machin, 2016).

3.5.4 QOL scales

One of the first QOL scales was created by an American psychologist John Flanagan in the 1970s, who measured QOL across a random sampling of 3,000 American adults using an interview technique. In a second step, Flanagan used the instrument to survey a similar number of people. The results of his national survey revealed that most people of both genders and different age groups felt that the QOL items were important to them. The original QOL scale contained 15 items representing 5 conceptual domains of QOL: physical and material wellbeing, relationships with other people, social and civic activities, personal development and recreation. However, Flanagan felt that some adaptations for persons with chronic conditions or disabilities might be needed in his scale. In 1981 he gave the first author permission to adapt his scale if necessary for patients with chronic illness. (Burckhardt *et al.,* 2003).

Since then, many QOL scales have been developed and were adapted to assess disruptions to lifestyles, interests and activities in patients with chronic illness (Both *et al*., 2007; Burckhardt & Anderson, 2003). The majority of methodologists in the health sciences have followed a policy of incorporating at least 3 dimensions in any scale or index purporting to measure health or QOL, namely physical function, mental status, and the ability to engage in normative social interactions (Devins, 2010; Spitzer, 1986; Post, 2014).

The psychometric testing of quality of life has evolved over time into a wide range of instruments and designed questionnaires (Post, 2014). The sheer volume of tools can hinder the comparisons between different studies with the same characteristics or needs (Pequeno *et al.,* 2020). Hence, QOL might interpret and be defined differently within and between disciplines, including the fields of health and medicine (Haraldstad *et al*., 2019). Although the methodology of QOL instrument development and validation is constantly becoming more rigorous, pervasive paradoxical and counterintuitive findings in measuring QOL raise questions about what QOL measures actually assess and how scores should be interpreted (Stewart & Napoles-Springer, 2000).

Nevertheless, QOL has become a significant concept and target for research and in clinical practice (Chernyshov, 2019) and over the last 6 decades many QOL scales have been created and they can be categorised into three main groups; generic, speciality specific and disease specific QOL scales (Both *et al.,* 2007).

The most widely used “generic” tools for adults are Short-Form 36-Item Health Survey (SF-36), Short Form-12 Health Survey (SF-12), and The European Quality of Life-5 Dimension (EQ-5D), while the most widely used “dermatology-specific” QOL tools for adults are the Dermatology Life Quality Index (DLQI) Skindex-29 and Skindex-16, (Paudyal *et al.,* 2020). In children, the most commonly used Dermatology-specific QOL instruments are Children’s Dermatology Life Quality Index (CDLQI) (for age 5 to 16 years), Infants’ and Toddlers’ Dermatology Quality of Life (InToDermQOL) (for age birth to 4 years) (Ali *et al.,* 2020).

Disease-specific QOL tools include; Infants’ Dermatitis Quality of Life Index (IDQOL), Quality of Life Index for Atopic Dermatitis (QOLIAD), Childhood Atopic Dermatitis Impact Scale (CADIS), Dermatitis Family Index (DFI) for family members of patients with eczema, Cardiff Acne Disability Index (CADI), Acne-Specific Quality of Life Questionnaire (Acne-QOL), Skin Cancer Index (SCI), The Functional Assessment of Cancer Therapy-Melanoma (FACT-M) and Chronic Urticaria Quality of Life Questionnaire (CU-Q2oL; Chernyshov, 2019). Other tools, which are not usually used in the NHS dermatology clinic for assessment include; World Health Organization Quality of Life Brief Version (WHOQLO-BREF), Patient Reported Outcome (PRO), Psoriasis Disability Index (PDI), and Scalpdex (Ali *et al.,* 2020).

The following are some of the common published tools for assessing QOL: -

I- Generic QOL instruments

1. Short Form-36 Health Survey (SF-36) was designed and used in epidemiological and clinical research and practice by American social scientists working for a health insurance survey (Ware, 2004). SF-36 is a multipurpose, short-form health survey with 36 questions. It yields an eight-scale profile of functional health and well-being scores, as well as psychometrically based physical and mental health summary measures and a preference-based health utility index. It has shown to be useful in surveys of general and specific populations, comparing the relative burden of diseases and in differentiating the health benefits produced by a wide range of different treatments (Both *et al.,* 2007). The items in the SF-36 represent professionals' assumptions about issues relevant to health status and relate to the previous 4 weeks, except the item about general health (last year). It takes about 7–10 minutes to complete the SF-36 and it is available in more than 50 different languages and has been tested extensively for cultural equivalence. Although it has been assumed that the minimal clinically important difference (MCID) of the SF-36 scales was about 3–5 points, the MCID may vary more between scales and diseases (Shikiar, *et al.,* 2005; Ware, 2004). The SF-36 has been used as a reference QOL measurement in validation studies of dermatology-specific instruments such as the DLQI and Skindex (Abeni *et al.,* 2002). The SF-36 has also been used in cross-sectional studies and in clinical psoriasis trails (Shikiar *et al.,* 2006). The physical component score (PCS) and the mental component score (MCS) of the SF-36 correlated well with the DLQI (Wallenhammar *et al.,* 2004). In contrast to the DLQI, the SF-36 detected gender differences in patients with hand eczema (Both *et al.,* 2007; Wallenhammar *et al.,* 2004). The SF-12 was developed from the SF-36 for use in large surveys and longitudinal studies and includes seven PCS items and five MCS items with 2-6 response options. The SF-12 takes less than 5 minutes to administer the single page SF-12, which can be scanned, and alternative forms such as computer administration exist (Grozdev *et al*., 2012).

2. WHOQOL. In 1998, the WHOQOL-100 scale, which was designed prospectively in 15 health centres worldwide was published. Its items refer to the prior 2 weeks and use a five-point response scale. Conceptually, 24 ‘‘facets’’ with each four items and four general questions (total is 100 items) were grouped in six domains, but factor analyses retained only four domains (WHOQOL Group, 1998a). The WHOQOL assess overall QOL and not just Health Related Quality of life (HRQOL). It includes domains such as ‘‘environment’’ and ‘‘spirituality’’. More than half of the variance of the 24 facets were explained by ‘‘positive feelings’’ suggesting that this is an important predictor of an individual’s overall QOL (Skevington, 1999). The convergent validity of the WHOQOL was not optimal because it did not consistently correlate with SF-36 as expected (Bonomi *et al.*, 2000). Each of the over 40 translations have been performed in accordance with a strict protocol and none of the initial ‘‘national’’ questions had to be included in the final WHOQOL-100, which makes it a truly cross-cultural instrument. The WHOQOL-100 has been investigated in psoriasis patients treated with an Ingram regimen outpatient program (Skevington *et al.,* 2006). Apart from social and environmental aspects, all domains were significantly more affected among psoriasis patients compared to healthy individuals (Noerholm *et al.,* 2004). In 1998, a short form of the WHOQOL-100 instrument (i.e., WHOQOL-BREF) was developed for brief QOL assessments in epidemiological surveys and/or clinical trials (WHOQOL Group, 1998b).

3. Sickness impact profile (SIP) was one of the first self-reported health measures published in 1976 and revised in 1981 (Bergner *et al.,* 1981). It focuses on objectively measurable impact of illness on daily activities and behaviours and much less on the mental aspects of diseases. It contains 136 items divided over 12 scales. Apart from five independent scales, these scales can be grouped into a physical (four scales) and psychosocial domain (three scales). The SIP does not include a pain scale and asks respondents to tick only the items that are applicable to them on a given day. This speeds up the administration but complicates the interpretation of missing items (Blackford *et al.,* 1996). The items are weighted based on the level of dysfunction the item represents. The scores obtained (range 0–100) can be calculated per scale, domain and as an overall score. However, of the 136 items that sum up to the overall score, only 82 items fitted an extended Rasch model suggesting that an overall score is not appropriate (Lindeboom *et al.,* 2004). The SIP has been reported as a valid and reliable tool (Coons *et al.,* 2000) with some important limitations. It works best in patient groups with moderate to high disability associated with mobility impairment (e.g., psoriasis patients with arthritis). The SIP however suffers from ceiling effects in general population samples, suggesting that it does not discriminate well among relatively healthy individuals (Andresen & Meyers, 2000). Twenty-three items showed significant item bias across age, gender and diagnosis (Lindeboom *et al.,* 2004). Depending on patients' health, it takes about 30 minutes to complete the SIP and it can be self-administered. The SIP has been translated into several languages using varying methods (Andresen & Meyers, 2000).

4. Nottingham Health Profile (NHP) was developed as a survey tool to reflect the lay perception of health status in the United Kingdom (Hunt *et al.,* 1986). The NHP assesses subjective health with binary responses (yes/no) to 38 items in six sections. The social domain is underrepresented in the NHP, but it includes sleep (Essink-Bot *et al.,* 1997). The NHP results can be analysed by summing the number of positive responses in a dimension or weighting items to calculate a dimension score (range 0–100). A factor analysis yielded two higher order factors confirming the two domains of the NHP, but this structure could not be confirmed by Rasch analysis (Prieto *et al.,* 1998). The simple NHP scoring format has the advantage that missing values are low and it can be completed swiftly (5–10 minutes). However, if individuals score yes (i.e., the problem is present) and they get worse they cannot express this deterioration, hence the NHP has been reported to be not very sensitive to minor levels of impairment and change over time (Coons *et al.,* 2000). The NHP has been used in validation studies of patients with eczema and psoriasis and correlated poorly with the DLQI, but the ‘‘emotional reactions’’ and ‘‘mobility’’ domains were more responsive than some of the DLQI domains (Badia *et al.,* 1999). The NHP has been used to test the convergent validity of the Dermatology-Specific Quality of Life (DSQL; Morgan *et al.,* 1997).

II- Dermatology-specific QOL scales

1.Dermatology Life Quality Index (DLQI)

DLQI was the first dermatology-specific quality of life questionnaire and was developed by Finlay & Khan, in 1994 (Finlay & Khan, 1994). It consists of 10 questions and evaluates 6 domains of life; symptoms and feelings, daily activities, leisure, work/school, personal relationships and treatment. Each question is scored based on a four-point Likert score. Scores are added to yield a total DLQI score of 0 to 30 (see Appendix–VI). The higher the score, the more the patient’s QOL is impaired e.g., band 0 (score 0–1) means no effect on QOL, band 1 (score 2–5) means a small effect, band 2 (score 6–10) means moderate effect, band 3 (score 11–20) means very large effect, and band 4 (score 21–30) means extremely large effect on a patient’s QOL (Hongbo *et al.,* 2005). DLQI assesses QOL over the last week. It has high patient acceptability, short completion time (around two minutes) and extensive validation, resulting in its widespread use in both clinical settings and clinical therapeutic research trials globally (Basra *et al.,* 2008). It is also integral to several national registries and guidelines. In the UK, NICE recommended using the DLQI to assess quality of life of adult patients aged 16 and older suffering from skin diseases including psoriasis and eczema (NICE, 2012).

In 2017, Finlay proposed the new word “quimp” to encapsulate the concept of “QOL impairment” and to facilitate the integration of thinking about QOL into routine clinical practice (Finlay, 2017). The European Academy of Dermatology and Venereology (EADV) Task Force on QOL and Patient-Oriented Outcomes recommended the word “quimp” for routine clinical and research use (Chernyshov, *et al.,* 2019). In 2019, at the Harmonising Outcome Measures for Eczema (HOME) meeting (HOME VII), it was agreed to recommend DLQI to measure the QOL of adults (Homeforeczema.org. 2019).

The DLQI may lack conceptual validity in patients with minor dermatological conditions or in diseases primarily affecting mental health such as vitiligo and alopecia (de Korte *et al.,* 2002; Nijsten *et al.,* 2006a, 2007). In psoriasis patients, a confirmatory factor analysis showed a clear second-order factor structure suggesting the underlying unidimensionality of the DLQI (McKenna *et al.,* 2004; Nijsten *et al*., 2006a). Correlations between DLQI and other HRQOL measures were high and in the expected direction, except that the DLQI correlated less with mental and emotional aspects. The DLQI has been proven to be responsive to change but may not be very sensitive to detect small impairments because of the substantial ceiling effect. Items 1 and 2 account for most of the DLQI’s variability (Badia *et al.,* 1999; Morgan *et al.,* 1997). The MCID of the DLQI varied between 3 and 6 points in patients with chronic urticaria and psoriasis (Shikiar *et al.,* 2005, 2006). A large proportion of the items behaved significantly differently across gender and age (Nijsten *et al.,* 2006a, 2007). Multiple translations have been used and a cultural equivalence study in psoriasis patients suggest that the scoring of all items was affected by nationality (Nijsten *et al.,* 2007). Nevertheless, the DLQI is the most commonly used HRQOL instruments in dermatology and is used in most HRQOL studies in patients with skin diseases (Ali *et al.,* 2018; Chernyshov, 2019).

2. Skindex-29 is another dermatology specific QOL tool developed in the USA to detect changes in time (Chren, 2012). It inquires about how often (Never, Rarely, Sometimes, Often, All the time) during the previous four weeks the patient experienced the effect described in each item (Paudyal *et al.,* 2020). The first Skindex consisted of 61 items, but a refinement study resulted in 30 items of which 29 items (except item 18) are assigned to three scales with separate scores. Its scores are reported as three scale scores, corresponding to the three domains; seven items address the Symptoms domain, ten items the Emotional domain, and twelve items the Functioning domain. All responses are transformed to a linear scale of 100, varying from 0 (no effect) to 100 (effect experienced all the time). A scale score is the average of a patient's responses to items in a given domain (Chren, 2012). The Skindex-29 scored well for most criteria, except interpretability of scores, structure and item bias. Several items show item bias across gender, age, disease severity and diagnosis (Nijsten *et al.,* 2006a, 2006b). Skindex-29 completion requires about 10 minutes and a computerised version is available. The Skindex-29 has been translated from US English into many languages (Chren *et al.,* 1996; Abeni *et al.*, 2002). In a review about the HRQOL instruments in psoriasis, this tool was considered the measure of choice (de Korte *et al.,* 2002). The Skindex-29 has been used to test the validity of other (disease specific) HRQOL instruments. Two brief versions of the Skindex-29 exist (Skindex-16 and Skindex-17). The former is a shorter single-page version and also scores from 0 (no effect) to 100 (effect experienced all the time) and responses are aggregated in because it has been refined into a single page. Skindex-16 is useful for studies in which respondent burden is a concern; Symptoms (four items), Emotions (seven items), and Functioning scales (five items). Hence, Skindex-16 directly measures inconvenience rather than frequency of experience (Chren, 2012; Paudyal *et al.,* 2020). Since it was published in 2001, the Skindex-16 has been used in several skin conditions and in the validation of the melasma-specific HRQOL instrument (Balkrishnan *et al.,* 2003). Skindex-17 is a Rasch reduced version of the Skindex-29 (Nijsten *et al.,* 2006b). It has a psychosocial and a symptom scale. The five-point scoring system was re-grouped into three categories and demonstrated logical response order for all but one item. More than 85% of the variance of the three Skindex-29 scales was captured by the two scales of the Skindex-17 suggesting that little information was lost. No item bias was detected across gender, age, disease severity, and six diagnoses. A validation study of the Skindex-17 in psoriasis patients from other European countries confirmed its good psychometric properties (Nijsten *et al.,* 2007).

3. Dermatology-Specific Quality of Life (DSQL) In 1997, US researchers published the DSQL to quantify the effects of skin disease on physical discomfort and symptoms, psychological well-being, social functioning, self-care activities, performance at work or school and self-perceptions (Anderson & Rajagopalan, 1997). In total 52 items were included, which were derived from the SF-36. Of the 52 items, eight were global questions scored on a 0–10 scale assessing intensity or satisfaction and the remaining items on a five-point ordinal scale assessing frequency. The DSQL is self-administered and takes less than 15 minutes to complete. All items asked about the last month and were grouped into seven scales. A summary score was obtained by simply adding all raw scores. In the DSQL score development study, the psychometric properties were reasonable and included construct validity, internal consistency and factor analysis and it was responsive (Anderson & Rajagopalan, 1998). DSQL reliability was assessed from the internal consistency of the items and correlations were made between DSQL scores from a 3 to 7 day retest. Validity was assessed from correlations of DSQL scales with global ratings of bothersome symptoms and perceived severity and by discrimination of clinically defined severity groups (Anderson & Rajagopalan, 1997).

4. Dermatology Quality of Life Scales (DQOLS). Fifty outpatients from a UK university dermatology department were asked to write down all the ways their skin condition affects them by the subheadings; feelings and personal relationships, daily and social activities and symptoms (Morgan *et al.,* 1997). Subsequently, the developers created the DQOLS yielding 17 psychosocial, 12 physical items, and 12 symptom items. A five-point response scale was used assessing patients' current experience. The three domains have separate scores ranging between 0 and 100. Explanatory factor analysis showed four subscales of the psychosocial and activities scales. The internal consistency was excellent for the psychosocial and activities scales, and the retest reliability was tested as well. Some of the techniques in the psychometric evaluation of the DQOLS were unusual such as the use of different patient samples to estimate retest reliability and the comparison between Dermatology-Specific Quality of Life (DSQL) and NHP scores to assess sensitivity (Bland & Altman, 1986). Several hypotheses were tested to assess DQOLS construct validity and its face validity was considered good using the DLQI as a reference. It takes 5-10 minutes to complete this instrument (Morgan *et al.,* 1997).

3.5.5 Why DLQI was included in the study tool?

In 2002, de Korte and colleagues critically appraised the suitability of QOL questionnaires for psoriasis research. They reported that the available psychometric data demonstrated the reliability and validity of the generic scales; Nottingham Health Profile (NHP), the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36), the Sickness Impact Profile (SIP), as well as the dermatology-specific scales, the Dermatology Quality of Life Scales (DQOLS), the Dermatology-Specific Quality of Life Instrument (DSQL) and the Skindex-29. They found that the included generic questionnaires allow comparisons with non-dermatologic diseases but do not allow assessment of relevant dermatology-specific aspects and are not sensitive to subtle effects of psoriasis on QOL. They recommend the combination of the Skindex-29 with the generic SF-36 for QOL assessment in psoriasis patients (de Korte *et al*., 2002). This study however did not include the DLQI and other international QOL scales, hence this report did not provide a wider appraisal of the dermatology scales.

The DLQI is recommended by the BAD (2019a, 2019b) and by NICE for QOL assessment in patients with skin diseases (NICE, 2012). It is simple to use and very quick to be filled out (Ali *et al.,* 2017, 2018; Basra *et al*., 2008; Chernyshov, 2019). Systematic reviews reported that DLQI was the most commonly used tool to measure QOL (Rehal & Armstrong, 2011; Hill *et al.,* 2016). Indeed, since its creation, the DLQI has been rapidly used in national and international clinical trials for the assessment of treatment efficacy in parallel with measures of clinical severity (Ali *et al*., 2018). The DLQI facilitated many studies on the impact of skin diseases on patients' QOL. Many national and international guidelines recommend DLQI assessment in dermatology, and some of them contain detailed recommendations on treatment goals and changes of treatment approaches based on DLQI score banding and minimal clinically important difference (Chernyshov, 2019). Choosing the DLQI can also solve several parameters that may influence which QOL tool is to be used, including: -

1. Both patients and dermatologists prefer brief instruments and DLQI requires a short time to complete which is crucial in a busy dermatology clinic (Edwards *et al.,* 2002).

2. Validation characteristics of the QOL instruments is another important parameter. DLQI is a well-validated instrument and has a better chance of being widely used (Chernyshov, 2019).
3. DLQI is already recommended by NICE (NICE, 2012), hence using differing scoring systems for QOL instruments make it difficult to compare and interpret the results.
4. International surveys reported a correlation between the DLQI score and other assessment tools. A recent survey was conducted on 84 patients with eczema and found SCORAD values correlated positively and linearly with DLQI (Lugovi'c-Mihi'c *et al.,* 2021). Similarly, a survey conducted on 87 patients with psoriasis reported a statistically significant correlation between PSAI and DLQI (Khawaja *et al.,* 2015). Another survey which included 111 patients with psoriasis reported that the level of stigmatisation assessed by using the 6-item Stigmatisation Scale and with the 33-item Feeing of Stigmatisation Questionnaire, were correlated significantly with PASI scores and each one-point increment in PASI score was associated with a 0.425 point increase in DLQI value (Kowalewska *et al.,* 2021). A further survey included 174 patients with psoriasis and reported a positive correlation between DLQI and both HADS-D and HADS-A Scales (Bakar *et al.,* 2021). Interestingly, a survey on 602 adults with eczema (determined using modified UK Diagnostic Criteria for eczema) found a stepwise decrease of SF-12 mental health scores and increases of DLQI scores, in all models for moderate and severe eczema (P < .0001), reflecting significant QOL impairment (Silverberg *et al.,* 2018). However, the correlations of the findings in the above surveys should be interpretated with caution as using different methodologies in surveys could lead to selection bias if the data gathered from participants who do not represent the general population or if the researchers use different diagnostic or

inclusion/exclusion criteria in their recruitment process (Chernyshov, 2019; Dressler *et al.,* 2019).

3.5.6 DLQI benefits and limitations

Although the DLQI facilitated many international studies on the impact of skin diseases on patients' QOL and can act as an effective instrument in monitoring the burden of the disease, it has limitations such as its uni-dimensionality; it only provides a snapshot at a moment in time, has a short recall period of one week, and concerns over score interpretation when multiple not relevant option in 8 of the 10 items in DLQI are chosen this can reduce the overall maximum score (Basra *et al.,* 2008; Paudyal *et al*., 2020: Pequeno *et al*., 2020). DLQI is not designed to explore all emotional aspects, assess patient needs or measure the impact of disease on wider social and professional relationships.

Further, a large number of DLQI modifications have been used that may indicate an unmet need for adequate health-related quality of life instruments in dermatology. A recent systematic literature review was conducted to identify and categorise all modified questionnaire versions and scoring methods of the DLQI. They included 81 articles reported on 77 studies using 59 DLQI modifications. Modifications were used for a combined sample of 25,509 patients with 47 different diagnoses and symptoms from 28 countries. The most frequently studied diseases were psoriasis, hirsutism, acne and alopecia. The modifications were categorised into the following groups; disease, symptom and body part specifications (42%), changes in existing items (34%), scoring modifications (27%), recall period changes (19%), response scale modifications (15%) and illustrations (3%). The authors indicated that a large number of DLQI modifications have been used which may indicate the need for adequate health-related quality of life instruments in dermatology (Rencz *et al.,* 2021). However, this systematic review used a search strategy specifically targeting the DLQI, hence the review might have missed a few studies with modified DLQI questionnaire versions that did not mention DLQI in their abstracts or among their keywords.

Interestingly, two dermatology specific QOL scales (DLQI and Skindex-29) were recently compared through a face-to-face semi-structured interview with 28 adults with a diagnosis of eczema or psoriasis. Interviews were analysed using content analysis. Participants were generally satisfied with length and layout of both questionnaires. The majority preferred the Skindex-29 for its ease of understanding, use of a longer recall period, incorporation of items on a variety of emotions and better captured their lived experience. Nevertheless, participants reported that both questionnaires failed to incorporate important aspects of their lives, for instance the impact on professional relationships (Paudyal *et al.,* 2020). One of the limitations in this study was using convenience sampling rather than purposive sampling and the authors claimed that this action was necessary because of time and money constraints. The study also included a small sample size from one country hence further research is needed to elicit participants' views in a more diverse sample, varied settings and considering further available questionnaires.

A systematic review aimed to determine whether there is any correlation between the DLQI and psychiatric scores. All randomized trials where full DLQI and psychiatric scores were provided were included. Only 7 clinical trials met the inclusion criteria of the review. The authors reported that the Hospital Anxiety and Depression Scale (HADS) was the most used psychiatric measure and the total DLQI score correlated well with score changes in the depression component of HADS, though not as well as with the Anxiety component. They suggested that interviews and screening for depression are still vital for assessment of patient psychological well-being (Ali *et al.,* 2018). However, the review included a small number of trials. Only papers where the absolute scores or change in scores for the DLQI and for psychiatric measures were provided, were included. Further work on more data sets is needed for more accurate and refined correlation values.

Despite its limitations, the DLQI is recommended by NICE (NICE, 2012) and its addition to the study tool's open-ended questions can assist the physician to evaluate patient needs, emotions, challenges and feedback that cannot be assessed by using the DLQI alone. Together, the open-ended questions and the DLQI in the study tool can provide the following information for the health service provider: -

1. Patient feedback on the treatment
2. Patient's comorbidities
3. Alternative treatment used by the patients
4. Disease triggering factors
5. Patient's coping mechanisms
6. Patients feedback on the service they received from their GP and dermatologist
7. Type of support the patient needs (if any)
8. Type of coping mechanisms the patient used (if any)
9. Any other comment or suggestion to support patient management/self-management
10. QOL assessment

Before obtaining ethical approval, the questionnaire items were reviewed/discussed with two academic supervisors to determine face validity of each item and to make modifications to items that were awkwardly worded or that needed to be adapted for patients with chronic skin diseases (Appendix-II).

3.6 Reflexivity and qualitative research

Reflexivity is about acknowledging my role in the research, by continual reflection upon the research activities where I clearly describe the contextual intersecting relationships between the participants and myself (Dodgson, 2019). In a social context, a reflexive relationship is a feedback loop or bidirectional relation with both the cause and the effect affecting one another in a relationship in which neither can be assigned as causes or effects (Archer, 2007). In a research context reflexivity is similar to the processes of defining measurement tools for validity in quantitative research (Morse *et al*., 2002; Pope *et al*., 2000). Being reflexive means being attentive to cultural, political, social and ideological origins of my own perspective and voice as well as perspectives and voices of those I interviewed and those to whom I report my research (Firestone, 1987).

As a dermatologist keen to improve my clinical practice and support patient care, my prior experiences, personal assumptions, judgments and beliefs can influence the research process, particularly during the interview with the participants (Anderson & Rajagopalan, 1997). Reflexivity not only increases the credibility of the findings in a qualitative study but also deepens our understanding of the research work (Wisdom *et al*., 2012). It can help researchers become aware of how the values, opinions and experiences they have brought to the research can be a positive thing (Britten, 1995; Ritchie & Lewis, 2003). This is important in qualitative research because there are so many ways in which the researcher experience could affect the study, from the creation of data gathering tools, to collecting the data, analysing it and reporting it (Pathak, 2013).

Qualitative research has been subjected to criticisms more than quantitative research (Babbie & Mouton, 2001). This is mainly because qualitative study usually relies on smaller sample sizes of participants and their views may be considered subjective, unreliable, ambiguous, contradicted, cannot be replicated and may change if the interviews were conducted with a different population or in different settings (Babbie & Mouton, 2001; Chew-Graham *et al*., 2001). The subjectivity in qualitative research however can be a problem and a solution (Neuman, 2000). Britten (1995) argued that any piece of research is undertaken by subjective individuals and this subjectivity needs to be acknowledged, while Chew-Graham and Mays (2001) claimed that interviews in qualitative research should be treated as a piece of social interaction whereby the researcher's contribution is as interesting as that of the participants. The researchers' outlook on participants' life experiences and their observations has a high likelihood of influencing the process of collecting, analysing, and interpreting data (Pope *et al*., 2000). Hence, understanding the bidirectional relationship between researcher and research is an important concept in qualitative methodology (Mays & Pope, 2000).

Reflexivity can minimise subjectivity and allows the researcher to arrive at an in-depth understanding of the meaning of the phenomenon under investigation (Braun & Clarke, 2006). The researchers therefore have to put aside their own understanding of the subject of investigation and open their mind to understand and listen to what they are told by the participants. During the analysis phase it was important for the researcher to continuously reflect on his position in the research process and to remain focused on the content of the interviews (Babbie& Mouton, 2001; Morse & Field, 1995).

In this study, the focus of the research remained on understanding the phenomenon from the participants' perspective. Sufficient time was spent repeatedly listening to the recorded interviews to explore, discuss, reflect and address their needs in managing their chronic skin condition. Sufficient time was also spent on analysing the data to ensure that the findings accurately reflect the way in which the participants construct meaning and the researcher consciously guarded against presenting their personal experiences, own biases and judgments (Pathak, 2013).

As the principal investigator, I completed all aspects of the study including recruitment of participants, gathering consent from participants, coding, data collection and analysis. Having a background in dermatology and psycho-dermatology helped me to understand and relate to the participants' psychological and clinical challenges and build a rapport with them. It may however be regarded that having clinical and academic experience can influence the way in which the research study is conducted, analysed, or assessed (Ritchie & Lewis, 2003). As a single investigator I have the potential to introduce bias and subjectivity to the data collected (Braun & Clarke, 2014).

In designing and developing the study tool and conducting the survey I initially devised the survey questions based on my experience and my goals to support patients with psoriasis and eczema, but I also discussed the tool with my academic supervisors and referred to literature about current known practice for creating a questionnaire. In the interview I was aware that when interviewing the patients, I needed to remain neutral, setting aside my own views and reactions and to try to listen from the perspective of a researcher. It was however not always easy for me to be totally objective and to set aside my personal experience, especially if the participants were unable to understand the presented question.

Therefore, being a dermatologist, I might influence or have impact on the response of the participants in the interview (Johannesen *et al*., 2008). They might have felt embarrassed, uncertain, or reluctant to provide their honest or accurate answers (Sturges & Hanrahan, 2004). Nevertheless, in order to ensure that the data collected and explored was a true reflection of the participants' views and opinions in the participants' transcripts the interviews were audio recorded and the transcripts were reviewed by two academic supervisors who continuously provided structured feedback, throughout the research phases to ensure the researcher set aside his own preconceptions, judgement or assumptions and reflecting upon how such factors may influence the analysis process.

3.6.1 Generalisation, Validity, Stability and Reliability in qualitative research

Generalisation

Generalisation in qualitative research is thought to be achieved when there is clear demonstration that the chosen sample of the participants is a true reflection of the population studied and draws accurate conclusions and reflection of the data provided by the participants (Murphy, 1998; Ritchie *et al*., 2003). Morse (1999) proposed that if qualitative research is considered not generalisable then it is of little use, insignificant and hardly worth doing, while Denzin and Lincoln (2005), claimed that although qualitative research provides a multiplicity of information, its results cannot be generalised across different contexts, cultures or populations.

Despite the disagreement on the generalisability of qualitative study results, such research is concerned not so much with whether data is true, but with capturing and understanding what is said at a point in time or the phenomenon under investigation and to ensure that the research findings reflect what the participants say and what is happening (Babbie & Mouton, 2001). Furthermore, qualitative research provides unique results that cannot usually be obtained by using other research methods as no two participants can perceive and react to the same events (or diseases) in the same way (Snape & Spencer, 2003).

Validity

Validity measures the extent to which the theories or explanations derived from the research data are true and correctly capture the phenomenon under investigation (Rosenthal & Rosnow, 2007). Hence, validity reflects how truthful the research results are (Patton, 2002). However, as the validity is measured by the extent to which the analysis reflects what was said by the participants (Gibbs, 2002), it can be improved by consistent checking of the data obtained from the participants until a point where the data analysis process becomes self-correcting and the researcher is able to decide when to continue, stop or alter the research process (Morse & Field, 2002).

Further, validity in qualitative research can be improved by reflexivity and by the extent to which the researcher provides sufficient detail to enable the reader to interpret the meaning and context of what is presented (Pope *et al*., 2000). Validation is therefore in part dependent on the transparency of the data collection and analysis including describing the procedures used or presented and the process by which the end product has been reached (Ritchie *et al*., 2003). The description of the details of the data collection, research methodology and data analysis processes in this research is outlined in keeping with the above hallmark to ensure the validity during the research process (Denzin & Lincoln, 2005; Healy & Perry, 2000).

Furthermore, triangulation which was deployed in this mixed method study, involves integration of different data sources (qualitative and quantitative) and different methods of data collection in order to produce a meaningful understanding of patients' needs and patients' challenges in managing their skin disease (Hutchinson & Wilson, 1991). Triangulation however may not ensure validity, but it is a way of ensuring comprehensiveness and more reflexive analysis of the data (Mays & Pope 2000). Triangulation can provide a research account that is rich, robust, comprehensive, and well developed (Pope *et al*., 2000; Ritchie *et al*., 2003; Wisdom *et al*., 2012). In this study, triangulation disclosed many similarities between data collected through different sources and helped to produce wider information on the researched subject for our understanding.

Stability

Stability is the state or the degree of being stable (Babbie & Mouton, 2001). It is used in qualitative research as an indication of validity and trustworthiness of data (Patton, 2002), and is concerned with whether the observations can be replicated during the data collection process (Pathak *et al.,* 2013). However, in order to ensure data stability, it is important to avoid subjectivity and continuously reflect on the objectives of the study to ensure that the participants are guided to remain within the domain of the study (Babbie & Mouton, 2001). This was challenging as the participants expressed their subjective and emotional experiences with the diseases and with the healthcare system. Nevertheless, during the analysis phase the same challenges appeared, and it was important to identify and carefully assess the diversity of the data and remain within the scope of the study (Dodgson, 2019).

Reliability

Reliability is defined as the extent to which results of the qualitative study are consistent over time (Healy & Perry, 2000). It measures the extent to which the research findings will remain the same across repeated investigations in different circumstances with different investigators and the extent to which such findings are generalisable (Morse & Field, 1995). Establishing reliability within qualitative studies, can be daunting, as they are prone to elements of misinterpretation or personal biases (Chew-Graham, May, & Perry, 2001).

According to Thurmond (2001), if every person who is involved in the same data analysis came to the same outcome, then it is more likely that the findings are 'true' and therefore reliable. In this qualitative data, participants constructed their views differently answering the same questions in the interview. Hence, it might not be possible for data to remain consistent across repeated investigations with different participants from different backgrounds (Burns & Clarke, 2006; Murphy, 1998). Nonetheless, the analysis was not only dependent on the researcher's interpretation, but also considered how other sources concerning the same topic or themes would account for similar findings (Creswell & Plano Clark, 2011).

Although, conducting a mixed method study on the same population and triangulation of the data can enhance validity and reliability in qualitative research (Hayes *et al*., 2013; McEvoy & Richards, 2006), patients' views might change over time, so may their opinion on the effectiveness of using an intervention or a tool. Chapter-6 will compare the findings of the survey (study-1) and interviews (study-2) with similar national and international studies aiming to enhance stability and validity of the study findings and report the findings of a third-party inquiry within the pragmatic approach of this research (Healy & Perry, 2000).

It is however, important to carefully and fully describe methodology in each study. This involves the explaining of any ambiguities with participants during the interview, confirming interpretations of interview data with supervisors and discussing the findings in a systematic manner with comparison to existing literature (Mays & Pope, 2000; Patton, 2002).

3.7 Conclusion

To answer the multidimensional research questions raised, a pragmatic approach was adopted using a mixed method approach. The latter offers wider opportunities in gaining a deeper understanding of complex health issues than would otherwise be possible via the use of either quantitative or qualitative data on its own. The chapter discussed the benefits and the challenges of conducting a mixed method study and developing a paper questionnaire (study tool). The chapter discussed the rationale for including a QOL scale in the study tool and highlighted the reflexivity and the limitations of the qualitative research. The next two chapters will report the details of the survey and interview studies conducted in this research, respectively.

4. CHAPTER FOUR - STUDY ONE – POSTAL SURVEY

This chapter reports on the postal survey, which was conducted as the first stage of this mixed method research to assess the participants' comorbidities, quality of life, feedback and needs using the study tool. The survey was voluntary and offered to adults with psoriasis and eczema. As the questionnaire in this survey contained open-ended questions, the research generated both numerical and narrative data. The latter identified three main themes and twelve subthemes highlighting the participants' feedback and comments.

This chapter includes an introduction explaining the research rationale and objectives, methodology, ethical approval, data collection, data analysis, study results, study discussion and study limitations. The results of the survey are discussed in text, tables and figures and they include the psychological burden and challenges facing patients with psoriasis and eczema as well as their unmet needs. The discussion will reflect on the advantages of the study tool in addressing patients' needs and barriers for self-managing their chronic illness. The chapter ends with reporting the limitations of the study and a summary of its findings.

4.1 Introduction

Psoriasis and eczema are common chronic skin diseases, and they are often associated with psychological and metabolic comorbidities that negatively impact on patient quality of life (Andersen *et al*., 2017; Augustin *et al*., 2015; Na *et al*., 2019; Schofield *et al*., 2009, 2011; Silverberg *et al*., 2019; Singh *et al*., 2017; van Beugen *et al*., 2017; Villani *et al*., 2015).

The burden of psoriasis and eczema goes beyond skin involvement and their impact is not necessarily proportionate to the severity and the extent of the skin rash (Augustin *et al*., 2015; Langan *et al*., 2012; Noormohammadpour *et al*., 2015; Vaidya *et al*., 2015). They are not only chronic skin diseases, but systemic inflammatory disorders affecting other vital organs (Balieva *et al*., 2017; Dalgard *et al*., 2015). Patients with such diseases are susceptible to long-term cardiovascular diseases, obesity, hypertension, diabetes mellitus, high blood lipid profile, arthritis, inflammatory bowel diseases and even cancers (Andersen *et al.,* 2017; Augutin *et al.,* 2015; Griffiths *et al.,* 2017; Langan *et al*., 2012; Parisi *et al*., 2013). These comorbidities can have a further impact on the quality of life of the affected patients and their partners or families as well as on the patient's career and income (Balieva *et al*., 2017; Eccleston *et al*., 2015; Griffiths *et al*., 2017; Langan *et al*., 2012; Lim *et al*., 2017; Stefanadi *et al*., 2018).

The relationship of patients with chronic skin diseases and with the healthcare provider can last for a number of years and can incur financial strain on the patient and healthcare system in both; rich and poorly resourced countries (Lim *et al*., 2017; Hay *et al*., 2014; Johns *et al*., 2013). However, despite the longevity of these relationships many of the psychological and financial strains experienced by the patients go undisclosed and unreported (APPGS, 2013; Burt *et al*., 2017; Na *et al*., 2019; Moncrieff *et al*., 2018).

Patient feedback can play a major role in their disease recovery and gives a direct insight into the quality of care an organisation delivers (Edwards & Imison, 2014; Finlay *et al*., 2017; Monk & Hussain, 2019). Indeed, if quality is to be the centre of everything we do, it must be understood from the perspective of patients who are using the healthcare service (Atherton *et al*., 2019; Boylan *et al*., 2019; Hernan *et al*., 2019; Kumah & Kesse, 2018).

Patient feedback can be a powerful tool, providing it is listened to and acted upon (Boylan *et al*., 2019; Hernan *et al*., 2019). Feedback data from routine clinical practice is found to be useful in health care cost-effectiveness research and in improving the quality of the service (Hernan *et al*., 2019; Rigby *et al*., 2015).

With the limited consultation time available from the healthcare provider (Irving *et al*., 2017), patients with a chronic skin disease have only a few minutes and unprotected opportunities to discuss their concerns and needs (APPGS, 2013). Such opportunities may be further diminished if the patient is nervous, shy, embarrassed, depressed or unable to express their daily challenges with the disease (Burt *et al*., 2017; Griffiths *et al*., 2017; Nelson, 2013; 2015).

In the UK, an All Party Parliamentary Group on Skin (APPGS), which was established in 1994 has long been concerned that dermatology services across England are overwhelmed, due to staff shortages at the consultant level, and insufficient dermatology training at the primary care level (APPGS, 2013). There is no reliable dermatology coding system that can accurately assess patient psychological and metabolic comorbidities or measure the impact of chronic skin diseases. The healthcare provider looking after such patients often lacks accurate epidemiological data that can predict or implement cost-effective preventive measures (Edwards & Imison, 2014; Wagner *et al*., 2001; von Hospenthal, 2013).

To improve the quality of the health service for patients with skin diseases, the APPGS stated:

> “*The need for a more tailored set of measurement tools is crucial if the psychological needs of patients are to be assessed efficiently within a very short period of time* (of the consultation)” (APPGS, 2013 p.38).

However, apart from the generic NHS feedback questionnaire and the DLQI score, there are no assessment tools that have been used in the dermatology service in the UK on a regular basis. The generic NHS feedback questionnaire cannot measure or provide information on patients’ needs, psychological comorbidity and their daily challenges at home, work, or public places (Monk & Hussain, 2019; NHS, 2019; Nuffield Trust, 2018). Providing effective health care should not be limited to treating the skin rash, the whole person needs to be assessed including a regular check of the health problems and comorbidities, understanding the type of support, needs or education they require to resolve their daily challenges in dealing with the chronic disease, as well as understanding their healthy lifestyle barriers in order to self-manage their illness and comorbidities effectively (Ankawi *et al*., 2019; NICE, 2012).

Ignoring patient feedback and/or excluding patients’ involvement in their care can have a significant negative impact on the quality of the healthcare service, patient satisfaction, adherence to their therapy, or on their self-management (Al-Abri & Al-Balushi, 2014; Boylan *et al*., 2020; Elwyn *et al*., 2012; McKinstry, 2000). Additionally, effective self-management is not simply about gathering feedback, it is also about engaging and autonomously motivating the patients to develop a sense of interest, value and competence to self-manage their challenges and to feel self-sufficient and related to a caring service provider or care giver (Bandura, 1997; Dombestein *et al.,* 2019; Ryan & Deci, 2000).

After reviewing the literature, I adopted a conceptual framework from 3 self-management/motivation theories (SDT, SRT and SET). I proposed that using the study tool (a paper questionnaire with open-ended questions and DLQI; Appendix-II) on a regular basis can motivate/engage the patients to address their unmet needs, assess their comorbidities, and QOL and support their involvement in decision making and self-management. Appropriate measurement of patient experience, rather than patient satisfaction, is important for improving healthcare as it allows targeted intervention where necessary (Atherton *et al*., 2019; Boylan *et al*., 2019). Equally, repeated measurement of patient experience can optimise patient care (Monk & Hussain, 2019).

To assess the study tool an explanatory mixed method research was conducted starting with a postal survey to assess the potential of the study tool in gathering patients' information that addresses their needs, views, disease triggers, coping mechanisms, metabolic and psychological comorbidities, treatment preference and patients' feedback. This was followed by interviews with the patients who participated in the survey to gain a deep understating of their experience with the disease and with the health care service and to obtain their views about using the study tool to support their medical care.

4.2 Postal Survey

This survey is part of the mixed method research to assess the potential of the new study tool in addressing the needs, feedback and comorbidities of patients with psoriasis and eczema.

4.2.1 Objective of the study

To assess the potential of the study tool (Appendix-II) in assessing the views, needs, comorbidities, coping status, QOL and feedback of patients with psoriasis and eczema aiming to support their involvement in decision making and self-managing their chronic conditions.

4.2.2 Method

A pilot study was conducted first before the postal survey to assess the acceptability of the study tool by the participants and whether any change was needed to improve its quality. The study tool consisted of eight open-ended questions and a DLQI questionnaire. The open-ended questions were introduced for the following reasons: -

- They are necessary when piloting questionnaires as they can identify further issues for inclusion in the survey and can disclose issues, which complement responses to closed questions and may increase response rates.

- To optimise the value and the quality of the data that can help the researchers to make more strategic use of them by being clear about their role and understanding the type of data they wish to generate when they design their study.

- A clear strategy for generating quantifiable safety net data that can be missed by the closed questions will encourage attention to non-response bias and the reliability of coding.

- To empower patients to voice their thoughts, feelings, and psychological challenges with their chronic incurable disease and to address their personal and specific needs.

(O'Cathain & Thomas, 2004; Rattray & Jones, 2007)

Apart from the open-ended questions and in order to measure how much psoriasis and eczema have affected patient' life over the last week, the study tool included the DLQI questionnaire (Appendix-II). The latter is a simple, self-administered and user-friendly validated dermatology specific questionnaire. It is designed for use in adults, i.e., patients aged 16 years and over. It can be simply handed to the patient who is asked to fill it in without the need for detailed explanation (Appendix-VI; Finlay & Khan, 1994). It contains 10 questions and is calculated by summing the score of each question resulting in a maximum of 30 and a minimum of zero. The higher the score, the lower their rating of their quality of life (BAD, 2019b).

4.3 **Ethical approval**

The research proposal was first submitted to the Research and Development (R & D) Department at the sponsoring Hospital on the 6th of April 2017 and was also emailed to the research centre at the University of Cumbria (UoC), who is supervising the project. On the 30th of May 2017, the university approval was granted with no amendment required on the proposal. On the same day, the research project was submitted electronically to the Integrated Research Application System (IRAS) for approval. On 11th July 2017, the Research Ethical committee (REC) requested minor changes in the Patient Information Sheet (PIS) (Appendix-I) of the research, which were made and re-submitted (as PIS version-2) electronically through the IRAS website. On 24th July 2017, the R & D department of the sponsoring hospital agreed to conduct the research and on 16th August 2017, both the REC and the Human Research Authority (HRA) emailed their approval to conduct the research. As an essential requirement for conducting the clinical research, I completed the Good Clinical Practice (GCP) course on 18th of August 2017 and started the logistical process of conducting the research.

Inclusion criteria: -

- Adult male and female patients aged 18 years and above with psoriasis or eczema
- Participants, who are able to provide consent, read and understand the English language.

Exclusion criteria: -

- Patients under 18 years old
- Patients who are unable to provide consent, read and understand the English language.

4.4 Pilot study

The objective of the pilot study was to assess if the study paper questionnaire (study tool; Appendix-II) is acceptable, easy to understand its questions and has no mistakes or ambiguous questions. This would help the respondents to provide accurate answers (Jenn, 2006). The open-ended questions were provided to offer the patient autonomy and a platform to express their needs, comorbidities, and feedback freely (Kishore *et al.,* 2021). From 1st December 2017 and for one month 23 successive eligible patients with psoriasis and eczema aged 18 years or over, who were visiting the dermatology outpatient clinic for a routine follow up consultation at Barking, Havering and Redbridge University Hospitals (BHRUH) in Southern England, were recruited. After finishing the consultation with the dermatologist, consecutive eligible patients were offered the study's patient information sheet (Appendix-I) and the study questionnaire (Appendix-II) to fill out. In addition to the 10 questions included in the DLQI, the study questionnaire was supplemented with eight open-ended questions and empty spaces for participants to elaborate on aspects of their care (Appendix-II). Patients who were interested in participating in the study were asked to fill out the study questionnaire and enclose it in a provided self-addressed stamped envelope. The participants were asked to seal their envelope and to leave it at the department reception or to fill the questionnaire at home and post it back using the provided self-addressed stamped envelope.

4.5 Postal survey

The postal survey was started soon after the pilot study from January 2018 and for 3 months. The response rate in the pilot study was excellent (100%). All the 23 piloted patients answered almost all the open-ended questions in the study tool and provided diverse information about their needs and challenges with their skin diseases. Therefore, no amendment was made to the paper questionnaire (study tool). Sample size was calculated by choosing Solvin's formula [n = N / (1+Ne2)]; where (n) is sample size, (N) population size and (e) is a margin of error (Presley *et al.,* 2021). Using a large sample size may reduce the margin of error, enable the researcher to generalise results and reduce sampling bias, but it can be costly, takes more time and efforts to achieve. My supervisors and I agreed to select a sample size of 505, based on a population of 750,000, CI 95%, and margin of error between 4-5% (Qualitrics, 2022). The postal survey process included posting the study Patient Information Sheet (Appendix-I), the same study tool used in the pilot study (Appendix-II), and a self-addressed stamped envelope to 482 consecutive eligible patients with psoriasis and eczema, who were managed by the dermatology department at the above hospital. Patients, who agreed to participate in this survey, filled the study questionnaire and sent it back using the enclosed self-addressed envelope. Patient confidentiality was protected in the pilot study and in the postal survey by writing a study number on the questionnaires instead of writing patient details, NHS or hospital number. Participants were given a 3-month period to reply to the questionnaire. No funding was received for this research and no incentive was offered to the participants. The printing of the study papers and the postage costs were covered by the dermatology service in the hosting hospital. The inclusion and exclusion criteria were the same as the pilot study. Completion and return of the study tool were deemed consent to participate in the study as highlighted in the patient information sheet “By posting back your questionnaire you are providing your consent and agreeing to have your data used in the survey” (Appendix-I).

4.6 Data collection and analysis

The obtained participants’ data in the survey was transferred into a spreadsheet and their study number was matched with their hospital number. Their responses were reviewed with their hospital notes and their hospital correspondence. The data was then analysed by gender, age, comorbidities, topical treatment preference and its side effects, patient feedback on the service received, patient coping mechanisms, patient needs, disease triggers, and by the DLQI score. The collected data of the respondents and non-respondents to the postal survey was compared and their categorical variables were disclosed in Table-3.

Participants' written comments were reviewed, and similar words and sentences were matched and coded using thematic analysis of Braun and Clarke, (2006; please also see Chaper-5, page 285). Three themes and 12 subthemes were identified from the narrative data analysis (Figure-8). All the research process was conducted by one investigator (myself) and all the steps of the research were regularly supervised by two academic supervisors.

4.7-Results

Of the 505 study envelopes used in this study (23 through the pilot study and 482 through the postal survey), 114 (22.5 %) were filled and returned back, including all pilot study participants and 91 of the postal survey's participants. Thirty (26.3%) participants had eczema, and 84 (73.7%) participants had psoriasis. The female/male ratio was 58/56. The age range was between 18 and 88 years and the average age was 51.2 years. Of the 391 patients who declined to participate in the postal survey, 101 (25.8%) had eczema, and 290 (74.2%) had psoriasis. Their female/male ratio was 195/196 and they had a similar age range, but with an average age of 44.4 years (Table-3).

Table-3: Participants' characteristics

Participant Characteristics	Number
Total patients invited to participate in the study	505
Total patients agreed to participate	114
Female / male ratio for participants (n = 114)	58 / 56
Female / male ratio for non-participants (n = 391)	195 / 196
Mean age for participants	51.2 (range 18 - 88 years)
Mean age for non-participants	44.4 (range 18 - 88 years)
Psoriasis / Eczema ratio for participants	84 / 30
Psoriasis / Eczema ratio for non-participants	290/101

4.7.1 Medical comorbidities

The physical and metabolic comorbidities were present in 95% of participants, as follows: 45.6% had joint pain or arthritis, 22.8% had high blood pressure, 15.7 % had high blood lipid profile, 14% had poor mobility, 12.2% had diabetes mellitus and 11.4% were suffering from obesity (Figure-2).

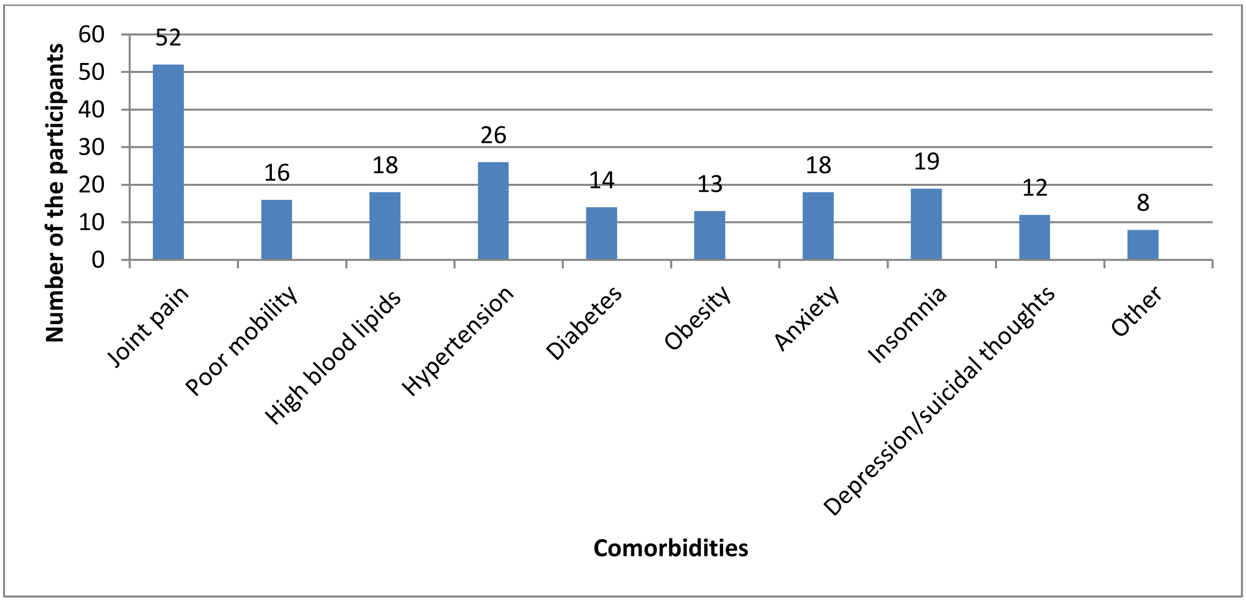


Figure-2: Participants' comorbidities

4.7.2 Psychological comorbidity

The psychological comorbidity of the participants included the followings: 28.9% could not cope alone with their chronic skin disease, 16.6% were unable to deal with the stigma of their skin disease, 16.6% had insomnia, 15.7% were suffering from anxiety, 10.5 % had depression and suicidal thoughts and 8.7% reported that they have no family support to self-manage their skin disease. Stress was the dominant disease triggering factor for the flare of the skin disease in 63.1% patients, and the cold weather was the second most common trigger for the skin rash flare in 45.6% patients (Table-4).

Table-4: Psychological comorbidity, coping status and triggers of skin disease flare

Psychological comorbidity	**No.**	**%**	
Coping with chronic skin disease			
Yes	72	63.1	*"unless you are someone that suffers with it you will never fully understand the impact it can have on your life" (*Participant no. 38)
No	33	28.9	*"without medication I wouldn't be able to cope"* (Participant no. 45)
Psychological challenges			
Lack of family support	10	8.7	"*I live alone*" (Participant no. 13)
Inability to deal with stigma	19	16.6	"*people have asked me if I've had animal bites, stings. Wish to have more public information in places like swimming pools, health centres…etc*" (Participant no. 13)
Psychological symptoms			
Insomnia	19	16.6	*"lack of sleep"* (Participant no. 15)
Anxiety	18	15.7	"*More psychological/emotional help*" *(*Participant no. 8)
Depression and suicide thoughts	12	10.5	"*just wish it would just go away and a cure can be found for it*" (Participant no. 55)
Triggers of skin rash flare			
Stress	72	63.1	"*stress started it and stress makes it worse*" (Participant no. 86)
Cold weather	52	45.6	*"extreme temperature "* (Participant no. 52)

4.7.3 The Dermatology Life Quality Index (DLQI) score of the participants

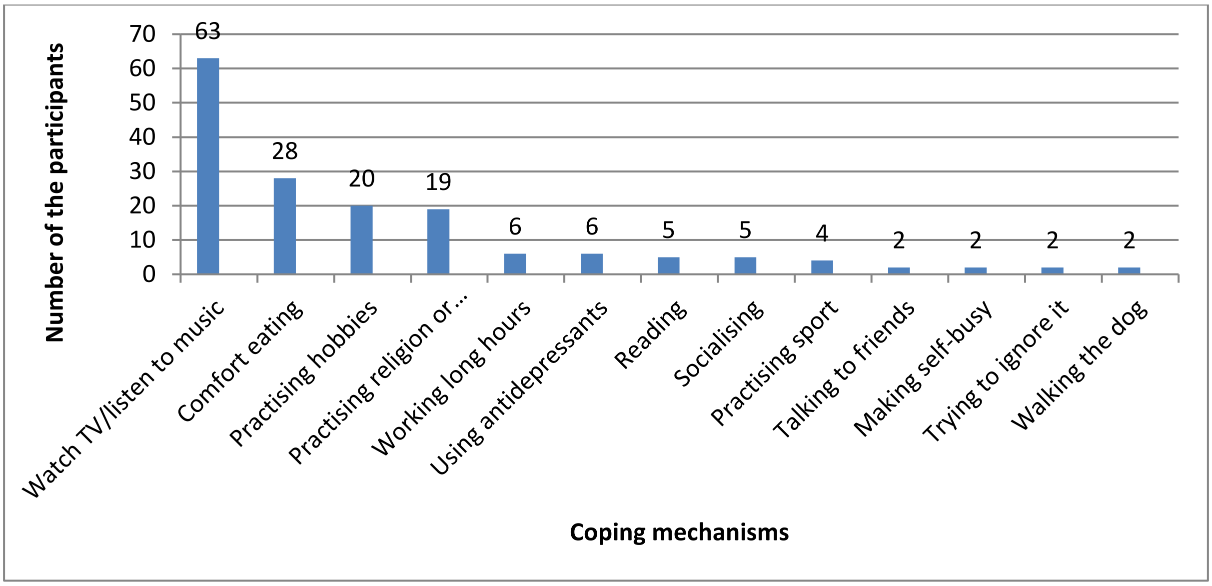
The DLQI score ranges from 0 to 30, 37% of participants scored more than 10 including patients who were receiving treatment for their skin diseases i.e., more than a third of the participants reported that their skin diseases had a very large effect on their life (Hongbo *et al.,* 2005; please refer to the DLQI banding Chapter-3, page 204). The average DLQI for male participants was 8.45 and for female participants was 8.1. The average DLQI in eczema patients was 10.7 and in psoriasis patients was 8.29 (Table-5).

Table–5: Participants' DLQI score

Group	Mean of DLQI Scores
Mean DLQI for male participants	8.45
Mean DLQI for female participants	8.10
Mean DLQI in eczema participants	10.70
Mean DLQI in psoriasis participants	8.29

4.7.4 Coping mechanisms

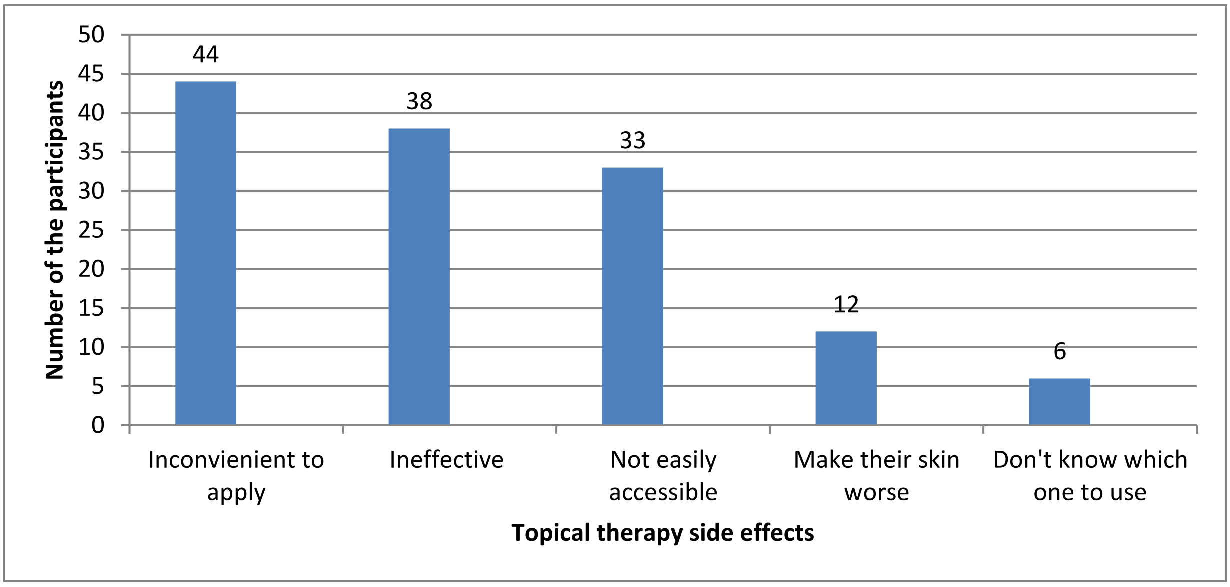
The coping mechanisms used by the participants to deal with the challenges of their chronic skin disease were; watching TV or listing to music for 55.2% of participants, comfort eating for 24.5%, practising hobbies for 17.5%, practicing religion or praying for 16.6 %, working long hours for 5.2%, using antidepressant medication for 5.2%, reading for 4.3%, socialising for 4.3%, practising sport for 3.5%, talking to friends for 1.7%, making self-busy and time planning for 1.7%, trying to ignore it for 1.7%, sleeping for 1.7%, walking the dog for 1.7%, and using fidget spinner for one participant (Figure–3).



Figure–3: Coping mechanisms used by the participants

4.7.5 Topical skin therapy used by the participants

The majority (93.8%) of participants used topical skin products to manage their skin disease. Their reflection on using such therapy was as follows; 38.5% stated that topical therapy was inconvenient to apply as frequently as is recommended, 33.3% of them found it ineffective, 28.9% participants stated that a repeat prescription of topical therapy was not easily accessible, 10.5% felt that topical therapy makes their skin worse and 5.2% participants did not know which one to use and how frequently (Figure-4).

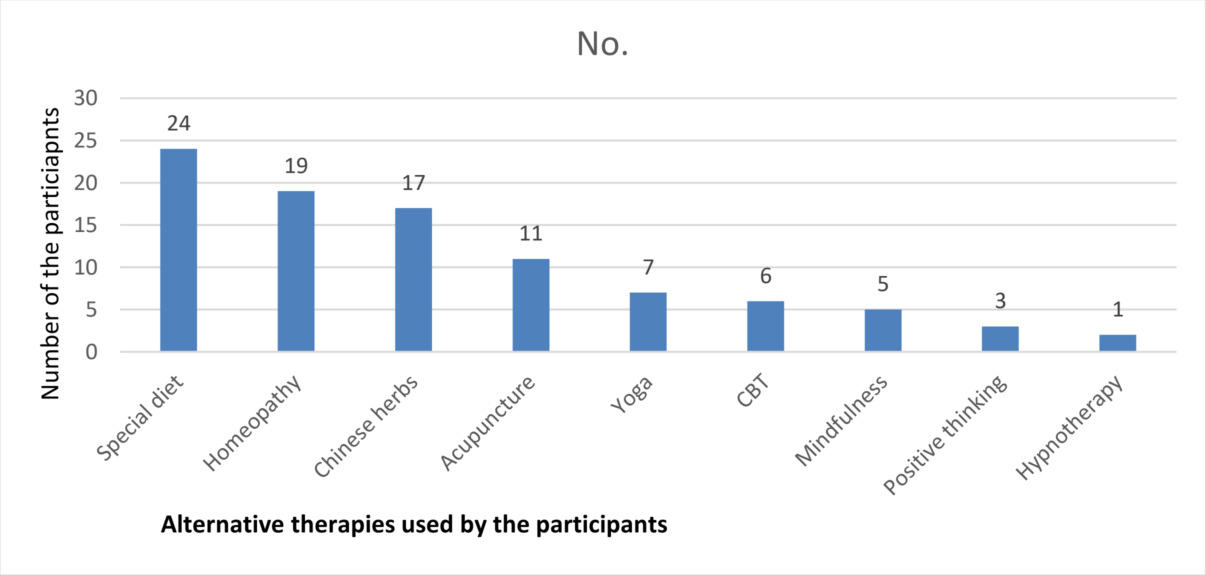


Figure–4: Participants' feedback on using topical therapy for their skin disease

There was also a contradiction in patients' views regarding the effectiveness of topical treatment. Around 8% participants found Dermovate ointment was helpful for their skin rash, while 3.5% found it unhelpful. Similarly, 4.3% participants found Dermol cream was helpful for their skin rash, while 2.6% found the same cream was unhelpful. This contradiction might be expected in a random group of unmatched patients. Not all of them respond to the same treatment or to a placebo in the same way (Light *et al*., 2019; Nash *et al.,* 2015). Additionally, 41 participants left comments relating to the side effects they experienced from using topical therapy, including five participants who thought that topical treatment has short benefits and three participants felt that this treatment made their skin rash worse. Fourteen participants however thought that they did not notice any side effects from such therapies and the rest of the participants did not leave a comment to answer the same question.

4.7.6 Systemic and alternative therapies used by the participants

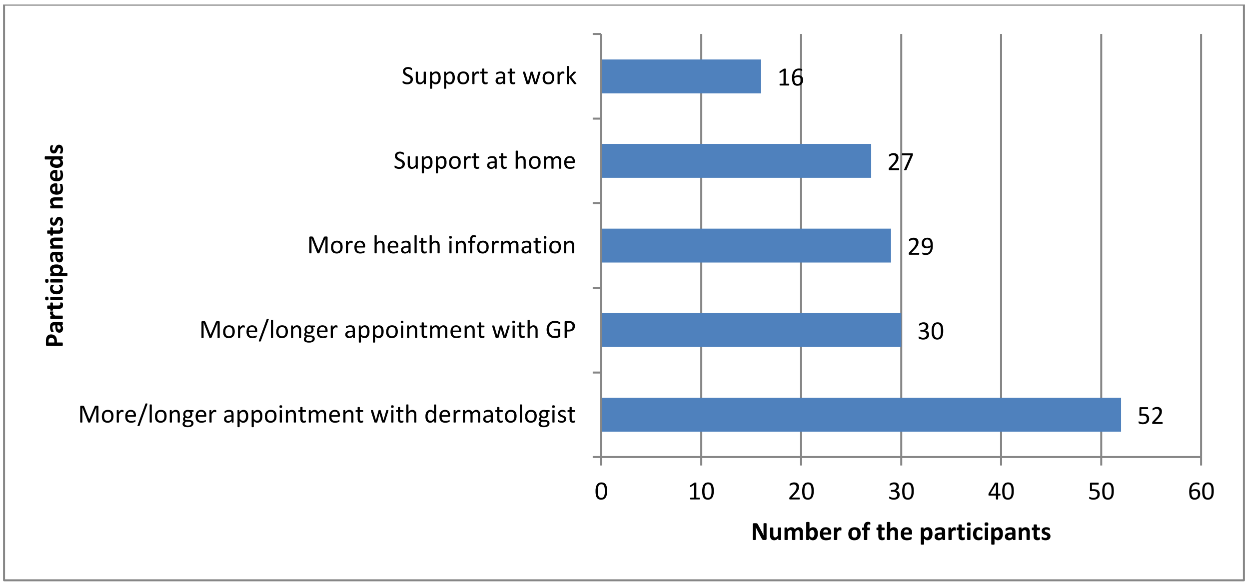
Almost 28.9% participants were on systemic therapy including 3.5 % of psoriasis patients were on biologic therapy. Notably, 44.7% of participants had tried alternative therapies to improve their stress and skin condition including 21% tried a special diet (e.g., gluten free or dairy free), 16.6% tried homeopathy, 14.9% tried Chinese herbs, 9.6 % tried acupuncture, 6.1% tried yoga and meditation, 5.2% tried CBT, 4.3% tried mindfulness, 2.6% tried positive thinking and one participant tried hypnotherapy (Figure-5). The participants' answer regarding the impact of the alternative therapy in curing their skin disease was negative. However, some of them found alternative therapies did ease their distress and/or enabled them to cope with their chronic disease, while others thought that it could make their skin rash worse.



Figure–5: Alternative therapies used by the participants to manage their skin condition

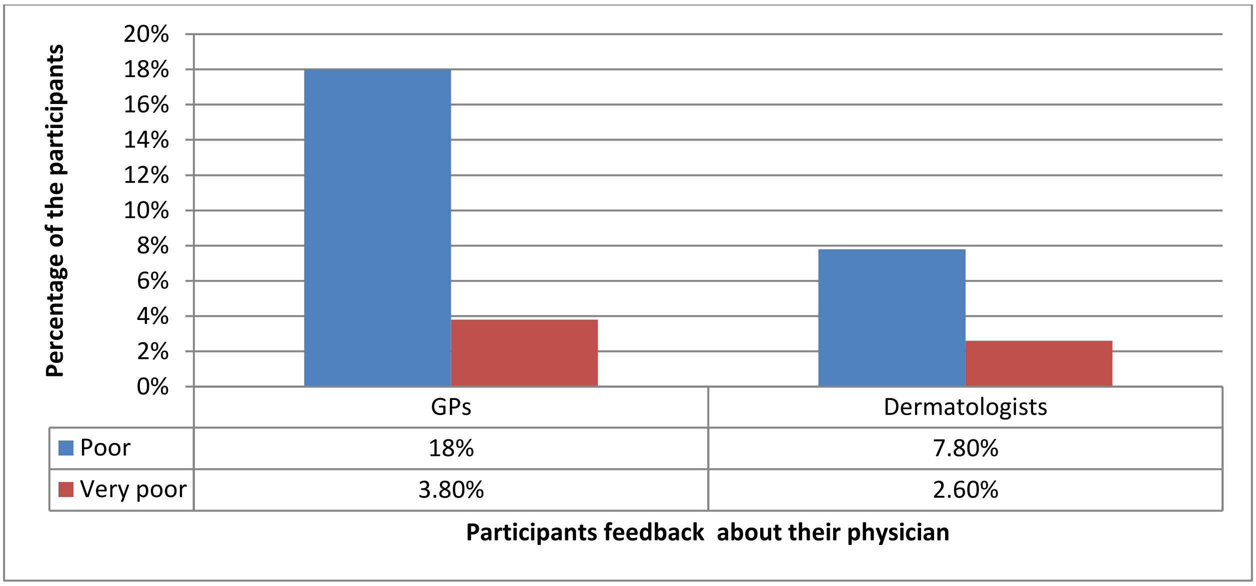
4.7.7 Patient needs and feedback about the health service

As for patients’ needs, 45.6% participants asked for more and longer appointments with their dermatologist, 26.3% asked for more and longer appointment with their GP, 25.4% asked for more health information, 23.6% requested support at home and 14% of them requested support at work (Figure-6).



Figure–6: Participants’ needs

Regarding participants’ feedback on the service they received, around 18% of participants rated the service they received from their GP as poor and further 3.5% participants rated it as very poor, while 7.8% participants rated the service they received from their dermatologist as poor and further 2.6% participants rated it as very poor (Figure–7).



Figure–7: Participants’ feedback on the service provided by their GP and dermatologist

4.8 Thematic analysis of patients comments on the open-ended questions

Many participants left comments in the spaces provided for elucidation in the open-ended questions of the study questionnaire. These comments were subjected to the thematic analysis of Braun and Clarke (2006, 2014, 2019). An inductive technique was adopted, meaning that the themes were driven by the data rather than existing theory or evidence (please also see chapter 5). Figure–8, shows the 3 main superordinate themes that were identified from the thematic analysis. They included problems associated with having skin disease, problems associated with self-managing skin disease and patient needs. The superordinate themes subsume 12 sub-themes. They will be discussed next, using extracts from the participants' responses to amplify the points raised.

Theme 1: Problems associated with having a chronic skin disease

- (1.a) Impact of peoples' ignorance of the chronic skin diseases' sufferers
- (1.b) Pain and disability associated with chronic skin diseases
- (1.c) Challenges for controlling triggering factors of skin diseases
- (1.d) Issues with coping mechanism to deal with chronic skin diseases

Theme 2: Problems associated with self-managing chronic skin diseases

- (2.a) Problems with the GP service
- (2.b) Problems with the dermatology service
- (2.c) Problems associated with the treatment of skin diseases
- (2.d) Issues with using alternative therapies to manage skin diseases

Theme 3: Patient needs

- (3.a) Participants' needs for health information
- (3.b) Participants' needs for better/longer consultation time
- (3.c) Participants' psychological needs
- (3.d) Participants' personal needs and feedback

Figure–8: Thematic map of the participants' comments in the postal survey

4.8.1 Theme-1 Problems associated with having chronic skin diseases

Many participants expressed different aspects of their long-term personal, social, psychological, physical, occupational, environmental and financial challenges in living with incurable chronic skin disease for a significant period of time. These challenges were divided into four main subthemes 1.a-1.d:-

- (1.a) Impact of peoples’ ignorance of the chronic skin diseases’ sufferers
- (1.b) Pain and disability associated with chronic the skin disease
- (1.c) Challenges for controlling triggering factors of the skin disease
- (1.d) Issues with copping mechanism to deal with chronic skin disease

Subtheme (1-a) Impact of peoples’ ignorance of chronic skin diseases’ sufferers

There were a number of participants who expressed the psychological impact of people’s ignorance about chronic skin diseases on their quality of life, mainly because of public perceptions and their limited knowledge about the nature of skin diseases, and/or lack of understanding around the condition(s).

One participant described her frustration in expressing her psychological suffering from having a chronic skin disease:

> *“unless you are someone that suffers with it you will never fully understand the impact it can have on your life“* (Participant no. 38)

Another participant wrote of her struggle inside and outside work due to the lack of understanding of her colleagues at work:

> *“lack of understanding by colleagues at work and lack of understanding in society about how complex my condition is”* (Participant no. 104)

One female participant with psoriasis who enjoys swimming described her embarrassment and the unpleasant comments she received from the public about her skin rash while she was practising her favourite hobby in leisure centres:

> “*I live alone, I really enjoy swimming but embarrassed by the skin appearance of legs, people have asked me if I've had animal bites, stings. Wish to have more public information in places like swimming pools, health centres…etc*” (Participant no. 13)

Clearly, there is a need for public health education such as providing an awareness campaign or information in leisure centres about skin diseases to educate the public about the non-contagious nature of psoriasis (van Beugen *et al.,* 2017).

Another female participant expressed her struggle in living with a chronic skin disease that forced her to hide her skin rash to avoid the stigma while being in public places:

> *“always cover up my body as much as I can”* (Participant no. 66)

One participant expressed the impact of the skin disease on her confidence, self-esteem and on her social activity:

> *“if skin is not healthy and clean you are not confident and don't go out and see people”* (Participant no. 27)

The use of the term “clean” by this participant may reflect their own beliefs about skin or those of others to whom they have interacted with in the past (Alpsoy *et al*., 2017).

Without offering the study tool the above participants may not be motivated to express their frustration and distress (Al-Abi & Al-Balushi, 2014). The study tool may have empowered the participants and offered them the autonomy to express important hidden psychological comorbidities. Psoriasis and eczema have a negative impact on psychosocial functioning and there is a need for psychosocial support mechanisms for those with chronic disfiguring skin diseases (Nash *et al.,* 2015; Silverberg *et al*., 2018).

Subtheme (1-b) Pain and disability associated with chronic skin diseases

Many participants described the ways in which their chronic skin rash caused them pain in different circumstances and settings and their hope for effective treatments to improve their quality of life.

One participant with psoriasis struggled with a painful inflamed skin rash affecting the soles of her feet, which affects her daily mobility:

> “*bad feet skin, makes it difficult to walk*” (Participant no. 34)

Another participant acknowledged the painful impact of the skin disease on her coping ability before the treatment of her skin disease. She appreciated the role of the treatment on her quality of life:

> *“without medication I wouldn’t be able to cope”* (Participant no. 45)

One participant expressed her frustration and "mental" pain in living with the incurable long-term skin disease and hoped for a cure for her illness:

> "*just wish it would just go away and a cure can be found for it*" (Participant no. 55)

The painful dry sore skin rash can significantly limit a patient's personal, social, occupational and leisure activities:

> *"getting ready takes hours and I cancelled most events except work*" (Participant no. 46)

In the absence of patients' feedback reported in the study tool, it might be argued that medical professionals are only in a position to treat a small range of the symptoms experienced by their patients (Boylan *et al*., 2020).

Subtheme (1- c) Challenges with triggering factors that aggravate skin disease's condition

Participants described a wide range of individual triggering factors that can impair the effectiveness of the skin disease's management. Some of these factors cannot be easily or always eliminated from a patient's routine lifestyle or environment such as weather, lack of sleep, lack of sunlight, pollen, dust, falling ill or having infections, using commercial washing products or excessive washing of the skin or bathing.

> *"hot weather, extreme temperature, itchy clothes, wool"* (Participant no. 52)

> *"contact with egg, food, furs, wool" (*Participant no. 5)

> *"lack of sleep"* (Participant no. 15)

> *"hot/humid place, friction from clothes rubbing in sensitive area usually from work"* (Participant no. 35)

These triggers need to be explored and discussed during the follow up consultation with the healthcare provider. Support should be offered to eliminate these factors as much as possible, especially stress which was the dominant triggering factor in this population (see Table–3). One participant summarised the impact of stress on skin diseases and the vicious cycle between stress and chronic skin disease in one sentence:

> "*stress started it and stress makes it worse"* (Participant no. 86)

Four participants (Participants no. 26, 40, 45 and 48), thought that their rash is constant all the time and did not think that their disease could be aggravated by triggers.

Other participants disclosed a range of triggering factors that are quite individual and diverse. They need to be discussed and eliminated as part of a patient's holistic management plan (Jobling, 2007). Without using a feedback mechanism most of these factors would likely go unreported or unaddressed.

Subtheme (1-d) Copping mechanisms to deal with the chronic skin disease

In addition to the coping mechanisms reported by the participants (Figre-3), below are some of the quotes, which represent the wide range of coping mechanisms that the participants adopted to ease the stress incurred from living with chronic skin illness:

> *"reading, playing with granddaughter, singing in a choir" (*Participant no. 13)

> *"attending social activities, going out with friend" (*Participant no. 15)

> "*talk to someone" (*Participant no. 21)

> *"walk in the park in the morning help as I can clear my mind" (*Participant no. 23)

> "*try to stay alone and start cleaning, sleeping or hiding from everyone" (*Participant no. 27)

Arguably, each patient may have individual interests, beliefs, habits, and hobbies that may not be disclosed to the medical staff in a routine healthcare consultation. The study tool offered an opportunity for the patients to disclose many important psychological mechanisms that can help physicians to understand their patients' comfort zone in order to minimise their symptoms. The study tool has acted as a screening instrument identifying hidden psychological aspects of patients living with chronic skin illnesses including cognitive, emotional and behavioural changes that need to be discussed and managed by their physician aiming to provide an effective management plan for such patients.

4.8.2 Theme-2 Problems associated with self-managing skin diseases

There were significant negative feedback comments left by the participants in the study tool regarding the type, quality and the standard of the medical service and the treatment they received from their healthcare provider in primary and secondary care. These comments were divided into 4 subthemes 2.a-2.d:-

- (2.a) Problems with the primary care or GP service
- (2.b) Problems with the dermatology service
- (2.c) Problems associated with the treatment of the skin disease
- (2.d) Issues with alternative therapies used to manage skin diseases

Subtheme (2-a) Problems with the primary care or GP service

Five participants did not think that their GPs were helpful in assessing, diagnosing, or managing their skin disease or complying with the dermatologist's recommendations:

> "GP *needs more knowledge. She just told me to google it. GP just gives you a cream and sends you home"* (Participant no. 4)

> *"I feel like sometimes my GP labels skin conditions with a brush and doesn't look at cases individually"*(Participant no. 18)

> *"GP only ever gives repeat prescriptions"* (Participant no. 49)

> *”30 mg tube* (drug vehicle) *is not enough, and GP don't give more”* (Participant no. 65)

> *“I hope that my GP read their emails from the hospital’s dermatologist in order that I can get my repeat prescription of medication without me having to make unnecessary phone calls to them and the hospital” (*Participant no. 70)

> *“I find it a problem getting new medication from the specialist transferred to my GP prescriptions”* (Participant no. 111)

One participant felt that she gained more help from patients having a similar skin problem rather than from own her GP:

> “Sometimes *I get more help from people with same problem. GP doesn't help. They just prescribe medicine that given in hospital and you can’t ask them which medicine work for me”* (Participant no. 27).

Two participants (Participant no. 87 and no. 98) were struggling to obtain a prescription of their immunosuppressive drug, Methotrexate from their GP.

Although the above comments represent the participants’ side of the story and lack the GP’s feedback, to a certain degree they match with the findings reported in a previous national psoriasis survey (Nash *et al.,* 2015). They may reflect a lack of trust of the participants in their GP’s dermatological skills.

Subtheme (2-b) Problems with the dermatologist

Several participants criticised their dermatologist’s approach or their management plan. They felt that their dermatologist was giving them limited or no information, options or choices of treatment or follow up appointment:

> “*the dermatologist does not seem to want to discuss different treatment or try anything else”* (Participant no. 48)

> “*doctors not testing for everything that could cause my eczema to flare”* (Participant no. 46)

Other participants were not happy with their dermatologist’s behaviour in terms of offering long follow up appointments or discharging the patient from the dermatology service:

> “*Dermatologists have rules with appointment and now want to see me yearly rather than every 6 months”* (Participant no. 18)

> “*I think dermatologist shouldn't discharge me. They should review me every 6 months to 9 months”* (Participant no. 42)

Two participants explicitly expressed the lack of empathy or inappropriate approach of their dermatologists. One of them generalised his personal view on all hospital consultants, and specifically criticised the dermatologist consultant looking after his skin problem:

> *"Hospital consultants have spent very little time for their patient, some of them show no care, they do not take this issue seriously…Doctor doesn't show any responsibility toward patients specially this department*" (Participant no. 73)

> *"The dermatologist told me I look better, and I was the worst I had ever been*" (Participant no. 22)

Another participant felt that dermatologists contradict themselves when providing advice and treatment to their patients. He was however more impressed by the care provided to him by the dermatology nurses than that provided by the dermatology consultants:

> "*I think doctors contradict themselves as I was told 2 different pieces of information of how, when to use the creams apart from nurses!!! Lovely at dermatology department, but not doctors"* (Participant no. 21)

Previous psoriasis studies reported similar findings; participants were dissatisfied with their dermatologist's communication and management (de Vere Hunt *et al.,* 2021; Krueger *et al.,* 2001; Nelson *et al.,* 2013, 2015). The study tool empowered the participants to formally criticise and appraise their dermatologist and pass their voice to the health service provider aiming to improve the quality of healthcare.

Subtheme (2-c) Problems associated with the types of treatments used for skin disease

The participants reported their views and feedback on using topical therapy. The latter includes medical products to be applied directly on the skin rash in the form of ointments, creams, lotions, sprays, shampoos, or gels. The participants expressed the side effects and the challenges associated with using topical therapy.

> “*very difficult to use oily cream every day as recommended by dermatologists due to working full time and other commitment in busy life*” (Participant no. 15)

> “*ointments are greasy”* (Participant no. 54)

> “*moisturising skin is time consuming so as brushing skin to clean flaky white’s scales”* (Participant no. 66).

> “*stain clothes and bedding”* (Participant no. 103)

Others felt that topical therapy is ineffective, make their skin disease worse and/or it would be better to stay without using them:

> “*using topical therapy causes flareness, dry skin, weeping, scaly skin and hair”* (Participant no. 2).

> “*I recently stopped topical treatment. Now I don't use them I am 1000 times better. I still have scars, but I am not depressed or sore as I used to be these needs to be taken seriously*” (Participant no. 21).

> “*some creams/ointments make skin sensitive and irritant*” (Participant no. 46)

> “*topical treatment causes red skin, marks and bruises”* (Participant no. 23)

> “*makes rash worse and burns*” (Participant no. 74)

Apart from the above side effects, one participant highlighted the serious risk of fire from using paraffin-based skin products:

> “*very greasy on clothes, also safety issue of paraffin which is flammable*” (Participant no. 52)

Other participants acknowledged the short benefit of the topical therapy:

> “*work for a while and become ineffective”* (Participant no. 40)

> “*all ointments good for a while then stop working, and causes skin thinning*” (Participant no. 57)

In contrast, other participants did not experience side effects from using topical therapy by writing "*none*" to answer the same question regarding using topical therapy.

One participant expressed his anxiety and stress in having no access to his topical therapy:

> *"I have recently been told by my GP surgery that my emollient creams are no longer available for prescription as they can be bought over the counter for more expensive which am not happy about having to pay extra...I need ointments/creams to remain on prescription at prescription price…having the worry of affording creams, I need does not help my skin with stress"* (Participant no. 18)

In this subtheme, the study tool seemed to motivate the patients to report their feedback about the topical therapy, which plays a vital role in psoriasis and eczema's self-management (Frantz *et al.,* 2019; Psomadakis & Han, 2019). The feedback supports some of the feedback reported in a previous European survey (Dubertret *et al.,* 2006). The respondents were dissatisfied with the topical treatment. The study tool can assist the physician to eliminate prescribing ineffective medication that may have a negative impact on the patient's adherence and management outcome as well as impose financial strain on the service resources and the budget of the patient (Lim *et al*., 2017; Nash *et al.,* 2015; Serup *et al*., 2006).

Subtheme (2-d) Issues with using alternative therapies to manage skin disease

Due to the incurable nature of psoriasis and eczema, the participants were asked if they had tried alternative therapies to manage their chronic skin condition. Some of them reported the types of therapies they tried as well as their views about such therapies. They documented a variety of remedies including homeopathy, special diet, lifestyle changes, mindfulness, CBT, self-determination sessions, antidepressants, yoga, meditation, acupuncture, chinese herbs, habit reversal therapy, nightshade, ayurveda or using combination of food supplements:

> "*I'm now vegan. Replace sugar with aqave and most organic products. Diet, positive thinking, yoga, colonic irrigation and detox juice diet for a week at a health centre… It has helped my skin problem*" (Participant no. 21)

> *"Research myself has put me where I am today. It's under control never red or sore, I still itch but nowhere near as bad. Don't use creams or steroids, they only supress what is trying to come out. Your body is telling you something is wrong and trying to heal. There is more to it than covering up the problem. Flares are your body breaking out and the creams are just not helpful...like putting makeup over the skin more research is needed"* (Participant no. 22).

> *"I think the link between thyroid, digestive system and B12 need to be looked into it. Would be useful to know if I have a leaky gut or there are specific foods my blood and my skin hate. My blood smells very metallic and nickel is common allergy. I wonder if I'm allergic to my own blood!"* (Participant no. 46)

The above comments reflect participants' interest/desire to express their needs for effective therapy. They searched for different treatment approaches and adopted new therapies and lifestyle changes to manage their illness. However, when the participants were asked if any alternative therapy or lifestyle changes, they tried had helped to cure their disease; their answer was no. Nevertheless, some of the above therapies or methods had helped to ease their symptoms or minimised the stress associated with their chronic skin disease.

4.8.3 Theme-3 Patient needs and support

The participants expressed different types of needs. Many of these needs were relevant for the self-management of their skin diseases. They were divided into 4 main subthemes 3.a-3. d:-

- (3.a) Participants’ needs for health information
- (3.b) Participants’ needs for better / longer consultation time
- (3.c) Participants’ psychological needs
- (3.d) Participants’ personal needs and feedback

Subtheme (3-a) Needs for more health information

Many of the participants expressed their needs for health information or complained of lack of information provided by the healthcare provider on skin diseases and types of new treatment/research available to manage their chronic illness:

> *“More advanced information”* (Participant no. 19)

> *"I would like to have more info about research and new treatment"* (Participant no. 27)

> "*Need update on new treatment available on NHS and privately"* (Participant no. 106)

Several participants described the impact of a lack of clear information on treatment and management of their skin condition. Lack of information can not only impair the therapeutic effects of the treatment, but can also put the patient at risk of potentially serious adverse drug reaction (Devaux *et al*., 2012; Vangeli *et al*., 2015):

> "*I was under the impression that I could only use the ointment for a limited time, but I was never told to stop taking any of them"* (Participant no. 75)

A few participants were not happy with the management plan given to them including the type and frequency of using topical therapy. They expressed confusion and frustration on the lack of information about the cause of their skin disease and the lack of effective treatment received from their healthcare provider:

> "*Applying ointments can trigger irritation. It is totally impractical to wrap myself in Clingfilm. I would like to know why I have eczema in my 70's and for treatment to be more effective. I need ointment to soothe the irritation when occurs"* (Participant no. 51)

The study tool also disclosed the frustration of the participants who were keen to understand the cause of their skin condition and requested better diagnostic tests and more support:

> "*Better diagnostic test to determine cause of late onset eczema at age 23*+" (Participant no. 7)

> "*to be able to find out what is causing the problems"* (Participant no. 53)

Other participants reported concerns over the long-term use of certain drugs such as steroid therapy. They were eager to understand or discuss alternative treatments or natural remedies for the management of their skin disease. However, they felt that their views were ignored and/or they were not given the opportunity to understand the choice of treatments available for their skin condition:

> *"I am not happy with the frequency of use of steroid cream recommended"* (Participant no. 51)

> "*more acknowledgements of steroid side effects. I feel that they are overused. More access to natural remedies as alternative to mainstream treatment so that people can explore other routes. I often feel that I am not listened to when I mention the use of natural medicine or express the desire to explore alternative treatment*" (Participant no. 104).

The above quotes reflect the potential role of the study tool in energising the patients to express their concerns and needs to self-manage their chronic skin condition. The study tool helped patients express their needs with the healthcare professionals. These needs cannot always be discussed or managed within the limited time of NHS consultation (Irving *et al.*, 2017).

Subtheme (3-b) Participants' needs for better consultation time

Participants asked for a proper consultation with their clinician and expressed their frustration about the duration of the consultation time:

> "*Consultation time is not long*" (Participants no. 12)

They also complained about the delay in the clinic time which can have a knock-on effect on the patient's other commitments or daily activity:

> *"Usually, clinic time is often late over an hour"* (Participant no. 44)

One participant requested more appointments with the dermatologist rather than the GP to deal with her chronic skin condition:

> "*More dermatologist appointment because GPs do not have advice and knowledge the same as the specialist dermatologist"* (Participant no. 44)

With the long waiting time to see a dermatologist and the unpredictable nature of skin diseases, which may flare and get worse at any time, participants also asked for regular follow-up appointments with the dermatologist to ensure regular support and medical input:

> “*Requires regular appointments with dermatologist to monitor skin condition which is getting worse day by day”* (Participant no. 15)

> “*Months passed by and the hospital don't send appointment for follow up”* (Participant no. 73)

One participant described the hospital appointment system, as unpredictable, and reported the struggle when asking the GP to be re-referred to the dermatology service:

> “*Appointments were often cancelled and rearranged and when I was seen by different dermatologists, the skin was looking ok, but the condition flares up constantly and I feel I was signed off too early … it is a constant battle and l can't get the creams. It felt a tough journey to be referred to have skin test*” (Participant no. 43)

In contrast, a few participants appreciated the dermatology service, their dermatologist, or the impact of the effective treatment they had been offered:

> *”I am happy with my dermatology appointment. I am grateful for your professional care”* (Participant no. 35)

> "*I am now taking Humira* (biologic therapy for psoriasis) *which has made my psoriasis disappear. Before Humaira it would been very helpful to see a dermatologist when in the middle of a flare up as sometimes by the time you get a consultant it is too late leaving you to manage the flare-up alone"* (Participant no. 38)

The above comments reflect the divergent views of the participants toward their health care service. Besides addressing patient needs and comorbidities, the study tool provided feedback on the quality of the health service that can be acted on to improve patient's access and the standard of care.

Subtheme (3-c) Psychological needs

Many participants wrote of their desire for the service provider to offer them psychological therapy or other supportive therapies to ease their psychological symptoms:

> "*More psychological/emotional help. There are needs to more emphasis on the emotional and psychological effects this disease has"* (Participant no. 8)

> "*help with stress, CBT, help with sleeping*" (Participant no. 36)

> "*stress reduction would be most beneficial*" (Participant no. 35)

> *"NHS need to provide gym membership for a year. Need positive thinking sessions with therapist, stress management sessions, gym/yoga sessions"* (Participant no. 66).

> "*is it possible to have acupuncture and Yoga sessions on NHS?*" (Participant no. 17)

A few participants asked for patient group support to share their skin disease stories:

> *"Some group support would be ideal. I usually try to search information online. Try to chat with people who got same problems*" (Participant no. 27)

The study tool motivated the participants to report their psychological needs, which may not be discussed during the short outpatient consultation. Such information can alert the service provider to take a supportive approach required to manage chronic skin diseases. Without using the study tool, the above patients would not be able to disclose their psychological suffering.

Subtheme (3-d) Participants' personal needs and feedback

A number of the participants highlighted different personal needs and circumstances that can affect the management of their chronic skin condition:

> "*I am very satisfied with the care I have received. The only thing I was disappointed is that my recent light therapy (ultraviolet therapy) was limited to just over 30 sessions, which didn't clear my skin. Previously I was allowed more sessions 57 light therapy visits"* (Participant no. 63).

> “*I think I need proper treatment because…my joint pain is unbelievable painful”* (Patient no. 67)

> “*I need to access to different treatment; I want it quickly and not just being given the same medication”* (Participant no. 109)

One participant expressed their financial frustration in managing their skin illness or paying the cost of their prescribed or favourite treatment:

> “*I struggle with money*” (Participant no. 66)

Another participant expressed their challenges in living with chronic illness alone:

> “*I live alone*” (Participant no. 13)

Some participants addressed their personal wishes in travelling to a hot country to improve their skin condition:

> *“traveling to warm country can help my skin problem“*(Participant no. 2)

Two participants who have disabilities expressed their needs for specialised support that can assist them to address their needs:

> *"I have autism and learning difficulties…Need more help with the behavioural issues and habits of scratching when uncertain. Need input from someone who understand autism and how to help provide coping strategy"* (Participant no. 14)

The second patient had a significant hearing impairment and uses sign language to communicate with others:

> *"I have communication issues, not able to understand the instructor as I use British sign language. Being profoundly deaf found it hard to express my feeling, I would like to share experience with other deaf. I find it embarrassing to tell other of my skin condition*" (Participant no. 66)

From the above, the study tool seemed to empower, engage or motivate the participants to voice their personal and psychosocial challenges. Their interest, desire or motivation was driven by their need for better care (Ryan & Deci, 2000) and/or driven by their need for having rewarding health outcomes (Bandura, 1997). The tool offered them the opportunity to be involved in their management and the autonomy to report the barriers of their self-management. They criticised the quality of the healthcare service aiming to improve the standard of their health care and to satisfy their unmet needs for self-management.

4.9 Discussion

The objective of the survey was to assess the potential of the study tool in assessing the views, needs, comorbidities, coping status, QOL and feedback of patients with psoriasis and eczema aiming to support their involvement in decision making and self-managing their chronic conditions. Of the 505 patients invited to participate, 114 participated in the postal survey and expressed a wide range of important information related to the self-management of their chronic skin condition. The tool provided numerical and narrative data on the participants' psychological, personal, social, physical, and metabolic comorbidities that according to patient notes were not always discussed, assessed or managed by the healthcare provider.

The study tool offered the participants a free platform and the choice to express their needs and to be involved in their management. The participants asked for health knowledge and information about their skin disease to enable them in self-managing their chronic illness. They also disclosed important information about the social and medical barriers that may interfere with the self-management of their chronic condition. The study tool gave them the opportunity to be actively involved in the decision-making process of their management, criticise their treatment, and service provider, report the side effects of their medication, to seek alternative therapies, to connect and interact with their clinician and service provider.

The survey provided information on the following: -

- Participants' demography and the type of disease they have (Table-3)
- Their metabolic comorbidities (Figure-2)
- Their psychological comorbidity and coping status (Table-4)
- Types of coping mechanisms they used (Figure-3)
- Their DLQI scores (Table-5)
- Their skin disease triggering factors
- Their experiences of using topical therapy and its side effects
- Types of alternative therapy and lifestyle changes they tried (Figure–5)

- Their needs for health information and more flexible appointment system
- Their needs for psychological support
- Their feedback
- Their challenges in dealing with chronic skin disease in public
- Their problems with their GP service
- Their problems with their dermatology service

The study tool acted as an interactive intervention that engaged/motivated the participants to appraise their management and their healthcare provider. Many participants expressed their suffering and explained how they had tried different coping mechanisms to minimise their psychological pain. They asked their service provider for psychological support, stress management sessions and for group therapy with similar patients. This may reflect their desire to be autonomous, competent and related to a caring person, group or health service.

Most of the participants tried a wide range of coping strategies and alternative therapies or lifestyle changes, some of which may positively impact on their psychological and physical well-being (e.g., hobbies and socialising) and some of which might be potentially detrimental (e.g., working long hours, comfort eating). Without the study tool, the above patients' experience may not be discussed in the limited NHS consultation time and patients would not be able to explore their required support to self-manage their chronic disease.

The study tool provided a formal platform for the participants to address their rights for better healthcare, health information and to disclose their views, feedback and needs to the healthcare provider. The tool offered the participants the opportunity to report their frustration, personal, social, logistical, systematic and bureaucratic barriers that interfere with the effective self-management of their chronic illness. Participants were also able to identify positive experiences, which are just as useful in terms of feedback as negative ones (Monk & Hussain, 2019; Zuidgeest *et al*., 2011).

Collecting patient feedback can play an important part in the management of their disease (Al-Abri & Al-Balushi, 2014; Nash *et al.,* 2015; Reeves & Seccombe, 2008). It can also provide vital appraisal and a formal message to their service provider alerting them of the standards and quality of their healthcare (Edwards & Imison, 2014; Schofield *et al*., 2009; von Hospenthal, 2013). Twelve participants (10.5%) had depression and suicide thoughts, establishing the psychological comorbidity in such patients at an early stage can assist their physician to offer the needed support such as counselling or psychotherapies to manage their psychological burden without lasting damage (Connor, 2017; Jafferany & Pastolero, 2018; Nowak & Wong, 2016). Equally, screening for physical and metabolic comorbidities in this group of patients by using the study tool and managing them at an early stage can prevent disabilities and improve their quality of life (Dures *et al*., 2019; Parisi *et al*., 2013)

The study findings were congruent with many of the findings reported in previous surveys conducted on patients with psoriasis and eczema in the UK (Nash *et al.,* 2015), Europe (Dubertret *et al.,* 2006) and the USA (Krueger *et al.,* 2001; Silverberg *et al.,* 2018). These surveys assessed and measured the personal and psychosocial impact of psoriasis and eczema on the patients and found that the effective management of chronic skin diseases is mediated by personal and service limitations and that these can negatively impact on a patient's self-management outcomes, productivity, emotional and psychological wellbeing.

One of the NHS limitations is the short consultation time, which can inhibit both the physician (GP or dermatologist) and the patient when it comes to discussing and assessing the patient's physical and psychological comorbidities and needs. It may leave the physician with little opportunity to fully assess the patient and offer a holistic management plan (Monk & Hussain, 2015). The study questionnaire could solve such a problem as well as motivate the participants to be actively involved in addressing their comorbidities and needs. It provided an insight and understanding of patients' feelings, emotions, behaviour as well as capturing their explicit views and feedback on the treatment and the service they received.

Many participants were concerned about the impact of their chronic disfiguring skin rash is having on their confidence, self-esteem, social interaction at home, work or to socialise and engage in public places activities that might otherwise be important in managing their general health condition (Beattie & Lewis-Jones, 2006; Corrigan & Rao, 2012; Monk & Hussain, 2019; Na *et al*., 2019; Nash *et al*., 2015; Richards *et al*., 2004). Equally, the survey showed that the lack of public knowledge in the non-contagious nature of eczema and psoriasis and their perception of ideal body image and skin, can subject the sufferers of such diseases to criticism and multiple types and levels of abuses. The latter can leave the patients with a sense of fear, hopelessness, anxiety, avoidance, withdrawal as well as with a wide degree of depression (Alpsoy *et al*., 2017; Balieva *et al*., 2016; Grant *et al*., 2019; Singh *et al*., 2017). It can impact on their personal relationships, academic performance and occupational functioning (Barry *et al*., 2019; Clarke *et al*., 2020; Dalgard *et al*., 2015; Yang & Kourosh, 2018).

Without having a platform to express their needs such as the study tool, patients with skin diseases might be reluctant to disclose their emotional struggle in living with chronic skin conditions fearing being seen as vain and/or because of a sense of hopelessness or lack of understanding as to what can be done to help (Geale *et al*., 2017; Jafferany & Pastolero, 2018; Jobling, 2007; Kouris *et al*., 2017; Lim *et al*., 2018).

The management of psychological pain in the above patients forms an important part of the holistic approach to treating patients (Capoore *et al*., 1998; Lavda *et al*., 2012). Such an approach is likely to involve counselling, psychological medications, CBT, stress management sessions, mindfulness or training to enhance an individual's self-esteem or self determination to deal with their negative emotions and stress (Beck, 2011; Bedrov & Bulaj, 2018; Enander *et al*., 2019; Feldman *et al*., 2016; Ng, 2012; Petros & Solomon, 2019). Nonetheless, such multidisciplinary approaches are not currently available in many healthcare services or NHS Trusts (Mannion & Davies, 2018; Perry *et al*., 2019)

Additionally, NICE issued a guideline for psoriasis management (NICE, 2012), which recommended assessing patient metabolic, cardiovascular and psychological comorbidities as well as managing their skin rash and joint pain (psoriatic arthritis). However, as in previous qualitative studies, the current study showed that the service provider was mainly treating the skin and often ignoring the assessment and/or management of patients' comorbidities (Nelson *et al*., 2013, 2016).

Stress was affecting 63.1% of participants and around a quarter of the participants reported suffering from anxiety and depression. Reviewing patient hospital notes and correspondence, no psychological assessment, support or relevant referral was offered to the above patients. Living with the psychological symptoms may mean living with an invisible disability (Barankin & Dekoven, 2002). There is a vicious circle between stress and skin diseases. Ignoring the management of the former can trigger the flare of the latter (Cohen *et al*., 2007). The level of anxiety and depression symptoms can significantly correlate with suicidal ideation (Singh *et al*., 2017). In contrast, managing the stress can improve the symptoms of these diseases (Connor, 2017; Lavda *et al*., 2012).

Apart from psychological comorbidity, metabolic and cardiovascular comorbidities were not always discussed or documented in the patients' notes. Around one third of the participants suffered from obesity and a high lipid profile. Research showed that managing obesity can improve psoriasis and the patient's response to the treatment (Griffiths *et al*., 2017; Parisi *et al*., 2013). A similar failure has been reported in previous UK studies; physicians often miss the opportunity to assess the comorbidities under the skin and tend to focus only on managing the visible rash (Nelson *et al*., 2014; 2016).

Around 43% of the patients in the study were suffering from joint pain, and 13% of them reported poor mobility. According to the patients' notes, not all patients with joint pain were offered joint assessment or referral to a rheumatologist for further advice and support. Having physical disabilities and poor mobility can limit a patient's independence to perform daily housework, hobbies, pursuing certain jobs or careers and can also impact on their ability to weight management (Dures *et al*., 2019; Geale *et al*., 2017; Villani *et al.,* 2015).

The study questionnaire identified barriers to the relationship between the patients and the clinician. A concerning number of participants rated the service they received from their GP and dermatologist as poor or very poor. Research showed that one of the most relevant parameters influencing patients' wellbeing was satisfaction with their dermatologist (Monk & Hussain, 2019; Nash *et al.,* 2015). Patient/physician barriers can significantly affect the patient's self-management and compliance with the treatment (Petros & Solomon, 2019). There were also social barriers facing patients with chronic skin rash. Participants expressed uncomfortable comments when visiting public services such as swimming pools to practise their hobbies. Lack of public health awareness of skin diseases can leave such patients vulnerable to different types of abuse in public places (Barankin & DeKoven, 2002; Changing Faces, 2019).

Despite being one of the best health organisations in the world, the NHS is facing increasing demands on the service and the complexity of its management have affected the quality of the health service (Nuffield Trust, 2018; NHS England, 2018a). Participants complained about long waiting time to see a specialist and short consultation time with their physician. Ignoring patient needs and feedback can further impair the quality of care (Edwards & Imison, 2014). The study tool provided both an assessment and feedback. It has the potential to engage, involve, motivate, or empower the patients to disclose their needs, comorbidities and vital information on their self-management and on the quality of the health service they received.

Almost 94% of participants used topical medications, but not all of them found such therapy to be helpful, convenient or effective. Prescribing unwanted therapy can impact on patient's budget and healthcare resources. The tool indirectly assessed patients' compliance with their current medication and minimised recall bias, which can undermine the patient's self-management outcome. It encouraged patients to report their medication, while patients often forget to bring their current prescription or forget their medication names or doses (Hargis & Castel, 2018; Vangeli *et al*., 2015). There was no evidence in the patient's notes that the prescribed therapies are being used or if they have been disposed of. Providing ineffective therapy for months or years incurs a financial strain on the patient and on the service provider (Steen *et al*., 2017).

The survey showed that using the DLQI score alone in this study (Table–4) would not be very helpful, as it did not disclose patient comorbidity, needs and feedback and it did not always correlate with the severity of the disease or with the type of treatment received. The DLQI scoring system did not map all aspects of a patients' health including comorbidities and psychosocial challenges (Finlay & Khan, 1994). Adding the DLQI to the study tool provided a comprehensive assessment and multidisciplinary approach to support and improve the quality of life of such patients. The tool can alert the physician to take action and manage patients' new comorbidities to prevent disabilities that can impact of on their QOL.

It is envisaged that the longitudinal collection of patients' information by using the study tool at each consultation can provide regular patient appraisal on the healthcare service, assisting service providers to capture their service user' personal view and feedback that may not be addressed during the short consultation with the clinician. It also helps the health provider to assess their patients' current medication, distress level, coping status and comorbidities to tailor their care and resources accordingly aiming to promote patient's self-management of their morbidity and comorbidities. At the same time, using the tool at each follow-up consultation can help clinicians to avoid prescribing unnecessary medications that are ineffective or not regularly used by the patients.

The study tool combined positivism and constructivism paradigms. The tick boxes provided objective numerical data for deduction, while the open-ended questions provided subjective narrative data for induction (Morgan, 2007). Deploying thematic analysis of Braun and Clarke, (2006) on participants' comments in the study tool, identified a wealth of information that could be efficiently gathered and utilised to improve the patient experience.

Additionally, the postal survey can be time consuming and labour intensive (Cook *et al.,* 2009). Previous studies proposed using a mixed mode survey (e.g., postal and online survey) as an alternative and effective method to postal surveys alone (Sinclaire, 2013; Zuidgeest *et al*., 2011). This task will be discussed further in the next Chapter, which includes interviewing a sample of the patients who participated in the postal survey to capture their opinion on using the study tool or using any alternative tool or idea to assess and support their needs.

4.10 Limitations

The limitations of this cross-sectional study include: -

- It provides a snapshot of data and cannot assess temporal trends.
- Low response rates can reduce its power leading to tentative conclusions, which cannot readily be applied to all patients with similar diseases.

- The pilot study was conducted in a dermatology outpatient clinic and its high response rate might be influenced by the impact of the physician on the patients. Patients might be embarrassed to refuse their physician's offer to participate in the study. This bias can be minimised if the recruitment process was made randomly and voluntarily by the hospital staff without the knowledge of the physician.
- Paediatric patients and adult patients with language barriers or cognitive disorders were not included which can affect the validity and reliability of its findings.
- No comparison was made between study participants and control groups to detect the difference in the general population.
- No data was obtained from the service provider to assess their, resources/limitations.
- No contemporary comparative data on different survey modes and recruitment approaches was made in order to determine their strengths, limitations and costs.
- Survey data can sometimes be difficult to interpret or to confirm accurately, as certain terms used in the questionnaire such as measuring triggering factors (e.g., cold weather, stress, or anxiety), can be perceived differently by participants (Jenn, 2006).
- No attempt was made to repeat the survey and assess the consistency of its findings longitudinally and on different populations to assess the alteration in patients' engagement/motivation and the pick rate of the questionnaire over the time.

The above limitations can lead to unknown levels of bias (Fanelli, 2019). However, despite the range of limitations, the data collected in this survey was rich, detailed and offered significant insight into the experiences of patients using primary and secondary healthcare services for the management of two common chronic skin conditions. The survey's findings were also matched with many of the findings reported in similar national surveys (Nash *et al.,* 2015), European survey (Dubertret, *et al.,* 2006) and American surveys (Krueger *et al.,* 2001).

4.11 Conclusion

This postal survey demonstrated that the study tool had the potential to engage/involve the participants in decision making of their management and to voice their needs for better care. It provided evidence on the detrimental impact of psoriasis and eczema on the personal, psychosocial and emotional perspectives of patients and their parents or families. The tool enabled them to express their challenges in dealing with chronic disease and empowered them to report the gaps in their management. Respondents declared their desire for a better healthcare service, to be educated about their illness and be involved in the decision-making process of the management of their chronic illness. Patients' needs and feedback assessments can influence their management outcome and the study tool managed to assess participants' needs, comorbidities and feedback that cannot be routinely observed or are often prohibited by appointment duration or by service limitations. The tool provided a ground for future research such as developing an online version of the tool (patient portal system), which will be discussed in the next two chapters.

5. CHAPTER FIVE - STUDY TWO - INTERVIEWS

This chapter reports on the follow up interviews with patients that participated in the postal survey (study one). The aim of the interviews was to gain a deep understanding of patients' experience with the diseases and to elicit participants' views and thoughts on the use of some form of intervention (study tool or any alternative idea) at each clinical consultation to address and support their on-going needs. The interview explored participants' living experience with the chronic disfiguring disease and their feedback about the health service they received as well as their opinion on using an online version of the study tool (patient portal system) to address their needs, challenges, comorbidities and feedback in order to support their self-management. The chapter also discusses the rationale for conducting semi-structured interviews as well as the method including the interview process and data analysis. The chapter ends with reporting the findings of the interviews and the limitations of the study.

5.1 Introduction

The survey's findings suggest that there is a desire in many participants to engage in behaviours that might support the self-management of their disease, but they were waiting for a platform to voice their needs and to be involved in decision-making and treatment selection (Ersser *et al.*, 2010; Grady & Gough, 2014). They sought alternative therapy to ease their chronic symptoms. This may reflect the failure of the treatment offered by their GP or dermatologist. It is also important to note that the cost of some alternative treatments used by the participant may be prohibitive for many patients, so advice on how and where to receive support is also perhaps necessary (Feldman *et al*., 2016; Lim *et al*., 2017; Moncrieff *et al*., 2018).

Considering the limitations of the dermatology service, I proposed having an online version of the tool or a patient portal system to provide a convenient and comprehensive digital service to the patients that can be accessed anywhere and at any time. It is envisaged that providing a comprehensive digital service to the patients can further enhance their interest or motivation to use such a tool and be actively involved in decision-making of managing their chronic illness (Firth *et al*., 2019; Irizarry *et al*., 2015). Therefore, I included the proposal of the online version of the study tool in the interview questionnaire (Appendix-V).

Conducting the interview was an important part in this research as understanding patients' views, values, expectations, and feelings is not always possible by using a questionnaire or a postal survey (Reeves & Seccombe, 2008). The latter provided a snapshot of the patients' views and feedback, which could be altered by personal, social, occupational, financial, institutional, environmental, chronological or political factors, particularly in a diverse, dynamic or mobile population (Nash *et al.,* 2015; Silverberg *et al*., 2018). For a more reliable picture of patients' views, and in order to understand patients' explicit needs and how they might be met, the lived experiences of patients require further exploration (Britten, 1995).

Additionally, before implementing a new model of care such as the above study tool, the acceptability of patients (service users) about using such an intervention is needed (Al-Abri &

Al-Balushi, 2014; Carlton *et al.*, 2017; Hernan *et al.*, 2019; Sacristan, 2015). Hence, semi-structured interviews were conducted with the patients who participated in the postal survey to explore their opinions and views on using the study tool or any alternative idea or intervention to support the self-management of their chronic disease (Mays & Pope, 2000; Opdenakker, 2006). Furthermore, as a part of the mixed method research the interview aimed to integrate and triangulate the data with that of the postal survey study to gain more information and evidence than could be offered from a single study (Andrew & Halcomb, 2009; Denscombe, 2008; Hutchinson & Wilson, 1991).

5.2 Objective of the study

To obtain a deep understanding of the participants' challenges with their chronic skin disease and their views on using the study tool or any alternative idea or intervention at each medical consultation to address their needs, comorbidities and feedback, aiming to support the self-management of their skin disease and satisfy their unmet needs.

5.3 Method

5.3.1 Rationale for choosing interview

Within the tradition of qualitative research, there are three main broad categories of data collection: interviewing; participant observation and the use of personal documents (Pathak, 2013; Pope *et al.*, 2000). An interview method was preferred in this qualitative study as it was considered to be the most appropriate and direct method for exploring the health service user's view~~s~~, needs and feedback (Opdenakker, 2006).

Denzin and Lincoln (2005) claimed that in choosing interviews as a method of data collection, the researcher hoped to gain a deeper understanding of the participants' constructions through dialogue and through the language they use in constructing the different discourses. The benefits of interviews can be strengthened even further by conducting a face-to-face interview as it allows the researcher to observe non-verbal cues during the interview process and understand the complexity of the situation without imposing any prior categorisation (Britten, 1995; Sturges & Hanrahan, 2004).

An interview, however, can take a variety of formats including structured and semi-structured (Opdenakker, 2006). In this research, a semi-structured interview approach was adopted as it enables the interviewer to interact with the participants to clarify the context of the conversation (Denzin & Lincoln, 2005). Additionally, the questions presented in this study (Appendix-V), were developed to assess participants' views on the use of the study tool or any alternative intervention to address their on-going needs as well as to obtain their feedback on the health service they received; a semi-structured face-to-face interview allowed the interviewer to seek clarity and probe for deeper understanding of participants' views. It also enabled the researcher to respond to the participants' non-visual cues or other responses by modifying their questions appropriately (Sturges & Hanrahan, 2004). Hence, data analysis of a semi-structured interview can be helpful for the generation of rich and illuminating data that is directly reflective of the views of the participants (Morse & Field, 1995; Potter, 1996; Teherani, 2015). This is particularly suited to the current study's objectives.

Nevertheless, the researcher's presence during the interview can affect the subjectivity of the responses. Therefore, the researcher should have well developed interpersonal skills that combine empathy with analytical ability (Opdenakker, 2005). Without this, the respondents may be led in different directions and the interviews can be subjected to methodology and analysis bias (Healy & Perry, 2000). Indeed, the interview required personal efforts and time. Listening, responding appropriately, and asking questions in a straightforward, non-judgemental manner throughout the interview helped to build up a rapport with each participant and motivate the participants to express their thoughts and views (Snape & Spencer, 2003). For an in-depth analysis of the data the interviews were recorded to enable the researcher to listen to the recorded interviews, fully transcribe them verbatim, and check any missing details of the interviews and to be more responsive and reflective upon any issues that may have impacted upon the way the interview was conducted (Marshall & Rossman, 1989).

5.3.2 Ethical considerations

As in study one (please also see Chapter 4), local and national ethical considerations and approval were obtained to ensure that study two was conducted in an appropriate manner. All participants were given information about the study before signing the written consent form to participate in the research (attached as Appendix–IV). The participants were informed that should they wish to withdraw at any point during the interview they could do so without giving reasons. Permission to audio record the interview was also obtained from the participants.

The identity of the participants was removed from the transcripts and replaced by their study number to maintain their confidentiality. It was further explained to the participants that their five identifiers (their name, date of birth, address, hospital number and NHS number), would remain confidential. Consent was also obtained from the participants to publish the research without using the above five identifiers. The discussion regarding confidentiality of the participant's private information had helped to establish trust with the participants in the early phase of the interviews.

5.3.3 Sampling

There is variation in the existing research around sample size recommendation for an interview. The literature suggests anywhere from 5 to 50 participants is adequate to conduct a qualitative study (Crabtree & Miller, 1992; Mays & Pope, 2000; Morse & Field, 1995; Patton, 2002; Ritchie *et al*., 2003). Factors said to be important in determining the sample size in qualitative research include the quality of data, the scope of the study, the nature of the topic, study design, the amount and the types of information obtained (Pope & Ziebland, 2000). In general, the sample size used in qualitative work is often smaller than that used in quantitative mainly because of the in-depth understanding of a phenomenon, which is often centred on a particular issue, process, situation, subculture, scene or set of social interactions rather than measuring numbers and mathematical figures (Chew-Graham *et al*., 2001).

Further, the objective of this qualitative study is not concerned with making generalisations to a larger population of interest, but to create categories or themes from the data and to analyse relationships between categories to understand the personal views and experiences of the participants (Britten, 1995). The number of participants in this study therefore can be informed by the extent to which the research question has been addressed and when data reaches a point of saturation (Marshall & Rossman, 1989). The latter is defined as the point at which the data collection process no longer offers any new or relevant data or when new themes stop being identified and the researcher can conclude that there is no need for more interviews (Hutchinson & Wilson, 1991).

Saturation however may also depend on other factors and not all of them are under the researcher's control (Crabtree & Miller, 1992; Ritchie *et al*., 2003). Some of these include:

> How homogenous or heterogeneous is the population being studied?
>
> What are the selection criteria?
>
> How much money is in the budget to carry out the study?
>
> Are there keys for an in-depth understanding of the topic being examined?
>
> What is the timeline that the researcher faces?
>
> How experienced is the researcher in being able to determine when she or he has reached saturation?
>
> (Charmaz, 2006; Snape & Spencer, 2003)

Occasionally and in order to achieve the study objectives participants in the qualitative study can be selected by the researchers to provide rich descriptions from those who are willing to articulate their experiences and enrich the researcher's understanding (Hutchinson & Wilson, 1991). Nonetheless, selection bias from such a process may result and can impact on the credibility of the research (Murphy *et al.*, 1998). Therefore, in the current research consecutive patients who participated in the postal survey and agreed to participate in further research were invited for a face-to-face interview. As the participants had already participated in the postal survey, the inclusion and exclusion criteria for their recruitment were the same as in the postal survey (Chapter - 4).

In total, 22 interviews were conducted in this study, and they included non-selected consecutive participants who participated in the postal survey and agreed to participate in further research and/or interview after their participation in the survey. The details of the participants' backgrounds included 10 females (8 were suffering from psoriasis and 2 from eczema), and 12 males (11 were suffering from psoriasis and one from eczema). The age of the participants ranged from 25 to 76 years with an average age of 49.9 years. Ten of the participants were single and 12 were married. The participants had diverse backgrounds; 15 identified as Caucasians, 4 identified as Asian and 3 identified as Black. In terms of religion, 10 of the participants identified as belonging to the Church of England, 2 identified as Roman Catholic, 2 identified as Jewish, 2 identified as Hindu, 5 did not report their religion and one identified as a Muslim.

Although, after the first 12 interviews, it was found that there was little new information being gained, an additional 10 interviews were conducted to ensure that saturation point had indeed been reached by participants in terms of their diverse views, feedback and needs. The last interviews confirmed the information gained in previous interviews and demonstrated that the information gathered had reached a point of saturation.

5.3.4 The interview process

Between August 2018 and February 2019, I conducted a series of semi structured face-to-face interviews with 22 psoriasis and eczema patients who participated in the postal survey and agreed to participate in further research or interviews, by ticking the “yes” box at the end of their postal questionnaire (attached as Appendix–II). Initially, I contacted them by telephone to confirm that they were still interested to participate in further research or interview. All the contacted participants agreed to be interviewed. After having their verbal approval to be interviewed, a briefing on the purpose of the study, the format of the session, and issues of confidentiality were discussed as well as an appointment was made with each participant at a time convenient to both themselves and the interviewer.

The interview was organised and conducted at the same hosting hospital where participants were managed and recruited for the postal survey, which is also where I am employed. On the day of the interview and before obtaining the patient’s written consent, the background of the research was explained to the participants volunteering in the face-to-face interview including a full briefing on the purpose of the study, the format of the interview, as well as the ethical considerations and issues of confidentiality relating to participation. Soon after signing their interview consent form (demonstrated in Appendix-IV), they were asked open-ended questions (demonstrated in Appendix–V) to assess their personal opinions on the acceptability and feasibility of using the paper questionnaire (study tool) or any alternative idea or intervention at each consultation to address their needs and comorbidities to their service provider and to appraise the quality of their health care.

One researcher (myself) conducted the interviews. All the interviews were face to face, in English, audio recorded and lasted for around one hour. They were semi-structured and began with the same broad question for each participant (Appendix-V), but with allowing subsequent questions to be guided by the conversation between the researcher and each participant. The participants could speak freely in their own terms about the phenomenon in question. As the qualitative research emphasises the importance of context in analysing data (Denzin & Lincoln, 2005; Ritchie & Lewis, 2003), the researcher was able to follow and discuss interesting avenues of conversation that emerged in the interview to relate to the participants in subjective ways on their terms rather than on the researcher's terms.

All interviews were subsequently transcribed verbatim and anonymised by myself and checked thereafter by my two university academic supervisors. Standardised rules of transcription were employed (Snape & Spencer, 2003), to ensure that participants' pauses, use of slang, notations of emotional content were conserved ensuring that the transcript reflected as true as possible the views of the participants and that the possibility of misrepresentation was minimised (Bazeley, 2007). Standardised rules also ensured that transcripts followed the same format, allowing the participants to speak for themselves (Chew-Graham *et al*., 2001).

All participant identifiers in the transcriptions were removed to ensure confidentiality. After typing, reading and familiarising with the data, a coding process was applied for data analysis in line with Braun and Clarke’s (2006, 2019) thematic analysis guidelines. Different codes were compared on different occasions to identify and develop themes and subthemes (below). No statistical tool was used for data analysis as the sample size was small and was easy to be managed manually.

5.3.5 Data analysis

Mouton and Marais (1991) described data analysis as the process whereby a phenomenon is broken down into its constituent parts in order for it to be better understood. In this study, the thematic analysis process of Braun and Clarke (2006) was employed, and it included the following six steps: -

1. Familiarising with the data by active reading, scanning, examining and understanding the data and the conditions behind specific problems affecting patients with chronic skin diseases.
2. The process of generating initial codes based on research questions and on the researchers’ interpretation of the data.
3. The process of searching for themes from the generated codes.
4. Reviewing the identified themes again to eliminate or to collapse similar themes.
5. Defining and naming the final themes that were relevant to the research questions.
6. Reporting the themes and their subthemes individually with quotations to support or justify why they were chosen.

Thematic analysis was a preferred choice for this qualitative study over other approaches of analysis such as grounded theory or discourse analysis as the former is mainly inductive aiming to develop a theory from the investigated data, while thematic analysis can be either inductive or deductive (Bryant, 2009; Rosentha & Rosnow, 2007; Tuckett, 2005). Discourse analysis focuses mainly on understanding written or spoken language in relation to its social context by paying attention to the linguistic meaning of the text (Bazeley, 2007; Crabtree & Miller, 1992; May & Pope, 2000). Thematic analysis, however, does not rely on pre-existing theoretical frameworks or language analysis of a text and is therefore a more accessible approach with the ability to be used with a wide variety of frameworks (Braun & Clarke, 2006, 2014, 2019).

Further, thematic analysis can help to identify versions of autonomy from the participants' viewpoint rather than providing an absolute answer to the problem (Tukett, 2005; Turk *et al*., 2020). By providing clear links between themes and the aims of the study, thematic analysis can generate a rich thematic description of the whole data set, which is a useful approach and is particularly relevant to health service studies (Marshall & Rossman, 2011; Pathak *et al*., 2013; Smith *et al*., 2017; Wisdom *et al*., 2012). Indeed, in this study, thematic analysis (Figure–9) identified clinical and psychosocial themes and reported the gaps and limitations within the health service.

The framework approach to managing and analysing data in this research was a flexible process and included revisiting earlier stages in the analysis and reading the participants texts to rule out missing further key themes or issues (Braun & Clarke, 2019). As the qualitative study was mainly focused on analysing the spoken words that were transcribed to create a written text, the recorded interviews were transcribed verbatim within 2 days of being conducted and written text was created of each interview. The intention of this rapid transcription process was to allow the researcher to become familiar with the data as quickly as possible and to eliminate recall bias (Bazeley, 2007; Leedy & Ormrod, 2016).

Each transcribed interview was first analysed individually to arrive at an understanding of each participant. Common and similar answers were then identified. Analysis was a continuous process in which the participants' narratives were read on multiple occasions. Similar words, phrases or sentences were selected as codes to answer the research questions.

During the process of reading the individual protocols and codes, notes were made of the ways in which the participants constructed the meaning of the concepts that were being investigated. Each individual transcript was read several times to inspect and check that the constructions of the concepts were fully documented and to ensure that no new interpretations were seen from each re-reading. The reading of the transcripts continued until there was no evidence of any new trends or interpretations from the text identified.

In the selection process of the codes, examination of the text for contradictions, similarities and ambiguities were made and reported. Similarities and differences regarding the ways in which the participants spoke about the same or different themes were documented. The literature was regularly reviewed to make sense of the analysis and to ensure the stability and credibility of the findings. The themes are presented in relation to the broader context of this study, which included patients' views, needs, challenges, comorbidities and feedback. Direct quotations from the transcripts are provided as evidence for the identification of different discourses.

5.4 Thematic analysis - results

As in the postal survey, the participants' responses in the interviews were rich and diverse. The thematic analysis showed that all participants found the study tool was easy to understand, easy to use and easy to fill out. They all welcomed the idea of using such a tool at each clinical consultation with their service provider to address their needs, comorbidities and feedback. Nineteen participants (86.3%) stated a preference for an online version of the questionnaire as a convenient way for communicating with their healthcare provider. Some of the participants discussed the idea of using alternative methods to support their needs and expressed their personal experiences and views. At the end of the interview, many participants provided feedback about the quality of the service they received in primary and/or secondary care and expressed their challenges in living with and managing their chronic skin condition.

There were 5 main themes and 17 subthemes that were identified relevant to the research questions (Figure – 9).

Theme 1: Participants' views on using the postal questionnaire (study tool)

- 1.1-Feasibility of understanding the questionnaire
- 1.2-Feasibility of answering the questionnaire
- 1.3-Participants' opinions on what can be added to the study tool to support their needs
- 1.4-Barriers to complete the questionnaire
- 1.5-Frequency and timing of the questionnaire

Theme 2: Usefulness of using the questionnaire on a regular basis

- 2.1-Benefit for the patient's needs
- 2.2-Benefits for the patient's management
- 2.3-Benefits for other patients with similar skin diseases
- 2.4-Benefits for improving the quality and the time of the consultation

Theme 3: Participants' opinion on using other tools or methods to support their needs

- 3.1-Patient - physician electronic link
- 3.2-Patient group: forum and workshop
- 3.3-Patient information and education
- 3.4-Stress management and healthy lifestyle support

Theme 4: Participants' view on using an electronic version of the questionnaire (portal)

- 4.1-Convenience of online access
- 4.2-Portal versus paper questionnaire

Theme 5: Participants' feedback and comments

- 5.1-Problems with the health care service
- 5.2-Patient's feedback

Figure – 9: Thematic analysis of the 22 interviewed participants

Below are the details of the themes identified from the participant interviews supported with extracts from the transcripts.

5.4.1 Theme-1 Participants' views on using the paper questionnaire (study tool)

In this mixed method research, the paper questionnaire (study tool) is proposed to play a vital part in patients' engagement, involvement, assessment, and support. Hence, the evaluation of the acceptability and the effectiveness of the tool in supporting patients' needs was one of the main goals of the interview. The following five subthemes were identified:

- **1.1-Feasibility of understanding the questionnaire**
- **1.2-Feasibility of answering the questionnaire**
- **1.3-Participants' opinions on what can be added to the study tool to support their needs**
- **1.4-Barriers to complete the questionnaire**
- **1.5-Frequency and timing of the questionnaire**

Subtheme (1.1): Feasibility of understanding the questionnaire

All participants found the postal questionnaire easy to understand and to fill out:

> *"I found it easy to fill in and it was quite nice to answer the questions…. Nice to be asked about it"* (Participant no. 1)

> *"it was quite easy...quite easy to understand what the questions are about and easy to fill"* (Participant no. 7)

Some participants also agreed that filling out the questionnaire was easy, but they preferred using an electronic version rather than the paper questionnaire:

> *"Fine, but electronic version is always better to answer"* (Participant no. 9)

Subtheme (1.2): Feasibility of answering the questionnaire

Despite the diversity seen within the study sample, all the participants' responses were positive about using the tool. They stated that the questionnaire was simple, clear, concise, straightforward, easy to understand or easy enough to complete, and not very complicated:

> *"I found it quite easy answering the questions. I didn't have a problem answering them"* (Participant no. 2)
>
> *"It was good…it was quite clear, concise"* (Participant no. 16)

Whilst the acceptability of the participants using the questionnaire was positive and encouraging, they were asked more questions on the study tool to capture their views on its quality, effectiveness, advantages, disadvantages and on the frequency and the appropriate time for the patient to fill out the study tool.

Subtheme (1.3): Participants' views on what can be added to the study tool to support their needs

The majority of the participants were happy with the questionnaire as it is. They did not feel that there was a need to add more questions to support their needs or the management of their skin diseases. They also acknowledged and appreciated the advantages of the design of the questionnaire including the open-ended questions with empty spaces provided in the questionnaire to motivate/empower the patients to express their feelings and views about their chronic condition and about the quality of the health service:

> *"No, I don't think so. The questionnaire is good. There is not much else that could be covered"* (Participant no. 6)

> "*I can't think of anything to be fair. Any question that you pose always jolts your own memory to try to understand…I don't think that there is ever a question that I wouldn't answer because I think it would benefit me and if I can benefit myself and this will be great and good of everybody else, I am always going to be willing"* (Participant no. 20)

Participants also appreciated the benefit and the advantages of the questionnaire in supporting the management of their skin disease:

> *"I think you covered most subjects...I am happy to fill it in….it tells you how it affects us emotionally and the questions you asked are quite helpful"* (Participant no. 14)

> "*I think the patient is given the opportunity to say what he wants to say, and the consultant will have this information. If the patient is given the freedom to say what they want, then that's great and is good enough"* (Participant no. 22)

A few participants suggested adding more questions to the study tool including questions on coping with the skin disease, the impact of the skin disease on patient's personal lifestyle or on their social activities:

> *"I think sometimes asking a question like...how it affects us in a day-to-day way can help the professionals to understand patients…if this makes sense. It would be a positive thing if the dermatologist asks more questions on how we cope with it* (skin disease). *It makes us feel more listened to as well…I think…but I understand it is hard time wise. I think personally it would be nice"* (Participant no. 1)

> *"I think there was stuff about how it affects socially, but if it wasn't on there* (in the postal questionnaire), *may be something like that could be added, because some people are going out feeling a little bit how people see them with skin problems, so may be a bit on how it affects people socially and mentally"* (Participant no. 16)

Other participants acknowledged the advantages of the questionnaire's design including the MCQs and the open-ended questions:

> *"The option was given with the MCQs giving the opportunity for comments at the bottom of MCQ and if my problem was not among the list of MCQ, I can write what I want"* (Participant no. 7)

> *"it is satisfactory. It gives you the opportunity to expand. There are enough empty spaces there to write an explanation"* (Participant no. 19)

> *“I think the questions were fairly extensive. You can put the information down…I couldn’t really think of anything else”* (Participant no. 21)

Subtheme (1.4): Barriers that prevent the patient from using the questionnaire

The participants were asked about the barriers and the circumstances that may discourage or prevent them from completing the questionnaire at each consultation. Most participants expressed no barriers to using the questionnaire on a regular basis:

> *“I can’t think of anything stopping me from doing it”* (Participant no. 5)

> *“None...It is fine I can do it here or at home”* (Participant no. 10)

One participant expressed the circumstances that can prevent him from answering the questionnaire:

> *“If I was not certain of an answer, if there is a question, I wasn’t really happy with, I have to put that in the questionnaire…We could have certain circumstances that we can’t fill the questionnaire”* (Participant no. 21)

Other participants expressed time as a possible factor that can stop them from completing the questionnaire on a regular basis, but they acknowledged it can be completed any time before the next consultation:

> *“Time, I think. I think like everybody professional; patients are all stretched by time. I think that is the only thing to be honest…I can do it in the evening* (filling the questionnaire) *because I have to go to work. I don’t know, it is just little practical things I think“* (Participant no. 1)

> *“Just the time, but you have to make time for such things, don’t you? I am happy to fill it here or at home“* (Participant no. 8)

Some participants expressed their preference of using the online version of the questionnaire or the patient portal system as a convenient service that can solve the time factor:

> *“Time, if you are rushing around, but if it is an online portal then it is something you can go back to or save it if you get distracted and then go back and yeah complete it. I prefer a portal service”* (Participant no. 2)

> *“time needs to be found to make sure that it's done. If it is portal then there shouldn't be any problems at all, should be relatively simple”* (Participant no. 11)

> *“Most probably I prefer the questionnaire online as App. It is just preference, but I wouldn’t mind either way”* (Participant no. 21)

Subtheme (1.5): Frequency and timing for filling the questionnaire

As the study tool aimed to assess patients’ ongoing needs and feedback at each consultation and to identify their psychological and metabolic comorbidities at an early stage, the participants were asked whether they would agree to use the questionnaire on a regular basis at each consultation with their physician.

All the participants agreed that they were happy to use the study tool on a regular basis at each consultation. They also justified their rationale for doing so:

> *“Yeah, definitely, because patients with skin diseases have to keep coming back for follow ups and if they have chronic diseases sometime, they feel low or sometimes they feel high, all kind of things may be going on. I think it is a very good idea to use it...yea”* (Participant no. 9)

They also acknowledged the benefits of providing regular feedback on updating/optimising patient’s management plan:

> *“Yes, most definitely because it gives the information that you need which help you to decide a better treatment”* (Participant no. 19)

A few participants suggested using the questionnaire mainly during the flare of their skin disease:

> *"It is an individual thing. I think it depends on how people feel. I mean I am happy to do it, but I don't know if anybody else is, and I think it depends on the severity of the disease"* (Participant no. 8)

> *"Yes, when it* (skin disease) *is severe and affects quality of life"* (Participant no. 12)

Regarding the time of filling the questionnaire, although most of the participants preferred filling out the questionnaire "before" each consultation, two participants recommended filling the questionnaire "after" the consultation:

> *"Yes…but after the consultation because it gives people the option to give feedback and if they forgot anything, they could give feedback to you as well. Where if you give it beforehand* (before the consultation) *you would lose this opportunity and then you have got to remember things one months or 3 months down in the line"* (Participant no. 19)

> *"I suppose I prefer to use the questionnaire after the consultation because…if there is a change in medication it will be very relevant"* (Participant no. 21)

The above theme demonstrated the participants' acceptability of using the questionnaire (study tool) to address and support their needs. Nonetheless, patients with eczema and psoriasis often require long-term follow-up consultations with the health care provider; hence, the next theme explores the participants' opinions on the benefits of using the study tool at each consultation to support their long-term needs.

5.4.2 Theme-2 Usefulness of using the questionnaire on a regular basis

As this research is proposing that using the study tool on a regular basis can play an important long-term role in engaging/motivating and supporting patients with skin diseases, the participants were asked again to provide their view on whether there are advantages of using such a tool at each consultation with their physician. All the participants agreed and expressed the potential benefits with using the questionnaire to support their long-term management. Four subthemes were identified: -

- **2.1-Benefit for the patient's needs**
- **2.2-Benefits for patient's management**
- **2.3-Benefits for other patients with similar skin diseases**
- **2.4-Benefits for improving the quality and the time of the consultation**

Subtheme (2.1): Benefit for the patient's needs

All the participants agreed that using the questionnaire on a regular basis can help them to express their ongoing needs. Some of the participants discussed this in relation to their personal beliefs, values and expectations:

> *"I think so, because it makes you think about what you want to ask the doctor and what you want to say. I think it is a good idea"* (Participant no. 8)

> *"It is a good idea...you will know more about my feelings through the questionnaire. If the doctors listen to what a patient says, it would explain how it affects your sexual life, your home life. It gives more time to express your needs"* (Participant no. 14)

Participants also recognised the importance of the tool in supporting patients' self-management in between the follow up consultations by enabling them to contact the physician in an emergency if they need urgent help:

> *"Yes, it would, because, if the medication is not working then this highlighted to you and possibly it needs to be adjusted in whatever way, otherwise you are waiting for a long period of time between each visit and effectively you are not really treating the problem. It is certainly feasible"* (Participant no. 21)

Subtheme (2.2) Benefit for patient's self-management

The participants valued the benefits of using the questionnaire in supporting their self-management. They recognised that the study tool would enable their physician to read, and manage their new comorbidities, assess their unmet needs and self-management before writing a prescription:

> *"I think so, yes. Why do I think so…sometimes it is not really the psoriasis that is the problem…it is the consequences of what is going on. For example, if I was depressed because of the psoriasis, you will be able to refer me appropriately. So I think it is good"* (Participant no. 7)

“Yeah, definitely...because patients with skin diseases have to keep coming back for follow ups and if they have chronic diseases … all kind of things may be going on. I think it is a very good to use it...yeah” (Participant no. 9)

“Yes, because doctors will have the information in the questionnaire, and she/he knows what I have been prescribed and if that’s not working then he will be able to prescribe something else” (Participant no. 10)

“I think that it is useful that you are having this questionnaire. It is only doing good, because (a) - you are trying to get information from the patient and hopefully dealing with it, and you know everybody wants to express themselves and I think this is an opportunity for them to do so” (Participant no. 22)

“Yes*, because I suppose it gives you an insight of anything else that I may have problems with, so when we get to our consultation, we get straight into the bits that you need to talk about. So, I think by filling out this questionnaire, it gives you more in-depth from my side, how I am feeling about everything. It makes you understand where I'm coming from, as a patient…I would say yes because, obviously each case is different, but I think by doing that it gives the doctor a bit more of an insight to your specific case”* (Participant no. 11)

> *"I think it is very useful so you can give up–to-date information. You can obviously let the practitioner know about your current situation and condition and it gives an opportunity to improve the practice"* (Participant no. 17)

The tool can also assist the patients to build up or enhance the doctor-patient relationship or patients' relatedness to the service provider.

> *"I also feel it is a good opportunity to sort of develop the doctor-patient relationship. In fact, it is an ideal opportunity for the patient to report using the questionnaire. If they really feel they want to make points. You are going obviously to attract some sort of criticism may be that is unwarranted, but you have got to look to the bigger picture I suppose and give the people the opportunity to say that this is something I wasn't happy with"* (Participant no. 20)

> *"When I first got it* (skin disease) *and get another patch* (skin rash) *in the shower it was really concerning me...I really think that speaking about it and if your mind is right that really do to myself well"* (Participant no. 15)

> *"It gives the patients the opportunity to express themselves they can put down on the form what they are feeling whether it is mentally, psychologically, and when they come*

> *to see the doctor or the consultant, she/he will know how the patients feel before they sit down"* (Participant no. 18)

Participants felt that the tool could help the GPs or the dermatologists to understand how the patients cope with their chronic disease as the tool provides an assessment of the patients' psychological, personal and social status:

> *"Yes, I think that the GPs individuals themselves and patients have different types of psoriasis. I think it helps GPs to understand what kind of treatment best for each patient"* (Participant no. 13)

One participant however was concerned that their feedback might not be taken on board by the service provider:

> *"Limitation of questionnaire however when practitioner does not review information prior to appointment"* (Participant no. 12)

Subtheme (2.3) Benefits for other patients with similar skin diseases

Whilst all the participants agreed that using the questionnaire on a regular basis would help their skin condition, some of them thought that it could also help research in skin diseases and be of benefit in managing other patients with similar skin conditions:

*"When the doctors read what actually the patient is going through it might help other similar patients as well" (*Participant no. 10)

"*Yes, because the more you learn about my condition, it does help you and helps other patients also. The more to speak about it and research...it got to be a good thing"* (Participant no. 15)

"I think yes ...it is helps to find a cure or treatment that helps the majority" (Participant no. 20)

"I think it could be purposefully helpful if there is some sort of collation of information feedback which might benefit other people with the same problems…it can be a life document you could see where you have been and what you had" (Participant no. 4)

"it helps to build up a profile so more explanation you have the more details the better treatment could be tailored to individual person's need" (Participant no. 16)

Subtheme (2.4) Benefits for improving the quality and the time of the consultation

Whilst recognising their own unmet needs, participants expressed an understanding of the fact that the regular use of the study tool has potential benefits in improving the quality and the time of the consultation. Reviewing all the necessary information and medication in the tool can assist the physician to focus and manage patient's current needs:

> *"Definitely, because I can communicate more, there is only limited time when I come to see you. But I think it will save time. Saving time is very good with the NHS time, because we can get right to the point or right to the issue which is bothering me at that time"* (Participant no. 9)

> "*Yes, because it would inform the doctor before I come into the consultation and cut down his time"* (Participant no. 10)

> "Yes*, because consultation time limitation. The questionnaire can address issues that can't be discussed in outpatient appointment"* (Participant no. 12)

> *"sometimes you forget things as well so doing that in advance would be easier"* (Participant no. 5)

> *“I think it is good, because you don’t always remember what you want to ask before you get there* (in the follow up visit with the physician) *so a questionnaire brings up those subjects before you come, and you can prepare yourself”* (Participant no. 20)

> *“Yes, I think I would recommend…it will be great opportunity for people to sort of put information down and you would possibly wouldn’t have the time in the period allowed to sort of gain that amount of information“* (Participant no. 21)

The above theme demonstrates the acceptability, and the approval of the participants in using the study tool on a regular basis to support their needs and the self-management of their chronic condition. They discussed the benefits of the tool in offering them the autonomy to criticise their management and the opportunity to structure their needs and feedback.

The study tool acted as an interactive intervention linking the patient with the health care provider. It is envisaged that using such a link on a regular basis can enhance patients’ experience. Providing regular feedback can alert the health commissioner to review the service and/or tailor their resources toward patients’ needs. Potentially the tool can help to improve both patient satisfaction and the quality of the health service.

Nevertheless, although the participants were happy to use it on a regular basis, other tools, methods, or interventions that may help the patients need to be discussed and explored with the participants.

5.4.3 Theme-3 Participants' opinion on using other methods to support their needs

In order to understand and acknowledge patients' views, thoughts and needs, the participants were asked if they have any alternative ideas or methods other than the questionnaire that can help in supporting their needs and the management of their skin disease. Their responses were divided into the following four subthemes: -

- **3.1-Patient-physician electronic link**
- **3.2-Patient group: forums and workshops**
- **3.3-Patient information and education**
- **3.4-Stress management and healthy lifestyle support**

Subtheme (3.1) Patient-physician electronic link.

Participants discussed their interest in having electronic links with the health service provider particularly during emergency circumstances or when they need urgent advice in between the follow up appointments. Some of them expressed that such links could help to solve part of their ongoing stress, confusion, and struggle, which might result from poor self-management of their chronic diseases. Having an electronic link can enable patients to obtain urgent advice from their specialist, while waiting 3 or 6 months for the next appointment:

> *"I think some interim support would be helpful. I think I struggle when I have had my appointment with the dermatologist and I have a sort of treatment programme that I have to do, but it might be like months until I see somebody…I don't know if there is a text service which may be practical or something where I could just have a phone call with the dermatologist just in between the follow ups, because sometimes I get a bit*

confused with, oh I got to put this cream now or I get a bit stressed because it is getting worse and not getting better. I think just having somebody to call or even if it is scheduled. You are not going to see me in many months but if we can phone the dermatologist in between for treatment advice" (Participant no. 1)

"I am thinking more of...may be online video. Telemedicine. so if you have a new rash you want to show to your doctor, you can take a picture of it and send it to the appropriate channels or to the consultants and they can tell you the diagnosis, by this you might not need an appointment for that, may be giving information instead" (Participant no. 7)

"Consider communication by email" (Participant no. 12)

"May be an electronic way of communicating so as things happens because sometimes over the space of the 3 months' period you may forget something when the doctor asks you a question, you are at the hospital, you are a bit stressed" (Participant no. 16)

"Interactive link in the form of a text message or email with link...to remind the people to attend their appointment, purely because it gives the patient the ability to communicate with you on a regular basis, should there be any changes in their condition and also it gives you an update on how the medication is affecting the

> *patient's condition if it is improving, worsening or if staying the same. Where if I walk through the door you wouldn't know what treatment I am using"* (Participant no. 19)

> *"Things like computers, tablets and phones…are capable of recording their day to day living and what they done and what triggered certain things that might help because it is diarising it and you can backtrack things…. Using technology to look to your own symptoms and then you have some sort of records on what happened….so that might help" (*Participant no. 20)

Many participants showed interest in having an online version of the questionnaire and some of them preferred using a patient portal system. The latter is online software linking the patient with the service provider. It can be designed, developed, and managed by the IT team within the hospital (Portz *et al*., 2019; Sun *et al*, 2019). A portal version could be installed in the form of a mobile phone app:

> *"It is just more convenient to have a portal service, you can do whenever you are sitting on the phone and you have a spare 10 minutes, you can do then if you have got an iPad. You don't necessarily have to sit in front of the computer to be able to do it. If it was a paper questionnaire you have got to be at home to stick it in an envelope. I am always more inclined to type what I am thinking, if you ask me to write it"* (Participant no. 2)

"The portal system can give a consistent reminder. Sometimes things can happen if you have been started on a new medication, but you forgot your medication. The portal system can sign post a patient to where to get useful information and direct you to the right channel…The other option is to go back to your GP and ask them to write a letter to the specialist. But if there is a channel like portal system with interaction where you can ask for appointment in 3-6 months and…. If the flare happens how can I stopped it from getting worse" (Participant no. 7)

"If it is portal then there shouldn't be any problems at all. It should be relatively simple" (Participant no. 11)

*"A portal system would be great to communicate anything to you, but you might also have an App on Android phone or iPhone. People spent long hours on their phone a day" (*Participant no. 19)

"Portal system I think...I would recommend it. It will be a great opportunity for people to sort of put information down and you would possibly be allowed to gain that amount of information. The questionnaire was sort of comprehensive enough as I see. It has no need to be filled there and then if it is online just go to the website and then you can fill it. Either way really, I wouldn't mind to be in the phone (App) or online, just

> *go to the website to put information. Most probably I prefer the questionnaire online as App. It is just preference"* (Participant no. 21)

The above quotes may reflect the participants' desire to be autonomous and self-sufficient in self-managing their chronic illness. The electronic version of the tool can offer them the opportunity and the freedom to interact with the service provider in an emergency. It can actively involve them in their self-management (Reed *et al*., 2019; Rigby *et al*., 2015; Sun *et al*., 2019).

Subtheme (3.2) Patient group: patient forum, workshops, awareness group

Some of the participants expressed a desire and an interest in communicating with other patients who have similar skin conditions to share their personal experiences and successful treatment stories. They explained that such communication can make them feel comfortable and help them feel that they are not alone. They suggested making such contact through live or online patient forums, patient support groups, workshops, open days, or awareness day events:

> *"A kind of a forum where you meet other people...Both my brothers have skin problems and I tend to chat with them, but the people who don't know anybody else might help them. A live workshop would be good but getting people there may be difficult especially people with mobility problems. But I think most people are quite comfortable using the internet and online forums. I think talking to other people is good. You know when I come here for light therapy, I often chat to people with a similar condition sharing my experience"* (Participant no. 8)

"Ah…if you have group sessions with people who really suffer, so they can discuss what they are going through during the course of the day or the night. Both online and live workshops can be helpful, because some people may not be able to attend the live workshop for different reasons and if they have got a computer then they can do it online" (Participant no. 9)

"In severe flare or severe cases offer support group. People with similar cases can discuss what treatment, medications, creams work for them and why. Discuss daily routine of application of topical therapy" (Participant no. 12)

"They should have some kind of group thing where you have other people with psoriasis chat and have a better understanding and share their successful treatment stories. May be other patients might try a successful treatment. They may be benefit from changing their diet and things like that…. Patients need to help themselves not only using creams and putting moisturisers" (Participant no. 13)

*"Offering workshops, open days, awareness days, giving leaflets in different languages, local ads for awareness on treatment, procedures and all these things. I said at least couple times a year, but I know funding is problem to offer these events" (*Participant no. 17)

Patients with stigmatising skin diseases such as psoriasis and eczema may feel depressed, fearing the stigma and peoples' judgement (Alpsoy *et al*., 2017; Clarke *et al*., 2020). Patient forums and workshops can give them the opportunity to interact and feel connected to someone who shares these experiences, or to share successful self-management stories.

> *"Speaking with other people with the same experience. Maybe you could have like a class or other thing, if people are more open you become more relaxed, I think. For sometimes...I felt that mine (*skin disease) *was worse and it's never got to go, and no one has got it as bad as I have, but obviously people have it a lot worse and I didn't know that because I was thinking that mine is terrible. I think group therapy or a forum or whatever you want to do. It was going in my head* (Skin disease) *and I was falling apart but when I actually went to the hospital, I met a chap there who exactly has the same skin condition. He was saying it is itchy I can't do this, I can't do that, sometimes I put off social events because I got rash in my face, and I felt exactly the same, but before I went, I was thinking to myself it just me which is a mind-set"* (Participant no. 15)

> *"When I was at the hospital there was a poster on the side saying about a psoriasis support group and you can talk about your condition. I did in fact sign up for that and that was quite helpful to see how other people handled it. It was all online through the internet and you could create yourself almost like a little portal and you go, and you talk to other people with the same conditions, ask questions, and obviously answer if you know something that may help. Apart from that, no I don't think there is anything else"* (Participant no. 11)

Nonetheless, patient forums, workshops, or group therapy may not be suitable for all patients, especially if their skin condition is very mild or if they are shy, nervous, self-conscious, depressed, having disabilities, language barriers or having full-time demanding jobs:

> *"I don't think group therapy would be for me. As I say, because mine is quite mild and it doesn't really have an adverse effect on my life. I don't think I sort of would bother with that and also I work full time and I am busy anyway so that would be a time factor as well"* (Participant no. 5)

Subtheme (3.3) Patient information and education

Participants varied in their reported levels of satisfaction about the amount of information that they received from their physician about the available treatments and the details on how they should be used. Some of them expressed the need for education, guidance, or information on up-to-date research related to their skin disease and its management.

Other participants were keen to have information on the choice of treatment available for their skin problem including alternative therapy to manage their skin condition. A small number expressed dissatisfaction related to difficulties in obtaining or sharing such information:

> *"Maybe some kind of guidance on what may help and what doesn't help...because I'm a little bit unsure. So, yeah, I think that it would help giving more info or insight…. I*

> *have heard of the Chinese remedies and all of those things, but I have never tried them, no"* (Participant no. 11)

> *"In severe cases offer detailed and accurate information and test results. No point telling me that I am sensitive to all types of foods...etc."* (Participant no. 12).

> *"Education...Patients need to address that they have a skin problem. They have to look after their skin and have education and that again depends on the individual" (*Participant no. 13)

> *"Giving information...If there is new product. If the information coming through from the dermatologist that could help" (*Participant no. 21)

The above participants' quotes may reflect their desire to be educated about their disease or to be self-efficient and competent in self-managing their chronic illness.

One participant explained the importance of offering information before discharging the patient. He was concerned that he might struggle alone with the management of his skin condition if he develops further flares of his skin disease:

> *"Just more information is helpful, even though they have discharged me, if something is to happen again with my skin and if it is in your mind you can go to the doctor, speak about it and you do the best to sort the problem out. The more you learn about it the more it became clear in your mind what psoriasis is and why it can come about"* (Participant no. 15)

Subtheme (3.4) Stress management sessions and healthy lifestyle support

Some participants expressed their need for psychological support to control their stress as they felt they could not control it themselves and it can affect their concentration, performance, and quality of life. They suggested that the health service provider should introduce stress management sessions, a social network, group therapy, meditation, diet, or healthy lifestyle changing ideas to support their skin disease management:

> *"I think you need to put in the questionnaire if we are coping with stress or not. Sometimes I don't manage stress at all because it is beyond my control. I have a stressful job with deadlines likes other industries or the NHS. I do go to another clinic, where I get my back and joints pain treated, with chiropractic and they always have ways to help me. I don't know if the NHS can introduce stress management in the form of meditation or prayer and introduce it and incorporate it in the social network. I found a lot of it in You-tube with meditation and managing stress. People have no time for group therapy, but something you can concentrate on for 10 minutes in the morning to try to relax and to breathe properly and you can apply this during the day when you are in stressful situations" (*(Participant no. 9)

“Information on diet...I have few ideas about diet, but that has really never been discussed that much, so I think that it would be really something interesting to look into, because I have had eczema since I was a baby. I don’t think anyone really spoke into me about my diet and no one asked me what my diet was. I don’t eat very healthy; I try to, but working time and everything. I think diet would be interesting for me to explore, but it would be interesting to see a professional could ask patients a little more about diet, because I think personally diet has a big role in health” (Participant no. 1)

*“I think the NHS should come on board with some kind of suggestive things for exercises, meditation and nutrition. Because psoriasis and psoriatic arthritis are autoimmune diseases and I think there is strong correlation between nutrition and autoimmune diseases, not always but sometimes. NHS should look into it and consider nutrition and non-processed food, just whole food, simple cooking, very easy to live that way“ (*Participant no. 9)

“If you learn what lifestyle and foods are good…your body is like a machine so if you are putting in good nutrients may be that can help the skin also, I am not a dietician, but it is common sense, if you look after yourself in that way, I think you can manage your skin better” (Participant no. 15)

“Now I am speaking to you…things come to light in my mind, like managing your diet, just like managing other stuff and so on, but when I was filling the questionnaire, I couldn’t think of anything so I wrote none... lifestyle support can be helpful…just watch

> *what your alcohol units are, watch your fatty food. I do try to watch my fatty food. I do love chocolate, I might have the odd bar here and there and treat myself, but I am not a chocolate person. I used to be, but now the diet thing I changed and started to help myself anyway"* (Participant no. 18)

The above theme reflects the missing parts in the patients' self-management, which often are not routinely discussed, addressed, and managed by the health service provider (Nelson *et al*., 2013; 2014).

Their desire for health information, and to lead a healthy lifestyle, may reflect their wishes to be autonomous and competent to self-manage their illness. Similar patients' requests were reported in previous studies (Esser *et al*., 2010; Nash *et al*., 2015).

Notably, most participants showed interest in having a patient portal system as a convenient tool to communicate with the service health care provider. Hence, the following theme explores participants' opinions, and preferences on using the paper version of the study tool or its online version through a portal system.

5.4.4 Theme-4 Participants' views on using an electronic version of the questionnaire

Many of the participants expressed interest in using the online version of the questionnaire. They were specifically asked if they prefer using the portal system or the paper version of the questionnaire. Their responses were divided into two subthemes: -

- **4.1-Convenience of online access**
- **4.2-Portal versus paper questionnaire**

Subtheme (4.1) convenient service

Of the 22 participants, 19 (86.3%) were keen to use the online version of the study tool through a patient postal system rather than using the paper version of the questionnaire.

Participants suggested that providing the online version of the questionnaire is more convenient as it can be filled out at any time and in any place without being affected by time pressure:

> *"I would probably prefer to do it electronically because I am on computer all the time. I use computers all the time so it would be quicker than sitting there writing"* (Participant no. 5)

> *"I think so, because we are all going technically. We are doing more on the mobile phone. It is a channel of communication. Patient would have access. It could help with patient satisfaction, and patients know that they are not alone and if they have a problem, they can contact the team in one way or other"* (Participant no. 7)

> *"Yes...definitely, because it is easier, I think. You can fill the questionnaire wherever you are and wherever you are sitting. Convenient to everyone" (*Participant no. 6)

> *"Yes, I would say so, yes...Because it is slightly easier to access and everybody can access it at any time. Also, it is easier to use and quicker. I prefer it on the portal, than on the paper" (*Participant no. 11)

> *"For sure, yes...Purely because it is handy and more convenient…most people have an electronic device Android or iPhone, computer, iPad, whatever they have...I personally I spent my life travelling throughout the country for various construction jobs, so it wasn't always convenient for me to attend the appointment. Don't get me wrong, I do my best all the times, but that is not always a possibility, so with the portal system I can drop a message saying that I will not be able to attend because of my job"* (Participant no. 19)

Participants also appreciated the patient portal system in being paperless:

> *"Yes, definitely, definitely, definitely. It is more convenient, then you have to keep track of the papers and I am a paperless girl. Personally, myself I just send it all in email"(*Participant no. 9)

> *"Yeah, people now are more on technology, and I think people are changing culture…and paperless…People can communicate quickly as possible online and they can do their online messages in their own time" (*Participant no. 17)

The portal system can eliminate recall bias as it can assist the patients to list all their needs, comorbidities, and medication that they may forget to remember during the short medical consultation:

> *"Yes, I do, because if it is at home then people sometimes remember things and they can note that down online. Such as the name of the medication they take, which they may forget to remember them if they attend their hospital appointment"* (Participant no. 10)

Because of the potential benefits of the portal system in supporting and addressing patients' needs, some participants suggested providing a laptop for the patients to fill the online questionnaire in the reception area of the health service provider. This is specifically helpful for patients who have no access or experience of the internet or need support from the receptionist to assist them in filling the online form if needed:

> *"Yes, portal on website, that will be fine or online laptop in the reception area and after the consultation"* (Participant no. 3)

> *"I personally have no access to computer, so I probably answer no for electronically, however, if it is done while waiting for appointment or after you left the appointment"* (Participant no. 18)

A few participants expressed their preference in having access to the online version of the questionnaire or the patient portal system through a mobile phone application (App):

> *"Yeah...definitely, I think it just makes it little bit easier because everyone on their phone as well. We are living in such a tech world" (*Participant no. 1)

> *"Definitely, App would probably work best. However, any form of online communication would give better response and provide more help"* (Participant no. 12)

> *"Personally, I prefer an App in mobile, may be other people go to the reception to fill a questionnaire in a laptop, but I would rather be at home doing it on my own speed. It is a personal thing" (*Participant no. 21)

The above quotes reflect the participants' wishes in having a convenient intervention that can support their autonomy to address their needs remotely. The portal system can offer them the choice and the convenience in contacting their service provider in an emergency and assist in self-managing their illness (Portz *et al*., 2019; Sun *et al*., 2019).

Subtheme (4.2) Portal versus paper questionnaire

Three participants were not keen on the idea of using an online version of the questionnaire. They preferred using the paper version or having a face-to-face consultation with their physician. Their decision was based on either their lack of internet access, lack of computer experience or concerns of inability to answer the questions correctly online:

> *"I don't mind online feedback, but it would be for a younger generation. For me I have no brain for electronic technology. I prefer paperwork and I would rather speak to somebody rather than a machine...Sometimes the online services do not actually give you the options for the question you want to ask and that could be kind of frustrating. I don't do online banking or anything like this, I like to have my paperwork that just the way I do" (*Participant no. 15)

> *"I personally have no access to computer, so probably my answer is no for electronically"* (Participant no. 18)

> *"Well I think in my generation probably not. Perhaps the younger generation they would. Most young people use computer and keypad phone more than they write letters or even speak in the telephone. For me I prefer verbal discussion and writing. It is my own personal view" (*Participant no. 22)

5.4.5 Theme-5 Participants' feedback and comments

The final part in the interview was to give the opportunity to the participants to declare and report any questions, comments, feedback, or ideas that might help with the management of their skin condition. Their answers were divided into two main subthemes:

- **5.1-Problems with the health care service**
- **5.2-Patient’s feedback**

Subtheme (5.1) Problems with the health care service

Just like in study-1, the participants expressed their unsatisfactory relationship with their GP and dermatologist. Some of them talked about the GP’s responsibility when managing chronic skin problems and that they felt that GPs should take a more active role in helping their patients. Likewise, some participants found little help and lack of empathy from their dermatologist. They however felt that the study tool can help their physician to better understand patients’ challenges and needs and may assist in improving their management:

> *“It* (the tool) *is beneficial because you* (Doctors) *can understand how we feel a bit more … perhaps it helps me talking about what else can be done”* (Participant no. 2)

> *"I think if the consultant can understand what the patient feels and get the appropriate treatment then patients should be quite satisfied that they are getting as much as help possible”* (Participant no. 22)

> *“Well...the thing that I find a bit frustrating is just getting a repeat prescription for the cream...It can be a bit frustrating to have a tiny tube cream or ointment that doesn’t*

> *last long to finish in few days and it is time consuming to keep asking for repeat prescriptions" (*Participant no. 5)

> *"I think if they allow to have all the medication that needed. For example, my own case Balneum Plus* (skin emollient) *which I use every day has been withdrawn as far as a prescription item and that is one of the key products for me and I think probably for most people with psoriasis, they need washing liquid that is not going to be an irritant...one that could only do good. You know with emollient the patient can ask for a repeat every 2 months, but not necessary need that product every 2 months, but I think with the washing product of a specific nature then you use it every day. What you get in 2 months can last for 4 months or 6 months. So, I think that washing emollient is important"* (Participant no. 22)

Some participants discussed health service limitations including, accessibility to the appointment system and continuity of care. They expressed their struggle to book an appointment with the dermatologist when needed:

> *"I would say it is difficult to access the appointment system. I was finding difficult to have appointment. Because when you are in a full-time job and you are at work it is very hard to communicate and call the hospital and access dermatology department and the appointment system"* (Participant no. 17)

> *"I think the other thing is when perhaps a condition changes then the patient can make contact with the hospital or with the consultant rather than having to make an appointment with the GP and be redirected to the hospital...I think if somebody has got a chronic condition it should really be between the patient and the hospital and not going backword and forward to the GP to be referred"(*Participants no. 22)

Subtheme (5.2) Patients' feedback and comments

A number of participants felt that they were given insufficient time to discuss their chronic condition and needs. In part, they related their dissatisfaction to the failure of their physician to show empathy to their psychosocial challenges or simply to ask their patient "how they feel". They thought that their service provider was unable to provide effective treatment. They agreed that the study tool could assist in the improvement of their health care:

> "*I think sometimes, there are other factors that impact on my ability to keep treating myself. Sometimes I can get quite upset or anxious or I am stressed at work. Sometimes the treatment that has been given to me doesn't fit in with my working routine for example...I think understanding sometimes it is quite emotionally draining having this condition, so I think it* (the questionnaire) *could help in terms of managing"* (Participant no. 1)

> *"Doctors and nurses never really ask you how it (skin disease) is affecting your home life. I would give up football because of my skin problem. You don't know that until you ask about it. I went to football club last Saturday, but I didn't have a shower because*

> *of the rash on my body I can’t, so I made an excuse to leave early without having a shower...It affects my sexual life with my relationship and emotionally affects my relationship. It is in the back of my mind. Why she would be with someone with skin like this if you can live with someone with a better skin. I just like to turn the light off, so I don’t want to show my skin. My skin affects my emotions and the way I live my sport, my sexual life…I don’t think I can live here in the UK and need to move abroad to improve my skin in a sunny place. I can’t cope with this and it means committing suicide, because I don’t think I can’t cope”* (Participant no. 14)

Another participant expressed his psychosocial challenges with the chronic disfiguring skin disease and the lack of opportunity to discuss or manage such challenges within the limited time of the NHS consultation:

> *“To me psychologically if I go holiday my girlfriend doesn’t take any notice of it, so that is fine. I think probably people doesn’t take any notice but psychologically I feel they do, they look at marks on your body, on legs...I wouldn’t say the word counselling, but probably some in-depth ahh...what the word I am looking for…ahh… to speak to a consultant as we spoke in depth today...It is very hard for you to manage appointments and to drag out of anyone because patients are sitting in the waiting area waiting for you…you are not looking at the watch but you understand that there is a very short timeframe to see me and I am not expressing myself and I don’t want to take your time because am conscious of your time with the next patient sitting in here* [waiting area]…*so it is very hard, so I do I think the form* [study questionnaire] *is a good idea”* (Participant no. 18)

A few participants reported their thoughts and ideas for future service development. One participant benefited from talking with the dermatology nurses and felt that the nurses can be a good source of help to patients with skin diseases. Another participant appreciated the significant impact of the biological therapy on the improvement of her skin problems:

> *"When I did the light therapy, I think the dermatology nurses can be a source of help to contact them regularly" (*Participant no. 4)

> *"I started biologic therapy which cleared my skin rash, before biologic I struggled a lot...I needed a lot of things to help me to clear the rash"* (Participant no. 6)

Two participants expressed their personal needs for self-management. They discussed the impact of healthy lifestyle, diet, stress management or talking to people with similar skin problems on improvement of their disease:

> *"I know what I need to do personally, and I find that controlling certain foods can help me personally. A lot of fruit and vegetables, a lot of fish and lot of water every day, exercise. Managing stress. Because I have very stressful job, so when more jobs I have, my skin explode with all kind of problems. So, it is a combination of managing your lifestyle. I think that is true with any disease. You always do better in managing chronic situations with better food, excise just feeling better and getting enough sleep. This is*

> *my job in managing my nutrition and your job to manage everything else" (*Participant no. 9)

> *"I have gone vegetarian eating more vegetables. I eat meat once a week. It doesn't really work but I feel better in myself…I think everybody in the Trust I see in secondary and primary care they all try to help. It might help to talk to people with similar things" (*Participant no. 14)

The final theme in this study reflected the challenges experienced by patients in self-managing their chronic skin disease including failure of the health professionals to show empathy, failure to assess, recognise, discuss or manage the psychosocial challenges associated with chronic skin diseases and failure to provide effective management and support. The participants struggled to have information about their disease or to book an appointment in an emergency. Some expressed their desire to self-manage their chronic condition by searching for health information and following certain healthy lifestyles. The latter may again reflect patients' desire to be autonomous and self-sufficient to self-manage their chronic illness.

5.5 Discussion

Chronic skin diseases are not only regarded as stigmatising illnesses, but also disabling chronic conditions that can impair patients' self-esteem, confidence, social interaction, academic education, employment, income, personal relationships, sexual relationships, practising hobbies and achieving certain career or life goals (Bajorek *et al*., 2016; Barankin & Dekoven, Beattie *et al*., 2006; Bhatti *et al*., 2009; Clarke *et al*., 2020).

The results of these semi-structured interviews provided a wider and deeper understanding of patients' psychological comorbidity and their needs to manage a long-term incurable disfiguring and uncomfortable skin condition. The participants expressed their personal experiences and challenges in living with and managing their chronic condition and dealing with the limitations of the health care system. Unlike study one, the interviews provided more in-depth face-to-face information on the participants' emotional suffering. They expressed their unmet needs and addressed the psychological impact of psoriasis and eczema on their quality of life.

Many of the findings of the interviews reflect participants' interest to use the study tool was "interest driven by unmet needs". The tool offered them a platform and the freedom to express their needs. It encouraged them to seek support and offered them the choice "autonomy" to address their personal, social, psychological, and medical needs, as well as appraise the quality of the health service they received. They mentioned that the study tool could help them to focus on their current needs, keep a record of their new medication and comorbidities and structure their consultation. Consequently, the tool may help to build an up-to-date profile of their chronic disease self-management, improve the quality of the consultation, and save patient and consultation time and resources.

As in study one, the participants requested health information about their diseases and/or information on the impact of diet and healthy lifestyle changes on the management of their chronic illness. Several participants claimed that they found benefits from searching the internet for health information. Others suggested having patient groups, patient forums or workshops with patients having similar skin conditions to share their stories and treatment. The above needs may reflect their “desire to be related” to someone who cares, understands or supports their struggles (Ryan & Deci, 2000).

Indeed, some participants complained of the lack of empathy of the medical staff to their psychological suffering. Others asked for psychological support such as stress management sessions or CBT to manage the psychological symptoms associated with their skin disease. They did not think that the GP is at the right level of dermatology experience to give them the choice of treatment. This was reported in a previous national psoriasis survey (Nash *et al.,* 2015). They also expressed their difficulties in getting a prescription or an appointment when they have a flare of their skin condition. Subsequently, some participants sought private health support, lifestyle change, or alternative therapy.

In contrast, other participants recognised the work pressure, limited time, capacity, and resources available within the health service when attempting to provide such support. They acknowledged that providing psychotherapy or supportive services could be financially and logistically difficult to be achieved or sustained. Similar challenges were reported in previous studies; participants conveyed their needs for the health service to work efficiently and to ensure services are accessible (Monk & Hussain, 2019, Nash *et al.,* 2015; Nelson *et al*., 2013, 2014, 2016; Silverberg *et al.,* 2018).

All the participants agreed that the questions in the study tool were simple, easy to understand and to fill out. They also agreed that using the tool on a regular basis can address their ongoing needs, report their new comorbidities and allow them to be involved in decision making including providing their feedback about the service and the treatment they received.

A number of participants were concerned that they might not have enough time to fill out the questionnaire if they were rushing for other commitments. However, they acknowledged that the benefits of using the questionnaire in supporting their needs is outweighed the time factor. They also acknowledge that the questionnaire can be filled anytime in between their follow up appointments.

Most of the participants (86.3%) were keen to use an online version of the questionnaire or patient portal system, which can be accessed anywhere and at any time. They reported that a portal system would be a flexible, convenient and practical method to address their personal, social, medical, and psychological needs. They appreciated the benefits of the portal in enabling them to seek urgent support if they develop a flare of their skin diseases in between their follow-up visits.

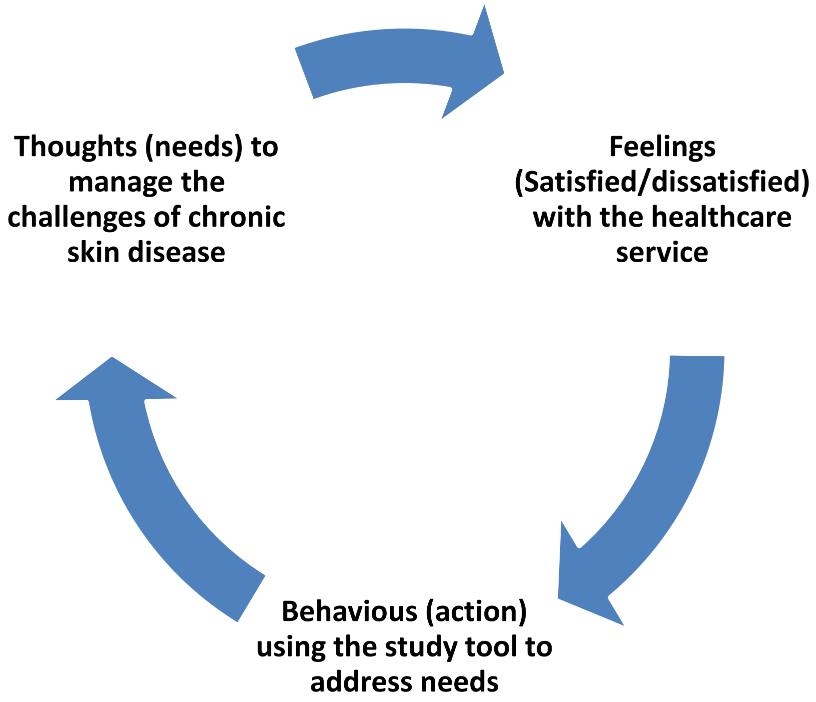
Many of the participants requested supporting services such as patient forums, patient health education and access or online links with the local mental health counselling service, CBT and other supportive patient groups and charities. It is possible these services could be electronically linked and featured in the proposed online version of the study tool or portal system to provide a comprehensive digital service to the patients (see chapter-6). Such a portal can save time and effort to travel and search for local supportive services. It could also reduce the follow-up rate or patient referrals to primary and secondary care (Irizarry *et al*., 2015; Portz *et al*., 2019). Hence, the portal system might potentially be a cost-effective model of care for patients with chronic illnesses (Boylan *et al.,* 2019; Rigby *et al*., 2015).

Three participants expressed a preference for using the paper version of the study tool as they felt uncomfortable or unfamiliar with using the internet and preferred to use the paper version of the tool. One participant was concerned that the patient's feedback might not be taken on board by the service provider. The latter factor can discourage the patients from using the study tool and subsequently negatively impact on their response rate or the benefit of the new intervention (Edwards *et al.*, 2002). A plan should be put in place to avoid such incidents e.g., offering a default electronic reply and assurance to patients when they submit their study tool online (Hazara *et al*., 2020; Rigby *et al*., 2015).

The united agreement of the participants on the usefulness of using the study tool to address their needs may reflect their desire to adopt a new behaviour (using a platform that can offer them the opportunity to address their unmet needs). They appreciated the potential benefits of the study tool in offering them the autonomy and the freedom to express their needs.

The study tool managed to engage the participants to express their views, desires, feedback, and their clinical and psychological needs. It acted as an interactive model of care that can empower patients to express their views, appraise the quality of their healthcare service, involve in decision-making process and self-management of their chronic illness.

The challenges facing patients with chronic diseases can be demonstrated below in figure-10. Patients' needs represent their "thoughts". Their continuous thinking about their needs for effective treatment can provoke a vicious circle of diverse feelings and emotions (Cohen *et* *al.,* 2007; Enander *et al.,* 2019). If their needs or desires cannot be satisfied, their thoughts can drive them to seek an action "behaviour" (e.g., seek medical support). However, this vicious circle has the potential to be broken with the introduction of the study tool, which can help the patients to address their needs and feedback for better care.



Figure–10: The cycle between patient's thoughts, feelings and behaviour

The majority of the participants (86.3%) were keen to have the online version of the study tool or patient portal system, which can offer them a swift and convenient digital link with their health service provider (Portz *et al*., 2019; Sun *et al*., 2019). This will be discussed further in the next chapter.

5.6 Limitations

The research did not include interviewing the service provider or health professionals to assess their views, opinions, resources and whether they are able to implement the use of the new intervention (study tool) at each consultation within the dermatology service. The research excluded children, their parents, and patients with language barriers, learning or cognitive disabilities. Such patients might have difficulty in understanding the questions in the study tool. Subsequently, this may negatively impact on addressing their needs and limit the benefits and the use of the study tool by such patients.

Qualitative research has been criticised for lacking generalisability, validity, stability, and credibility as it relies on a small sample size of participants who may provide their own subjective views (Opdenakker, 2006; Patton, 2002). This study may only reflect the views of the investigated 22 patients who were using a specific health service provider and may not be generalised to the whole of NHS' users. Their views may be considered as unreliable, ambiguous, and contradicted, cannot be replicated and may change if the interviews were conducted on a different population or in different settings.

Self-reported data in the interviews may not be answered as truly by the respondents, especially if the questions touch on sensitive or personal topics or the interviewers lack the experience to utilise a combination of probing and empathetic techniques (Chew-Graham *et al*., 2001). The respondents may therefore choose their own stories (Ritche *et al*., 2003). There is also confirmation bias as the interviewers may overlay on their assumptions or focus on their theory testing rather than on theory generation (Teherani *et al*., 2015). They may leave significant findings in favour of preconceptions. This can lead to conclusion errors (Devins, 2010; Healy & Perry, 2000; Murphy *et al*., 1998).

There is a possibility of volunteer bias as the small number of patients (22) volunteered in the interview may not fully represent the patients who did not participate in the interview or indeed the normal population. The level of interest or motivation in the volunteers to use the study tool on a regular basis may not match the same level of interest in the non-participants. The volunteers tend to be more educated, come from a higher social class and be more approval motivated (Creswell, 1994; Howe, 1985). Their interest or motivation to comply with a new intervention, adhere to their medication, seek health education about self-management or healthy lifestyle may not mirror with those patients who declined participation in the research (Neuman, 2000).

The number of interviewees with eczema was 3 while those with psoriasis was 19. Whilst the recruitment process for the interview was voluntary to avoid selection bias, the low number of eczematous patients can make their responses in the interview difficult to be accurately generalised or applied to all patients with eczema or truly reflect their opinions.

The interviews were conducted, transcribed verbatim, anonymised, and analysed by one researcher and without using a statistical tool or software. Therefore, the quality of the data obtained from the interview can be influenced by the level of the competency and experience of the researcher in gathering and analysing such data (Pathak *et al.,* 2013; Pope *et al.,* 2000).

5.7 Conclusion

In this qualitative study, all the interviewees agreed that the postal questionnaire (study tool) was acceptable, easy to fill out and feasible to use. They all (n= 22) welcomed using the tool at each healthcare consultation to address their on-going needs and comorbidities. They acknowledged the opportunity that can be offered to them by the tool to be actively involved in the decision-making process and their self-management as well as to voice their feedback on the health service they received. Most of the participants (n= 19) preferred using an online version of the tool as a convenient method that can be accessed at any time and in any place. In addition to the study tool, some participants suggested using alternative methods to support their needs such as patient groups, patient forums or workshops as well as offering patient information about their disease management. Although such services can be financially and logistically difficult to be implemented and sustained, the next chapter presents a proposal of an online version of the study tool that might offer the patient a comprehensive service to support their involvement in decision making and self-management of their chronic skin condition.

6. CHAPTER SIX - RESEARCH SYNTHESIS, AND STUDY - 3

This chapter discusses the synthesis and the triangulation of the research findings in study-1 and study-2, and relates these findings back to the available literature. The chapter highlights the potential impact of adopting the conceptual framework of "engagement/motivation driven by unmet needs" in creating a novel paper questionnaire (study tool) to enable patients with psoriasis and eczema to address their needs and to support their involvement in the decision making and self-management of their chronic diseases. The chapter presents a proposal of an online version of the study tool and reviews the potential and the barriers of using such a service for supporting patient self-management remotely. The chapter introduces a pilot study (study-3), which included a virtual meeting with an independent group of healthcare professionals to obtain their feedback on the proposed online service. The chapter ends with a discussion of the strengths and limitations of the research.

6.1 Synthesis of the research findings

The literature review provided evidence that patients with psoriasis and eczema have unmet needs and that their metabolic and psychological comorbidities are not always discussed, assessed or managed (Edwards & Imison, 2014; Nash *et al.,* 2015, Nelson *et al.,* 2013, 2014, 2016; Schofield *et al*., 2009; The King's Fund, 2014). It further identified knowledge gaps in managing such patients and the limitations of the dermatology service within the NHS. Patients are not regularly involved in the decision making and self-management of their chronic conditions. There is a lack of interventions that can assess such patients' ongoing needs, comorbidities and feedback at each consultation, to support their self-management (APPGS, 2013).

The literature review helped me to search for an alternative approach to support the needs of patients with psoriasis and eczema. After reviewing the motivation theories, I adopted the conceptual framework from three self-management/motivation theories (SDT, SRT and SET) and proposed using a self-developed paper questionnaire (study tool) to address patients' unmet needs at each consultation. As patients' needs and experience with their chronic disease and with their health service is subjective and changing, I adopted a pragmatic paradigm to assess the potential of the study tool.

Before conducting the survey and to assess the acceptability of the questionnaire I first ran a pilot study on 23 patients with eczema and psoriasis who were visiting the dermatology outpatient service at the hosting hospital. All the patients in the pilot study completed their questionnaire indicating a good response rate, and pointing to the effectiveness of the questionnaire's design, particularly its open-ended questions. The latter motivated the participants to provide narrative data, which disclosed wide and diverse information on their needs, comorbidities, coping, barriers for self-management and their feedback on the healthcare service they received. Hence, no amendment was made to the study tool.

After the pilot study, an explanatory mixed methods study was deployed and included a postal survey to assess patients' views, needs and comorbidities using the same tool used in the pilot study. The postal survey attracted the interest of 114 patients with eczema and psoriasis, to participate in the survey in order to address their needs, comorbidities, service barriers, quality of life score, coping, coping mechanisms and their appraisal of the health service (Figure-8). The postal survey was followed by semi-structured face-to-face interviews with 22 patients, who participated in the survey; to gain a deeper understanding of their challenges with chronic diseases and to capture their opinions on using the study tool or any alternative idea or intervention to support their unmet needs. The thematic analysis of the interviews (Figure-9) provided further insight and understanding of the challenges and barriers faced by individuals with eczema and psoriasis as well as their unanimous approval on the acceptability and benefits of using the study tool on a regular basis in supporting their needs.

Using two sources of data collection in this mixed method research provided an opportunity to triangulate the data of both the postal survey and the face-to-face interviews, to cross-validate and enhance the credibility of the findings and to capture different contexts and dimensions of the same phenomenon in the same population (Hutchinson & Wilson, 1991; Thurmond, 2001). The triangulation of subthemes identified from the thematic analysis of survey (Figure-8) and interviews (Figure-9) disclosed areas of agreement rather than divergence in both studies in answering the research questions. The participants in both studies reported similar gaps in patient health care management that have been overlooked or ignored by service providers.

The thematic analysis in study-1 (Figure-8) identified challenges and gaps in their chronic disease management; including failing to assess patients' coping status, the side effects of their therapy, considering an alternative therapy, and discussing and managing triggering factors for their illness. Patients expressed dissatisfaction with the approach of their physician. Some felt that they were given insufficient time and/or information to discuss their chronic skin problem or to understand their circumstances and needs. Others identified a failure of the physician to recognise their psychosocial comorbidities or show empathy. Similarly, in the thematic analysis in study-2 (Figure-9), participants expressed similar needs, challenges and feedback to those reported in the postal survey.

The rich information provided by the postal survey questionnaire reflected the effectiveness of the study tool in engaging/motivating the patients to address their unmet needs and the gaps or barriers affecting their self-management. It may also reflect their lack of hope to control their symptoms and/or their wishes for support (Nash *et al.,* 2015; Say *et al.*, 2006). The study tool acted as a platform for the patients to express their unassessed or unaddressed personal and psychological challenges and needs. It empowered them to express and voice their needs and to be involved in decision making of their treatment (Bandura, 1997; Ryan & Deci, 2000).

The participants' engagement, involvement or motivation to use the study tool appeared to be driven by their needs for better care or for rewarding health outcomes. They revealed many aspects in their care that often are not discussed or assessed during the limited consultation time of the healthcare provider; including treatment preference, treatment choice, treatment efficacy and its side effects, service gaps, service barriers, unreported comorbidities, healthcare professionals' behaviour with the patients, poor patient education and patient information, lack of patient forums/supportive groups, problems with the appointment system, waiting time and continuity of care, failure to manage psychosocial disorders associated with skin diseases and/or inadequate patient sign posting for managing psychological symptoms.

The tool also encouraged the patients to disclose types of coping mechanisms they adopted to deal with the burden of their long-term incurable illness. This may reflect the failure of the healthcare provider to assess and manage patients’ psychological comorbidities and/or the participants’ desire to self-manage their symptoms. Additionally, the tool enabled the disclosure of information on the limitations of primary and secondary healthcare services in supporting patients’ needs. Participants’ appraisal of the healthcare providers can play a vital role in reviewing and improving service quality, commissioning and development (BAD, 2014; von Hospenthal, 2013).

All the participants welcomed using the study tool at each consultation. The interviewees found the tool simple, easy to understand, practical and a supportive step in patient care. They also identified the potential role of the tool in appraising and improving the standard and the quality of their care.

Overall, three themes and 12 subthemes were identified from the postal survey (Figure-8), which reflect the ability of the study tool to address patients’ outstanding needs and to identify gaps in their healthcare service that may have contributed to their negative experience with their healthcare provider. The feedback of the participants also reflects the potential benefits of the tool in identifying, assessing and addressing the following unmet needs and barriers for self-management of their skin diseases: -

1- Having their voice heard and being able to share in their management decision-making and management plan.

2- Their psychological symptoms and stress to be recognised and managed.

3- Their needs to be met at the primary and secondary care levels.

4- Having better access to the appointment system.

5- Providing up-to-date information on their skin disease and on its management.

6- Providing information on diet and healthy lifestyle living.

7- Enabling patients to have an urgent appointment at the flare of their skin disease.

8- Enabling patients to obtain a GP prescription and without changing the prescribed drugs recommended by the dermatologist.

9- Offering alternative methods of communication with the service provider in between follow-up visits (telephone, video or online appointments).

10- Offering patient forums or workshops with patients who have similar skin conditions, either live or online for awareness and sharing treatment experience.

11- Tailoring treatment to suit an individual's lifestyle and needs at work and home.

12- Solving the stigma of having "contagious" skin diseases that discourage patients from using public services without being subjected to abuses or rejection.

13- Physicians to show empathy to the patient and offer them the relevant support.

14- Offering counselling, CBT, stress management sessions or psychologist/psychiatrist referral for patients with psychological symptoms.

15- Providing a holistic approach to self-manage chronic skin condition.

Equally, five themes and the 17 subthemes were identified in the interviews in study-2 (Figure-9). These themes offered more evidence and a deeper understanding of patients' unassessed and/or unsatisfied needs and the challenges they faced in managing their chronic skin condition. Furthermore, the interviews provided a check on the face validity of the tool. All the participants found the study tool was easy to understand and complete, and a useful tool for addressing their needs. Their approval on using the study tool on a regular basis may reflect their desire to be listened to and to be supported medically and psychosocially (engagement, involvement or motivation driven by innate needs; Ryan & Deci, 2000). Their approval may also reflect their desire for better self-management and a better health service (engagement, involvement or motivation driven by rewarding outcome; Bandura, 1997).

Many of the responses in study-2 reflect the beneficial role of using the tool on a regular basis in giving the patient the choice "autonomy" to express their ongoing needs. They appraised its potential for improving the patient-doctor relationship or building patient "relatedness" with a caring service as well as building their own "competence or mastery experiences" by gaining health information they need to self-manage their chronic condition and to achieve their health goals. The majority of participants were keen to have the "online version of the study tool" or "patient portal system". They discussed and acknowledged the convenience of such a tool in improving their health care experience.

According to the interest of the majority of the interviewees (86.3%) in having the online version of the study tool or "patient portal system", the next section introduces the portal system and presents a proposal of an online version of the study tool as well as a pilot study to discuss the proposal with a group of independent healthcare experts.

6.2 Patient portal system

A patient portal is a secure web-based system that allows patients to be electronically linked with their health service provider from any computer with internet access (Firth *et al*., 2019). It requires patients to log into their healthcare provider's website in order to access their health information (Hazara *et al*., 2020). The portal system can give patients convenient, 24-hour access to personal health information from anywhere in the world with an Internet connection (Dendere *et al*., 2019).

In many Western countries, portals have been developed to provide wide varieties of online services to patients such as viewing, cancelling or amending their appointment with their healthcare provider, checking their medical record or blood test results, making requests for medication, communicating with their doctor, nurse and support care, helping patients to keep track of their health record, and supporting patient's self-management (Firth *et al.,* 2019; Portz *et al*., 2019; Reed *et al.,* 2019; Rigby *et al.,* 2019; Sun *et al*., 2015). Certain healthcare institutions also offer a smart phone application (App) for their patients to access the portal through their mobile phone (Irizarry *et al.,* 2015).

Portal technology has evolved in recent decades. It can be stand-alone web sites, integrated into the existing web site of a healthcare provider or added onto an existing electronic medical record (EMR) system. The latter is an electronic version of the traditional paper medical chart stored on computers rather than in filing cabinets (Hazara *et al*., 2020). Potentially, portals can be developed to offer one or more of the following services: -

- Personal Health Records and recent doctor visits

- Current medications
- Immunisations and allergies history
- Access to laboratory results
- Securely messaging doctor
- Schedule appointments
- Check local benefits and coverage
- Download/print patient information on specific diseases
- View educational materials on chronic diseases
- Link with certain diseases’ charities
- Link to online patient forums and social services
- Link with local CBT and/or mental health service
- Update history and report medication side effects
- Online/video consultations
- Virtual Wards
- Digital therapeutics programmes
- E-consultations
- E-prescriptions
- Discharge summaries
- Digital Health Apps

(Laukka *et al.,* 2020; Portz *et al*., 2019; Rigby, *et al.,* 2015; Sun *et al*., 2019).

6.3 Proposal of an online study tool (portal)

Within the NHS there is no patient portal system that can offer the patients digital access to the above comprehensive online services and enable the patient to report their ongoing needs and comorbidities at each consultation (Boylan *et al*., 2020; Portaz *et al.,* 2020). Certain NHS hospitals and primary care Trusts, however, offer limited online services to their patients such as access to health records, appointment systems, and test results (Nuffield Trust, 2018). Similarly, the current questionnaires or tools available in the dermatology service within the NHS (discussed in chapter 2 and 3) are not designed to assess patient needs, comorbidities and feedback at each consultation or to engage patients in decision making and self-management of their care on a regular basis (Dendere *at al.,* 2019; Rigby *et al.,* 2015).

Hypothetically, a proposal of providing an online version of the current study tool with a digital link to comprehensive online services relevant to patient needs and self-management, might offer patients a more convenient tool to that of the paper version of the tool (Irizarry *et al*., 2015, Sun *et al*., 2019). Such a proposal can be designed to provide a regular assessment of patient needs, comorbidities and feedback, and offer the patients access to self-management information of their diseases and access to many supportive services including local mental health services, counseling, CBT, mindfulness, access to psoriasis and eczema charities, access to virtual patient forums and access to prescription refill. The portal would enable patients to monitor the progress of their health condition, address their needs and comorbidities, reschedule or cancel their appointment remotely, anywhere in the world, (e.g., during the pandemic or long holidays; Portz *et al*, 2019, 2020; Rigby *et al*., 2015).

Figure-11 presents an example of the diagram of the proposed online version of the study tool with digital access to multiple services to regularly support patients' ongoing needs and self-management. Before each consultation, patients can complete the online questionnaire to report their needs, comorbidities and feedback, as well as having access to local medical, mental, and social services relevant to their chronic skin condition. Providing comprehensive services might improve patients' "autonomy" and "competence" or "mastery experiences" to self-manage their disease (Bandura, 1997; Ebrahimi Belil *et al.,* 2018; Firth *et al.,* 2019). It might also increase the response rate of the patients to use the tool "motivation driven by needs" and enhance patient-physician relationships or "relatedness" (Ryan & Deci, 2000; Irizarry et al., 2015). Potentially, the proposed portal might improve the quality of care, management outcome and save money and time for the patient and for the health service in the longer term (Hazara *et al*., 2020; Rigby *et al.,* 2015).

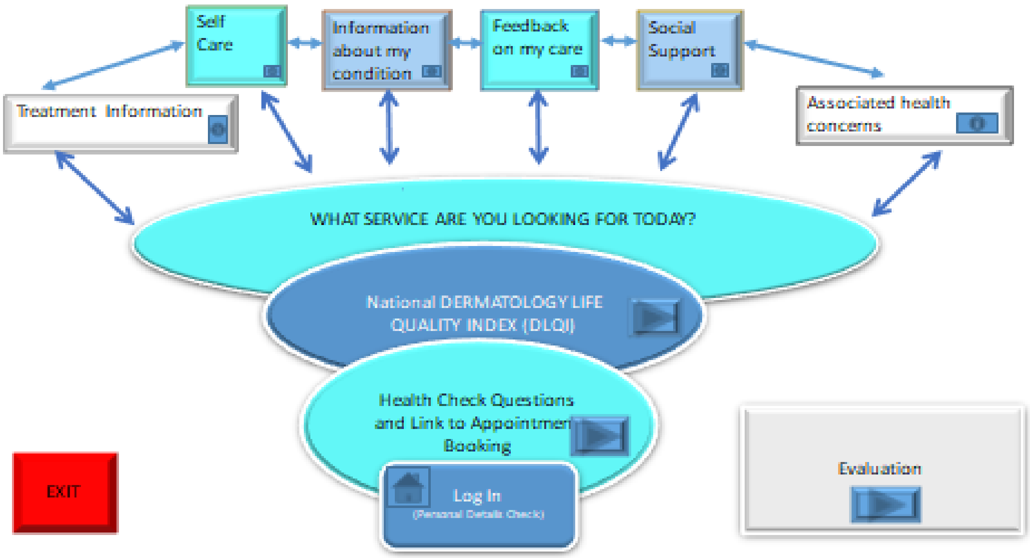


Figure11: A design of the proposed patient portal system

It is important to note that the above speculative proposal represents a novel intervention to the NHS and requires approval of stakeholders including the commissioners, health professionals, patient's representative and IT experts. They would need to meet to discuss and consider the benefits, flaws, risks, resources and the logistics of piloting such a model of care. They also need to decide the level of services and the clinical governance procedures that are required to deliver and sustain such services to their targeted population. Their discussion may include reviewing user needs, patients' background, their IT training, experience or concerns of using online services and its impact on their quality of care and on the quality of the dermatology service. Stakeholders should decide what, why, when, who, and how often to collect patient data and what, whom and how to store and utilise the data and within the NHS information governance policy (Boylan *et al.,* 2019; Nuffield Trust, 2018).

After piloting such a proposed portal, stakeholders may decide to revise or expand its potential to support patients across different specialities. They may decide to centralise primary/secondary patient care, link the portal with EMR or with specific costing and coding software to provide regular financial data on user activities, clinical governance data and audits on patient's feedback, comorbidities, current medication's cost and side effects. It is possible the proposed portal can be developed to act as a cohort study providing longitudinal prospective epidemiological data on the natural history of skin diseases on the investigated population. Such a proposal might revolutionise the NHS and fill knowledge gaps in patient care. It can assist health professionals/commissioners to regularly review and tailer their resources to improve their service quality (Dendere *et al*., 2019; Rigby *et al.,* 2015).

However, the disadvantages of the patient portal system need to be assessed, addressed and managed. They may include its linkage to a single health organisation (Hazara *et al.,* 2020). If a patient uses more than one organisation for healthcare, the patient normally needs to log on to each organisation's portal to access information. This may result in a fragmented view of individual patient data (Reed *et al.,* 2019). Equally, the portal might generate complex problems and extra workload for the health professionals who are providing and managing such a digital service (Firth *et al.,* 2019; Sun *et al.,* 2019). Recently, healthcare professionals' experience and feedback on the patient portal system was assessed in a systematic review, which included 13 qualitative studies: from the United States (n=9), Norway (n=1), the Netherlands (n=1), New Zealand (n=1), and Russia (n=1). The review generated mixed findings; negative experiences included poor functionality and insufficient training and resources. The authors recommended that stakeholders should try to reduce healthcare professionals' negative experiences when developing portal communication (Laukka *et al*., 2020).

Further, in order to generate high-quality data, the portal system should be designed in a simple and effective way that can be used by patients from different demographic backgrounds. Patients might need to be educated on how to use the portal and access information relevant to their chronic disease and self-management (Rigby *et al*., 2015). Furthermore, despite complying with NHS confidentiality regulations and information governance, security has always been a top concern for the patients when dealing with the adoption of an online portal that discloses their personal information (Boylan *et al.,* 2019; Sun *et al*., 2019). Portals might not be an option for patients who lack internet access, are uncomfortable or unable to use a computer for different circumstances and reasons (Dendere *et al*., 2019; Rigby *et al*., 2015). Considering patient choice, the paper version of the tool could be offered instead. Alternatively, the receptionist staff at the healthcare provider could support and/or train such patients to fill an online version of the tool by providing a laptop in the reception area of the outpatient clinic (Reed *et al*., 2019; Sun *et al*., 2019).

Nonetheless, the majority of the interviewees (86.3%) in this research preferred using the online version of the tool or portal and in order to gain health professionals feedback on such a tool, a virtual pilot study was conducted on an independent group of healthcare experts and a face-to-face meeting was organised with my departmental team and service managers. This will be discussed next.

6.4 Study-3 Pilot Study on Healthcare experts' feedback

Piloting or implementing a new model of care such as using a paper version, or an online version of the study tool requires service providers' and stakeholders' approval. As the latter could not be achieved within the pandemic period, a virtual pilot study was conducted on a group of independent healthcare experts from the sponsoring university. The participants included in the study were 4 nurses (2 females and 2 males) and 3 psychologists (one female and 2 males). They were recruited through a university advert. The objectives of the meeting were to garner their feedback on the extent to which the proposed portal system (Figure-11) responded to the findings from study-1 and study-2 and aligned with the conceptual framework of the research. The virtual meeting was conducted on 12th July 2021, and took more than 1.5 hours. The experts were asked to provide anonymous written responses and feedback during the meeting. Ethical approval for this virtual meeting was obtained separately from the University ethical committee, reflecting the change in direction due to ongoing COVID constraints.

After a short introduction on psoriasis and eczema, their comorbidities and management barriers, a summary of the of the research’s objectives and findings were discussed including the proposed portal system (Figure-11). The experts were asked the following questions:

Does the proposed model align with the adapted conceptual framework and can it be applied to healthcare?

This question may include e.g., Offer patients a choice? Allow patients to engage in the decision-making process? Encourage patients to be self-initiating? Access to self-care, coping skills or counselling? Offer patients health information, competence or mentors to increase their observational learning?

All the participants provided the same anonymous written answer - “*Yes*”.

They also provided anonymous narrative responses:

> “*I'd say that this model is probably more closely aligned to care that is provided*.” (Participant no.2)
>
> “*Yes, I think so; the platform seems to cover all of these areas*.” (Participant no. 4)
>
> “*Yes, I agree that this aligns with the model proposed. Would the model be able to include a place to write down goals, maybe a few key steps to achieve these and either recommend or include a goal 'tracker' to keep patients accountable*.” (Participant no.5)

> “*For social support, there could be a link/ section for carers, information on how to support patients and maybe a way of engaging with others in a similar situation (feel less isolated and hopeful*)” (Participant no.7)

Does the model respond to the needs expressed by patients?

e.g., Having their voice heard and being able to share in their management decision-making and management plan? Their psychological symptoms and stress to be recognised and managed? Having better access to the appointment system? Providing up to date information on their skin disease and on its management? Providing information on diet and healthy lifestyle living? Enabling patients to have an urgent appointment at the flare of their skin disease? Offering patient forums or workshops with patients who have similar skin conditions, providing a holistic approach to self-manage chronic skin condition?

> “*Given all the information that has been given to us, the model proposed should respond to the needs of the patients*” (Participant no.1)

> “*Yes, I may have missed this bit but was there a direct link for people to access psychological assistance if needed*?” (Participant no.3)

> “*Have you assessed any risks related to the deployment of this portal, and if so how have you mitigated them*?” (Participant no.6)

“*All this information is great; I am a particular fan of access to more detailed information in regard to treatments. It would be interesting to be able to consider the usage of this resource by those whose skin condition is disabling to the point of requiring a high level of care, from family, social and medical services*” (Participant no.7)

Any idea, question or suggestion:

“*Where there are links to charitable and/or support organisations? maybe add links to benefits applications/advice or citizens advice could be added for those whose conditions do not allow them to continue in work*” (Participant no.1)

“*Could you measure which areas of the portal patients were choosing to access as this would give you further insight into areas which need to be discussed during a consultation with a Healthcare Professionals*” (Participant no.2)

“*I wonder if the appointment booking option should be nearer the end of the tool, people may just make an appointment for ease instead of interacting with the links within? (Which look great). Could there also be a link for social media platforms?”* (Participant no.3)

“*Have you thought of developing this as an APP that could be accessed via a patient’s phone*?” (Participant no.4)

> "*Would the healthcare Professionals review the portal prior to seeing the patient*?" (Participant no.6)

In summary, the online meeting with the healthcare experts was positive and supportive in developing a patient portal system, which has been implemented in many western countries with success (Rigby *et al.,* 2015).

The above pilot study is the first step for implementing a new model of care. Future steps would involve the approval of the stakeholders who are providing and managing the proposed online tool which is essential. To explore this locally, I presented and discussed the potential benefits of the proposed portal system with our dermatology team in a meeting, which included 4 male dermatologist consultant colleagues, 2 male dermatology service managers, 2 female senior nurses, and 2 female junior doctors. Although my consultant colleagues were interested in the potential cost-effectiveness and advantages of the portal system in supporting patients' care remotely, they were concerned about the impact of the new intervention in generating unpredictable numbers of patient emails, which potentially could increase their workloads beyond their contracted job plan.

Some ideas to overcome such challenges were discussed in the meeting including offering a weekly paid session to each consultant to manage the portal workload. We discussed piloting the paper tool first and reviewing its impact on the consultant's workload. However, because of the increase in patients' referrals after the lockdowns, the idea of piloting the paper or the online version of the tool was not approved by our dermatology service managers. They could not fund such a project, mainly because of the increasing demand on the service beyond its capacity, which subsequently led to regular breaches in managing targeted urgent GP referrals.

As discussed on page 33, the limitations associated with the NHS are not restricted to a shortage of resources and staffing, there is also little opportunity for changing its rigid hierarchy and resistance to reform, adoption of new ideas, vision or innovation (Mannion & Davies, 2018). Organisational bureaucracy and complexity presents at different levels of the NHS and any change or novel idea presented to the NHS may require the submission of a complex application, which if progressed would need to undergo a time consuming legislative and funding approval process (Alldel *et al.,* 2011; Nuffield Trust, 2018; Perry *et al.,* 2019). This led some to conclude that the NHS is drowning in bureaucracy (Oliver, 2017)**.**

Furthermore, not all patients have internet access or are comfortable to use online services. Hence, if the proposed online version of the tool is piloted or implemented, the paper version of the tool should be still provided to such patients, otherwise the response rate and the data generated from the new intervention would be limited (Rigby *et al.,* 2015).

6.5 Research implication in relation to literature

After reviewing the literature, the research identified three knowledge gaps in managing patients with psoriasis and eczema and provided a conceptual framework and a new tool in the form of a paper questionnaire. The latter aimed to involve the above patients in decision making and self-management by assessing their needs, comorbidities and feedback at each consultation. The new tool was assessed by a novel mixed method inquiry which included a postal survey and interviews. The research provided evidence on the acceptability of all the participants on the potential benefits of using the tool on a regular basis to address their ongoing needs and to support their self-management “engagement or motivation driven by needs”.

There has not been a mixed methods research project conducted on adult patients with both psoriasis and eczema with similar aims and objectives in the UK. As discussed in Chapter-2, there were three large postal surveys conducted on psoriasis patients in the UK (Nash *et al*., 2015), Europe (Dubertret *et al*., 2006) and the USA (Krueger *et al*., 2001). Surveys were also conducted on adults with eczema living in the USA (Silverberg, 2015; Silverberg *et al*., 2018). The overall findings of these surveys mirror many of the findings discussed in the current research, in terms of the impact of the skin diseases on patients’ quality of life, and patients’ challenges with their treatment and unmet needs. Nevertheless, these large surveys did not recruit patients with two skin diseases, capture their qualitative experiences, and did not provide an intervention to support their studied populations.

The current research provided a novel intervention assessed by a novel mixed method study. The findings of the quantitative and qualitative studies showed the potential of the study tool in addressing patients’ needs, comorbidities and feedback as well as provided patients’ acceptability and approval on the benefits of using the new intervention at each consultation to report their unmet needs. Many participants envisaged that using the tool at each consultation could build up their autonomy and competence to be involved in decision-making and self-management of their disease. It could also give them a platform to voice their ongoing needs, and comorbidities that often are not discussed during a follow-up consultation (de Vere Hunt et al., 2021; Nelson *et al.,* 2013, 2014, 2016).

All the participants agreed to use the tool on a regular basis and the majority were keen in having the online version of the study tool as a convenient digital system that can offer them the flexibility to address their feedback and needs remotely anywhere and at any time. International studies showed that patient portal systems can provide the choice and a swift pathway for patients with chronic diseases to address their needs and feedback (Hazara *et al*., 2020; Irizarry *et al*., 2015; Laukka *et al*., 2020; Portz *et al*., 2019). The research speculated a proposal of the online version of the study tool that can be designed to provide a comprehensive service to support patients' ongoing needs and to assess their comorbidities at each consultation. The proposed portal was reviewed and positively appraised by a group of independent healthcare experts in a pilot study. The barriers for piloting such a proposal within the NHS were discussed earlier.

Overall, this research contributes to the growing body of literature by highlighting and addressing three main gaps in the knowledge of the management of psoriasis and eczema patients. The research provided a conceptual framework and a new intervention. The latter was assessed by a novel mixed method study which generated numerical and narrative data about the tool's acceptability and potential in filling the gaps in the above patients' care. The tool drew upon the conceptual framework from three theories (SDT, SRT and SET) and aims to empower patient's autonomy, competence, self-efficacy and relatedness. It has the potential to regularly assess patient needs, comorbidities and feedback and enhance patient involvement in decision making and self-management of their chronic condition. The research provided the acceptability of all the interviewed participants on the benefits of the study tool and its potential in supporting and addressing their needs and comorbidities at each consultation.

6.6 Research Strengths and Limitations

6.6.1 Strengths of the research

The research identified knowledge gaps in the investigated population and provided a new intervention (paper questionnaire) that can fill theses gaps. A novel mixed method study was deployed to assess the acceptability and the potential of the questionnaire. The open-ended questions in the new intervention (study tool) offered the patients a platform and the freedom to express their personal and psychosocial challenges that may not be usually discussed or managed within the limited consultation time (de Vere Hunt et al., 2021; Nelson et al., 2013, 2014, 2016). Without using the study tool, it might be difficult to involve patients in decision making of their care, understand their perspective and challenges with the disease, assess their needs, comorbidities and their view on treatment preference for better self-management and QOL.

In the interview (study-2), the research provided a deep understanding of the patients' experience with the chronic disease and with their health service provider. The participants unanimously welcomed the regular use of the tool at each consultation to address their ongoing needs and psychological comorbidities "motivation driven by needs". They found the tool acceptable, easy to understand and feasible to use from a patient perspective. The thematic analysis of data in study-1 and study-2 showed that the tool engaged the participants to report their comorbidities and diverse needs as well as to appraise their service provider. The majority of the interviewed participants preferred using the digital version of the questionnaire as a convenient method that can be used remotely anytime and anywhere. The research provided a potential foundation for future studies and a proposal for developing an online version of the tool or patient portal system that can provide a comprehensive service to such patients. The potential of the proposed portal were discussed earlier in this chapter, and it received positive feedback from an independent group of healthcare experts (study-3).

Overall, this research provided a novel mixed method study with two methods of data collection (quantitative and qualitative) and a novel tool to engage/involve the patients in decision making of their management by regularly reporting their comorbidities, treatment preferences, needs and feedback aiming to improve the quality of their care. The data generated in the postal survey may reflect the impact of the tool in engaging or motivating the participants to express their unmet needs “motivation driven by needs”. It may also reflect the benefits of asking the patients the open-ended questions in the tool to assess their needs and comorbidities in order to offer them a more effective management plan (Nelson *et al.*, 2013, 2016). The interviews’ data provided united participants’ approval of the study tool to support their needs at each consultation. The interviews also revealed participants’ wishes for health information about the management of this disease, healthy lifestyle and to having live or online patient workshops/forums to share their treatment stories and challenges with similar patients. Many participants asked for counselling, CBT, and stress management sessions. Although such services can be financially and logistically difficult to provide and sustain, the research suggested integrating and linking such patient’s supportive services electronically in the proposed portal system to offer the patient holistic care.

6.6.2 Limitations of the research

The postal survey (study one) provided a snapshot of data and cannot assess temporal trends. Its low response rate (22.5%) can reduce the generalisability of the findings of the study, leading to tentative conclusions which cannot readily be applied to all patients with similar diseases (Fanelli, 2019). Although, the response rate in postal surveys is usually low (Iglesias *et al*., 2000; Sahlqvist *et al*., 2011; Scott & Edwards, 2006; Zuidgeest *et al*., 2011), a systematic review proposed that the response rate to postal questionnaires can be enhanced by using different strategies (Edwards *et al*., 2002). After considering such strategies, the study tool has been modified (this will be discussed in chapter-7) aiming to increase patients' response rates without affecting its main objectives. Equally, options of paper or the online version of the tool can be provided to patients to improve the response rate to the new intervention. A more costly approach might include providing, a laptop in the reception area of the healthcare provider to assist and train patients who have no internet access or are less confident with using computers (Sun *et al.,* 2019).

Whilst this tool was designed for adults, excluding children, their parents and patients with language barriers, learning or cognitive disabilities from the research can impair the response rate, the quality of the data and can negatively impact on addressing their needs and limit the benefits of the study tool. The interviews included a small number of patients with eczema (n= 3) compared with patients with psoriasis (n= 19). This might not fully capture the experiences and the feedback of those with eczema. The questionnaire lacked information about patients' demography. Whilst the study tool was not designed for research purposes, demographic data can assist the service provider to audit their activities and tailor their resources toward the most affected population (Pinder, 2008). However, these important variables can be obtained from the patient digital NHS profile.

Even though all the interviewees welcomed the use of the study tool on a regular basis, (study-2) and a small group of independent health experts welcomed the proposal of having an online version of the study tool (study-3), their approval is not sufficient to pilot or implement the new intervention. Health professionals and stakeholders who will be responsible for delivering and managing the new model of care, is essential. Locally, my consultant colleagues were agreeable on the potential benefits of the new tool, but they were concerned of the extra workload that could be generated from using the tool at each consultation. My departmental service managers could not fund such a project as the hospital is under severe pressure to deal with the overwhelming demand of GPs' targeted and urgent referrals after the COVID-19 pandemic.

Further, the research provided one survey (study-1) and one set of interviews (study-2). There is no evidence that after the first attempt, patients would continue to engage with the study tool. Whilst the study tool can potentially fill gaps in patient care, the first phase of design was not tested in different settings or through a robust series of tests to assess its reliability and validity and to inform any further amendment needed in the tool to enhance its pickup rate and potential in supporting patient care (e.g., adding links to patients' forums, local mental health and skin diseases charities). A longitudinal study at different NHS settings is needed to measure patient engagement or interest to use the tool over time and to provide consistent evidence on the benefits/flaws of the proposed portal system in self-managing chronic skin conditions.

Although using the study tool on a regular basis may provide patient-centred approaches and capture individual patient needs more efficiently, this could be potentially idiosyncratic and inequitable as different patients are likely to have different expectations and interests. These issues need to be addressed, assessed and piloted before implementing a new model of care to ensure both the needs of patients and services are met. Equally, clinical trial might be needed to assess the benefits/flaws of the new tool compared with the standard level of care.

Whilst the conceptual framework for developing the tool was adopted from three motivation theories (STD, SRT and SET) used for supporting patients' self-management, the effectiveness and feasibility of most theoretical approaches to produce the intended change in participants' behaviour and to maintain the new behaviour in the health care settings is limited (Maclean *et al.*, 2002). Different theoretical assumptions lead to different quality improvement strategies and many factors can influence the implementation of such a change. It is therefore not easy to draw conclusions about the relative superiority of any theory or concept based on the available evidence from health care contexts (Grol *et al.*, 2007).

Motivation theories have limitations and may not always be suitable for every person (Alderson, 1998). Motivation in humans is influenced by many factors (e.g., personal, social, service obstacles and support levels), which cannot always be controlled (Pinder, 2008). Patients may have both extrinsic and intrinsic motivations and their levels of motivation may contradict or interfere with their own beliefs, religion, values, lifestyle, career, personal, psychological coping capacity, willpower, and with the types of health service support they have. These factors may influence the internalisation of their extrinsic motivation and self-efficacy (Bandura, 1997; Ryan & Deci, 2000). As discussed in chapter-2, SDT, SRT and SET require a complex set of support and may not motivate all NHS users to self-manage their morbidity and comorbidities. Different theoretical approaches and research in patients' behaviours improvements need to be considered simultaneously to develop an effective healthcare plan (Ntoumanis *et al.*, 2020; Sweet *et al.*, 2012). Within the context of this research, engagement, involvement or motivation of the participants to use the study tool was mainly driven by patients' needs; hence, SDT, SRT and SET may not be valid if the patients' needs were satisfied or unobtainable.

7. CHAPTER SEVEN – PRACTIONER REFLECTION OF THE RESEARCH PROCESS

This chapter will provide my reflection on the research process. The reflection involves an evaluation of research practice, methodologies, with a self-analytical assessment of the work carried out, including how to improve the questionnaire. In chronological order, the chapter discusses the key decisions that were made and evaluates the strengths and weaknesses of these. It will analyse each point with reference to the literature and outline how the questionnaire's content could be improved to create a future action plan.

7.1 Introduction

In 2016, I had the opportunity to conduct and publish a cross-sectional study on patients with psoriasis in South Yorkshire (Aldeen & Powell, 2016). The results of the survey showed that these patients had unmet needs and often unassessed, underreported or unmanaged metabolic and psychological comorbidities.

Being a dermatologist, I felt powerless to assess all the needs and comorbidities of such patients in ten minutes of consultation time. This was in addition to the other challenges facing psoriasis and eczema patients discussed in the literature review such as: -

1. Long waiting time to see a dermatologist in the public health sector (Irving *et al.,* 2017; Nash *et al.,* 2015; NHS Digital, 2018a)
2. Difficulties in getting an urgent appointment during a flare of their skin condition (Monk & Hussain, 2019)

3. Dissatisfaction with short consultation times (Ogden *et al.,* 2004).
4. Lack of patients' understanding about their disease and its management (de Vere Hunt *et al.,* 2021; Edwards & Imison, 2014)
5. Poor patient involvement in decision making or having choices on the available treatment (Elwyn *et al.,* 2012; Mannion & Davies, 2018)
6. Inconsistent assessment of psychological and metabolic comorbidities associated with psoriasis and eczema (Lim *et al.,* 2018; Nelson *et al.,* 2013, 2014, 2016)
7. Poor access to counselling services when needed (Massuod *et al.,* 2021)
8. Most GPs have very limited training in dermatology and are unable to manage or monitor psoriasis and eczema patients who are on systemic therapy (Benton *et al.,* 2008; Kerr *et al.,* 2010; Nash *et al.,* 2015; Schofield *et al.,* 2009).
9. In secondary care, dermatologists and nurses have an essential role in assessing and managing patients with chronic skin diseases. However, this might not always be feasible within the limited consultation time, limited resources or shortage of medical staff in district hospitals (Ehrlich *et al.,* 2017; Roberts *et al.,* 2021).
10. Lack of a holistic dermatology service and shortage of combined specialities clinic or multidisciplinary care which can provide a cost-reducing service by limiting inaccurate diagnoses, ineffective treatments, unnecessary referrals and at the same time increase patient satisfaction and improve patient outcomes (Patel & Jafferany, 2000).

The literature review presented patient feedback from national and international surveys and qualitative studies that were conducted on patients with psoriasis and eczema (Dubertret *et al*., 2006; Krueger *et al*., 2001; Nash *et al.,* 2015; Silverberg *et al*., 2018). They described gaps in provision and problems in patient care which need to be solved, but these studies did not provide an intervention, or a tool to support such patients and their ongoing needs on a regular basis (Dubertret *et al*., 2006; Krueger *et al*., 2001; Nash *et al.,* 2015).

The Patient's Charter emphasises patients' right to choose how their health is managed and also focuses on factors such as shared decision making, patient participation, and patient centredness (Coulter, 1999). Likewise, the psychological literature and self-management/motivation theories (SDT, SET, and SRT) highlighted the positive consequences of choice, indicating that greater choice increases intrinsic motivation, task performance, life skills, self-management, and higher outcome evaluations regardless of whether choice is actual, trivial, or illusory (Bandura, 1997; Baumeister *et al.,* 2007; Deci & Ryan, 1985; Iyengar & Lepper, 2000).

The above psychological theories helped me to identify three main knowledge gaps in managing patients with psoriasis and eczema. They also inspired me to reach a conceptual framework and to develop a tool that can regularly engage the patients to address their needs, assess their comorbidities, and report their feedback. At the same time the tool can support their involvement in decision making and in self-management. As discussed in chapters 2 and 3, there are many tools developed for dermatology patients' assessment (chapter-2), but they are not regularly used to assess patient ongoing needs, comorbidities and feedback (APPGS, 2013, p 11). In order to engage/motivate the patients to use the new tool, it should fulfil their needs "motivation driven by needs" (Boynton & Greenhalgh, 2005; Ryan & Deci, 2000).

The literature review helped me to identify some of the possible relationships between “patient needs, wishes, desires and QOL”. Reviewing self-management theories (SDT, SET, SRT) led me to adopt a conceptual framework “**Patient engagement, involvement, or motivation can be driven by their needs to improve their QOL or to satisfy their desires**”. I designed a paper questionnaire (study tool) which contained seven open-ended questions, one Likert question and a QOL scale. I proposed that the open-ended questions can engage/involve the patients in decision making of their care and enable them to report their needs, comorbidities and feedback. Indeed, the data collected from the survey showed that the participants expressed their diverse needs, wishes, desires, comorbidities, feedback, barriers and challenges that can impact on their self-management and QOL. Their responses also informed further amendment of the tool (Kishore *et al.,* 2021).

After considering patients’ needs reported in this study survey, I decided to expand the potential of the study tool to provide comprehensive support to the patients. I designed a proposal for the online version of the tool (portal) and proposed that the portal can be developed to provide extensive digital support to the patients such as access to patient appointment systems, laboratory results, drugs refill, health information for patient education, access to local mental health services, patient forums and dermatology charities to support their self-management (Allegrante *et al*., 2018, 2019; Barlow *et al.,* 2002).

To assess participants’ views about the portal, I included the proposal of the portal system in the interview questionnaire (Appendix-V). The majority of the interviewees (86.3%) welcomed the proposed online portal system as a convenient tool that can be used anywhere and at any time to support their needs (study-2). The proposed portal was also approved by a group of independent healthcare experts in a pilot study (study-3).

It is possible that the comprehensive services provided by the proposed portal could encourage, involve, or motivate the patients to use them on a regular basis instead of spending time and money travelling to different health services or attending unnecessary follow up appointments. Equally, physicians can assess patients’ ongoing needs and comorbidities online before prescribing or planning their management. Patients and physicians can mutually cancel follow-up appointments if deemed unnecessary.

The portal aligns with an international systematic guideline review (Muth *et al.,* 2019). This was conducted with patients with multiple comorbidities followed by a workshop-based consensus meeting with multidisciplinary experts from North America and Europe aiming at providing a holistic approach to the patient. The authors recommended full assessment of the patient’s morbidity and comorbidities. They also recommended that patients should be encouraged to express their personal values, aims, priorities including addressing medical, psychological, emotional, social, personal, sexual, spiritual, cultural needs, environmental care needs, expectations, and what level of involvement in decision making the person would like, before prescribing or planning their management (Muth *et al.,* 2019).

With the COVID-19 pandemic there has been a significant change in the health service approach and strategy to managing patients including the dermatology service (Mintoff *et al.,* 2021; Portz *et al*., 2020). Many healthcare services started using different modern technologies for better patients' choices, especially during of the pandemic (Stadler *et al.,* 2021). Remote consultations including telephone, video, email and telemedicine, are likely to grow in importance in the following years, as we retain some of the important tools we have utilised during the pandemic (Portz *et al.,* 2020). The proposed portal system can keep with this new way of working and would fit well to support patients' needs remotely (Dendere *et al*., 2019). However, and as discussed in the last chapter, because of the current NHS workload crisis generated by the COVID-19 pandemic, the proposed portal could not be funded or piloted for the foreseeable future.

7.2 Reflection on the research methodology

Selecting the right research method started with identifying the research question and study aims (Hill, 1984). In this research, the study aim was to understand and improve patients' experience. As patients' reality (ontology), such as their needs, wishes, hopes, desires and experiences are not a single reality (positivism) or multiple realities (constructivism), but subjective, context specific and changing reality, a pragmatic paradigm was deployed in this research (Hanson *et al.,* 2005; Hill, 1984). The latter involved conducting a mixed method inquiry to assess the acceptability and potential of the tool in addressing patients' unmet needs, comorbidities and feedback. The mixed method research provided a process of abduction aiming to form the best conclusion from using both induction and deduction processes of qualitative and quantitative research, respectively (Appleton & King, 2002).

As a physician aiming to improve service quality and support patients' needs, using mixed method inquiry helped me to understand their experiences and gain practical evidence that can answer my research question. The integration of quantitative and qualitative data enabled me to have a panoramic view of the research landscape, viewing phenomena from different viewpoints and through diverse research lenses (Hurley *et al*., 2017). It allowed me to explore patients' perspectives, service gaps and disclosed hidden comorbidities. It also enabled me to modify the study tool to answer multifaceted research questions (Denscombe, 2008; James, 1907).

Nonetheless, the process of mixing methods within one study, added complexity in collecting data and required more effort and more resources (Zhang & Creswll, 2013). Hence, many questions are left to be answered to justify choosing a mixed method research such as:

1- Does the research question justify the use of mixed methods?
2- Is the method sequence clearly described, logical in flow and aligned with the study aims?
3- Is data collection and analysis clearly described and well aligned with the study aims?
4- Why was explanatory sequential mixed method deployed instead of conducting exploratory or concurrent mixed method study?

The answers to the first 3 questions were discussed in chapter 3. The research question could be answered by conducting either qualitative or quantitative study, but the findings of each study alone may not be completely sufficient to explore patients' reality or their diverse perspectives and experiences with the disease and/or with the health system. It may not fully uncover the relationships that exist between the multifaceted research questions (Tashakkori & Teddlie, 2003).

The answer to the last question was also discussed in chapter-3. Quantitative data was collected and analysed first to evaluate the potential of the study tool in measuring and assessing the dimensions of patients' unaddressed or unmanaged problems (comorbidities, needs, challenges, barriers, coping status, treatment preferences, feedback). Conducting the survey first helped to inform the interview. The latter provided feedback of the participants on using the questionnaire on a regular basis, which is a vital step in tool development (Brazil *et al.,* 2005; Jenn, 2006).

Nevertheless, an exploratory sequential mixed method might be helpful to be conducted first to identify and shape the types of items that can be used in the study tool (Streiner *et al.,* 2015) or to start a ground theory inquiry (Bryant, 2009). This research however, provided open-ended questions in the study tool to generate narrative data which together with the literature review helped to inform further amendment in the study tool. The literature review provided evidence and data explaining the research phenomenon (i.e., patients' unmet needs; APPGS, 2013, Edwards & Imison, 2014; Massoud *et al.,* 2019; Nash *et al.,* 2015; Nelson *et al.,* 2013, 2014, 2016; The King's Fund, 2014), which helped to create the questionnaire's items (see chapter-3).

Although this research did not rely on a specific theory or grounded theory, it is envisaged that implementing the study tool, and regular or cyclical collecting and analysing of its data in an iterative manner might create a grounded theory (Bryant, 2009)**.** Retesting the tool at different times and settings can also eliminate selection bias, sampling error, data error, inaccurate assumptions or conclusions driven from a small sample size, inform further amendment necessary in the study tool and assess its reliability and validity (Brazil *et al.,* 2005; Healy & Perry, 2000).

The quality of the data in this research can be criticised for not providing inferential statistical data to make and test predications on a wider population or identify relationships between different groups and variables (Choi, 2013). The descriptive statistical data provided in the survey described the studied population and may not confidently be applied to the whole UK population. Descriptive statistics however provided a micro picture of the survey data (e.g., ratio and mean between participants and non-participants; Table-3), helped to identify errors and anomalies in the data and it can inform which inferential statistics can be used (Braghetto, & Figueroa, 2021). Equally, the main objectives of this research were to assess and understand patients' needs, comorbidities, feedback and their view about the health service and about the study tool. The narrative data in the survey and the interview were thematically analysed to answer the research objectives (Figure-8 and 9).

The study tool was approved by all the interviewees and most of them preferred the online version of the tool (portal) which has the potential to provide a holistic, or comprehensive service that can satisfy the needs of many patients. However, the implementation of the portal system requires a pilot study and approval of the health professionals and commissioners. This was not feasible because of the ongoing impact of the COVID pandemic on the NHS workload and the change in the NHS strategies to manage the mounting pressure of dermatology referrals. Notably, not all the patients, preferred or were able to use the portal or a new technology (Boylan *et al.,* 2020; Stadler *et al.,* 2021). As discussed in chapter-6, measures can be taken to provide a paper version of the study tool for such patients (pages 329 and 356).

7.3 Reflection on the quality of the study tool (questionnaire)

Despite a wealth of detailed guidance in the specialist literature in developing a questionnaire, methodological errors are possible (Boynton & Greenhalgh, 2005). Hence, the process of questionnaire design and development, must be supported by a logical, systematic and structured approach and strategies to demonstrate the reliability and validity of the new questionnaire (Rattray & Jones, 2005).

The item formulation is an integral part of the questionnaire construction and questions in the new tool that require the participants to respond should be relevant to the research questions and be acceptable to the target population and be culturally specific (Barnett *et al*., 2008; Botti & Iyengar, 2006; Kishore *et al.,* 2021).

Likewise, the process of interpretation of the questionnaire's results should be defined in sufficient detail to enable a practitioner to make an informed decision about whether to implement findings (Streiner *et al.,* 2015). This is especially important when we want to evaluate the effectiveness of care or treatment (Ogden *et al.,* 2008, 2004).

The interviews in this research provided unanimous approval of the interviewees about the acceptability and the benefits of the study tool for their management. They all found the questions in the study tool were easy to understand and to fill out. The response rate in the pilot study was 100% and its findings did not include reference to any issues in the questionnaire in terms of content, grammar, and format, hence no amendment was made to the tool during the survey. However, the response rate of the postal survey was low (22.5%). Whilst such a rate was reported in previous postal surveys (Edwards *et al.,* 2002;

Iglesias & Torgerson, 2000; Sahlqvist *et al*., 2011), the proposal of an online version of the study tool (portal) was welcomed by the majority of the interviewees in study-2.

The quality of a questionnaire can be enhanced by re-testing in different settings and on different populations to ensure the following: -

1. All the respondents understand the objective of the questionnaire
2. All respondents are willing to answer the questionnaire
3. Able to encourage respondents to respond honestly
4. A simple questionnaire that the respondents can understand and answer
5. Avoid biased terms or wording as different words can lead to different answers
6. Offer plenty of time for the respondent to respond
7. Every question should produce the best possible data for the research question
8. Retest the tool and ask for feedback from experts and patients as to whether they understand it
9. Provide accurate translation for non-English participants (excluded in this study)
10. Avoid ambiguous or double-barrelled questions.

The latter was present in question 2, item 9, which is asking about "Depression or suicidal thoughts". This can lead to difficulty in interpreting the responses when analysing the data (Edelen, & Reeve, 2007). Retesting the study tool and reviewing patients' feedback can help to amend such questions and sharpen the questionnaire items (Bolarinwa *et al*., 2015; Boylan *et al.,* 2020; Jenn, 2006; Sahlqvist *et al*., 2011).

In this research, the study tool was an unstructured questionnaire for clinical use to support patients' engagement in their care and self-management. Every question was developed to explore and support patients' experience with the disease and with the health service. Apart from item seven, (which was adapted from the Likert scale; Appendix-II) all the other items in the study tool were open-ended questions, to offer a platform to the patients to report their views, treatment, comorbidities and needs without limitations (Burckhardt & Anderson, 2003). As discussed in chapter-3, close-ended questions were not used as they can restrict the depth of participant responses and may leave both the researcher and respondents to share different underlying assumptions (Streiner *et al.,* 2015).

Open-ended questions engaged/encouraged the participants in this research to express their views and opinions freely without restrictions and limitations (Jenn, 2006; O'Cathain & Thomas, 2004). They provided broad and diverse information relevant to the research questions. They explored patients' ongoing needs, wishes, desires, challenges, comorbidities and feedback. Closed questions can fail to reliably address the key concepts detailed within the research questions (Rencz *et al.,* 2021). Consequently, the quality of data collected may be diminished, limited or incomplete (Zamanzadeh *et al*., 2015).

The narrative data generated in the open-ended questions of the study tool was thematically analysed (Figure-8) and provided explicit details on patients' experience with the disease and with the health service. It disclosed their unmet needs, coping status, coping strategies, problems with topical therapy, their treatment preference including alternative therapy use, and triggering factors for their disease. As discussed in chapter 3, the tool included a QOL assessment to regularly monitor the impact of the disease and its treatment on QOL (Please see chapter-3, page 193-4).

The literature provides different approaches for item formulation and scale construction such as Thurstone, Rasch, Gutmann, or Likert methods for framing an item (Kishore *et al.,* 2021). Also having an interview with the participants before the survey can identify and shape the type of items needed to be included in the questionnaire (Barnett *et al.,* 2008). Equally, a group of experts can provide an item bank for questionnaire construction (Essink-Bot *et al.,* 1997). In this research item formulation was based on the research question and on the data obtained from the literature review. Hence, the study tool may reflect my personal or clinical interest, values or judgment, and therefore may not be free from personal biases.

Apart from question 7 in the tool, I could have adapted or modified one of the previously used scales to design the study tool such as the Thurstone scale, but it was reported as labour intensive and time-consuming (Streiner *et al.,* 2015). Thurstone scales use empirical data derived from judges to ensure that attitudes or behaviours being measured are spaced along a continuum with equal weighting/spacing (Hunt *et al.* 1985). Frequency scales may be used when it is important to establish how often a target behaviour or event has occurred (Rattray *et al.*, 2004). Guttman scaling is a hierarchical scaling technique that ranks items such that individuals who agree with an item will also agree with items of a lower rank. The cumulative attributes of the respondents are measured with a group of items framed from the easiest to the most difficult (Katz *et al.* 1963).

Rasch scaling adds the stochastic component to the Guttman method which lay the foundation of item response theory (IRT) for scale construction (Chapple, 2003). The latter theory was first proposed in the field of psychometrics for the purpose of ability assessment (Edelen, & Reeve, 2007). The application of IRT models can not only improve scoring accuracy but also economise test administration by adaptively using the discriminative items (Reise, & Waller, 2009). These features might explain why in recent years IRT models have become increasingly popular in many other fields, such as clinical research, health sciences, quality-of-life research, and even marketing research (Holman *et al.,* 2003). It does not assume that each item is equally difficult, which distinguishes IRT from Likert scaling, in which all items are assumed to be replications of each other (Embretson & Reise, 2000).

There is a variety of IRT models, such as the Rasch model, two-parameter model, and graded response model (Hays *et al.,* 2000). In the Rasch model, all the items are assumed to have the same shape. In practice, however, this assumption might not be reasonable (DeVellis, 2011). To avoid this assumption, another parameter called the discrimination parameter was introduced. The resulting model is called the two-parameter model. The discrimination parameter is a measure of the differential capability of an item. A high discrimination parameter value suggests an item that has a high ability to differentiate subjects (Embretson, & Reise, 2000).

Patient Benefit Index (PBI) is another scale that can be adapted for designing the study tool. The questionnaire provides benefit assessment and consists of two steps: before treatment, patients define their treatment needs according to a standardised list. After treatment, the patient rates the degree of benefits achieved. Having benefits from the patient's perspective is an important step in medical decision-making and reimbursement (Augustin, 2009).

However, all of the above scales may only be computed if the patient has provided valid data. They also do not assess patients' needs, experiences, service gaps, barriers, comorbidities, coping status or feedback and do not offer open-ended questions to engage the patient in the decision-making process. The DLQI was selected and included in the tool to regularly assess QOL of the patients at each follow-up consultation (please see chapter 3, page 208). Apart from being recommended by NICE (2012), the DLQI was designed to be simple and easy to use in a busy clinical setting and wide experience of its use has confirmed its appropriateness (Hahn *et al.,* 2001; Lewis & Finlay, 2004).

7.3.1 How to improve the quality of the questionnaire?

After reviewing the literature and knowledge gaps, the first step of designing the questionnaire was to construct a conceptual framework (Jenn, 2006), which I adopted from the self-management/motivation theories (SDT, SET and SRT). This framework helped to frame the research process and enabled me to create questions/items to cover all relevant variables in the research question and exclude any irrelevant variable (Hawkins *et al.*, 2020). This process also helped to answer the commonly asked questions: "Did I miss any important questions in the questionnaire?", "Should I include/exclude this particular question?" (Jenn, 2006 p 33).

The study tool contains unstructured open-ended questions which need to be validated and evaluated individually and holistically. Input from experts in the same field was missing in the creation of the tool to provide face validity or an item bank that could assess key components of the research (Chapple, 2003).

Participants' levels of engagement and satisfaction were found to be reduced following extensive, rather than limited, choices in the questionnaire (Edwards *et al.,* 2002; Iyengar & Lepper, 2000; Sahlqvist *et al*., 2011). Therefore, to enhance the utility of the scale, the content of the retained items was reassessed, and items were removed where multiple items measured the same aspects. Short questionnaires are relatively quick to complete, and relatively economical and are easy to analyse (Iglesias & Torgerson, 2000; Ogden *et al.,* 2008; Rattray & Jones, 2007). Hence, the number of the items in the final version of the questionnaire were reduced to 5 (4 open-ended questions and one Likert item) in addition to DLQI scale (Appendix-VII). This reduction in the items was a step to enhance the response rate without affecting its aims and objectives (Kliemann *et al.,* 2016; Zuidgeest *et al*., 2011). The participant number in the study tool was replaced by the skin disease diagnosis (code). This to be filled by the physician during the consultation. Adding this code can help the service provider in auditing, costing and measuring the types of skin diseases in their population, their needs, comorbidities, and what resources/services can be deployed to support managing such comorbidities and needs (Kishore *et al.,* 2021).

Although the study tool is not designed for research purposes, demographics questions can allow service providers (or researchers) to describe and analyse their population data. Demographic questions were not added in the revised questionnaire as they can deter patients from using the tool (Iglesias & Torgerson, 2000; Sahlqvist *et al.,* 2011) and they can be obtained from the patient NHS digital profile (Boynton & Greenhalgh, 2005). Nevertheless, reviewing the questionnaire by health experts/epidemiologists may help to decide what demographic questions can improve the quality of the collected data, benefit patient care and health service quality and development (Hawkins *et al.,* 2020).

The first two items in the amended study tool were assessing current patients' medication, which play a vital role in their management and self-management (Hodkinson *et al.,* 2020; Lorig, 1996). Addressing patients' medication can offer the patient the opportunity to discuss their feedback about the efficacy and the side effects of such medication and their adherence and preference of their effective therapy.

The third item assesses patients' comorbidities which is part of treating the whole patient rather than focusing on treating the skin rash. Further, medication used for comorbidities management (e.g., beta blocker) may trigger or aggravate a patient's skin condition. Similarly, many immunosuppressive medication used for treating eczema and psoriasis may not be indicated if such patients have certain comorbidities e.g., cancer or AIDS. Furthermore, comorbidities screening is recommended by NICE guideline (NICE, 2012).

The fourth question remains the same; assessing patients' feedback of their GP and dermatologist. The response to this feedback can assist the service providers to review and improve the quality of the care.

The fifth item evaluates a patient’s coping status and offers another opportunity to the patients to address their psychological comorbidity and needs. Many participants in the survey and the interviews complained that their physicians do not ask them how they are coping with the diseases. The regular response to this item and to the DLQI scale at each consultation can monitor patients’ psychological status/QOL and aid the physicians to take the necessary supportive action or to modify their management plan.

Apart from item four, all the items, in the final version of the study tool are open-ended questions to provide autonomy and choice for patients. They represent a platform for the patient to be involved in decision making of their management and to address their unmet needs (Ozuru *et al.,* 2013; Riiskjaer *et al.,* 2012).

As this research excluded non-English speaking patients, translation of a questionnaire in a language which the patients are most proficient in, is needed. This is a crucial step because inaccurate translation can lead to erroneous results and conclusions (Jenn, 2006). The research also excluded children and in order to include such a population the questionnaire format, look, language, font and design should be appropriate to such an age group. Similarly, if the respondents involve older persons, a bigger font size may be used (Sahlqvist *et al.*, 2011). Finally, as in the patient information sheet (Appendix-I), confidentiality information is needed stating the objective of the tool/portal, affiliations, and explaining/ensuring confidentiality and how data is going to be used and stored (Ford, 1999).

7.3.2 How can the final questionnaire be evaluated?

Whilst the tool has the potential to support patients and the health service across all specialities, it lacks reliability (consistency) and validity (accuracy) assessment. These limitations are expected to be assessed and resolved after piloting and implementing the proposed portal in clinical practice. A good questionnaire should be able to establish qualities of reliability and validity for it to be able to produce correct information concerning a particular topic (Bolarinwa, 2015). If a questionnaire lacks these two very important characteristics, then the conclusions drawn from that particular study can be referred to as invalid (Jenn, 2006).

While reliability and validity are two different qualities, they are closely related and interconnected (Bolarinwa, 2015). We can have reliability without validity, but reliability is necessary for validity assessment (Burckhardt, & Anderson, 2003). For a survey, or measurement instrument, to have good validity it must also have high reliability. Without good reliability a survey is not validly measuring what it is intended to measure: it is measuring something else or other constructs (Abeni *et al*., 2002).

Therefore, the study tool and the proposed portal system requires reliability evaluation first before its validity assessment (Cizek, 2008). Reliability describes consistency or the extent to which that same questionnaire would produce the same results if the study was to be conducted again under the same conditions (Healy & Perry, 2000). This might be achieved by repeating the survey (test-retest) and giving the questionnaire to the same group of respondents at a later point in time then comparing the responses at the two time points

(Morse *et al.,* 2002). Any discrepancy in the answers could be due to a lack of clarity of the questions and this should be reviewed and rephrased (Jenn, 2006).

Internal reliability (assesses the consistency of the tool results across items within itself) and external reliability (assesses consistency of the tool across contexts), can be assessed by Cronbach's alpha and test-retest, respectively. Inter-rater reliability is the extent to which two or more raters (or observers, coders, examiners) agree and it addresses the issue of consistency of the implementation of a rating system. Split-half reliability is when the questions are split in two halves and then, the correlation of the scores on the scales from the two halves is calculated. Afterwards, the calculated correlation is run through the Spearman Brown formula (Chapple, 2003; Kliemann *et al.,* 2016).

There are different statistical methods to measure the reliability and validity of a questionnaire. The statistical choice often depends on the design and purpose of the questionnaire (Ogden *et al.,* 2008). However, in this research a deliberative inquiry or a meeting with the stakeholders is needed to pilot/implement the proposed portal system and to assess its reliability and validity.

7.4 Reflection on the proposed portal

The proposal of an online or portal system is speculative and a full exploration of the implementation of this is beyond the aims and objectives of this research (page 11). This research aimed to involve the patient with psoriasis and eczema in decision making and self-management of their chronic condition by using a paper questionnaire (study tool) at each consultation. Its objectives were to assess the acceptability and the potential of the paper questionnaire in supporting patients' ongoing needs, involvement in decision making and self-management. The study tool contains open-ended questions that could help the physicians who are managing such patients to offer them an effective management plan that could support their self-management. The research explored the literature and identified knowledge gaps in managing such patients and provided a conceptual framework and a new tool (paper questionnaire) that proposed to fill the gaps in such patients' management. The research assessed the potential of the new tool in a mixed method study and provided unanimous approval of the participants on the benefits of using the study tool on a regular basis to support and assess their unmet needs and comorbidities.

However, around 86% of the interviewees preferred using the online version of the study tool. I therefore, proposed that an online version (patient portal) could be designed and developed to provide comprehensive digital access to many medical and social supportive services relevant to such patients' care and self-management. I conducted a pilot study with an independent group of health professionals to obtain their feedback on the design (Figure-11) and the potential of the proposed portal in supporting patient needs. Their feedback was positive.

However, although the feedback from consultant colleagues and service managers about the proposed portal was positive, they were concerned about the unpredictable workload that could be generated from the portal which may fall outside their job plan or employment contract. Piloting or implementing the paper or the proposed online portal can face many institutional and logistical challenges at different levels of the NHS. This was discussed in the last chapter. Patient portal implementation and monitoring is a complex financial and logistical process. Multiple teams and efforts are required to design such a comprehensive online service and assess its impact on patients and on the medical staff who are supposed to deliver and manage the data generated from the portal on a regular basis.

Nonetheless, this current research provides evidence on the interest of the participated patients in having a patient portal that can offer them a convenient and comprehensive service relevant to their ongoing needs and comorbidities. Future studies may include meeting stakeholders to pilot such a proposed portal as well as to assess its impact, reliability and validity at different NHS settings in order to support the care of their targeted population (Laukka *et al.,* 2020).

7.5 Conclusion

This chapter provided my reflection on the research journey. It highlighted the benefits of reviewing the literature to identify knowledge gaps and to reach a conceptual framework and a proposal. The latter included offering a paper questionnaire (study tool) to patients on a regular basis to engage/involve them in their care, assess their comorbidities and support their needs for self-management. The chapter reviewed the rationale for choosing a mixed method study to assess the acceptability and the potential of the study tool and reflected on the design and the limitations of the study tool in relation to other assessment tools that can be used in the dermatology service. It presented and explained the amended version of the tool and discussed the measures needed to assess its reliability and validity. Considering the COVID-19 pandemic the chapter reflected on the advantages of developing an online version of the study tool (portal) to provide comprehensive services that can be more convenient to engage/involve the patient than the paper version of the tool. The chapter also reflected on the challenges and barriers for piloting and developing such a portal system.

8. CHAPTER EIGHT - FINAL CONCLUSION AND RECOMMENDATIONS

This final chapter discusses the implications of the current mixed method research on patients with chronic skin diseases including psoriasis and eczema as well as on the quality of the dermatology service. The chapter explores the potential role of the study tool in engaging or involving patients to play an active part in the management of their chronic skin disease and the impact of the paper and the proposed online version of the study tool in supporting patients' needs and improving the quality of healthcare services. The chapter ends with recommendations for future research in this field and a final conclusion.

8.1 The potential impact of the current research on patient healthcare

The purpose of medicine is to keep people healthy so they can contribute to society (Appleton & King, 2002). Psoriasis and eczema affect around 1-3% and 15-20% of the global population, respectively (Griffiths *et al.,* 2017; Pezzolo & Naldi, 2020). Having a long-term illness like psoriasis or eczema is detrimental for the wellbeing of individuals as well as society as a whole (Balieva *et al*., 2016). Helping such patients to get better and functioning again will not only help patients, but it will also help society to maintain its productivity and social system norm (Finlay, 2009).

The literature review highlighted the on-going strains and the limitations of the dermatology service within the NHS. These limitations have often impacted on patient comorbidities, waiting time, quality of care and management outcomes (Edwards & Imison, 2014; HoC, 2014;

NAO, 2016; NHS Digital, 2018a). This research disclosed knowledge gaps, adopted a conceptual framework and created a novel tool to involve, assess and support patients with chronic skin conditions' needs and self-management on a regular basis.

The mixed methods inquiry conducted in this research answered the research aims and objectives highlighted in the first chapter (Table1). The study tool was first assessed by a pilot study and then by a postal survey. The findings of the survey identified that the tool was able to engage patients to provide their heterogeneous views, needs, comorbidities and feedback. The tool also highlighted hidden gaps, needs, barriers and challenges in the management of patients with psoriasis and eczema who were using the dermatology service in the NHS.

The findings of the postal survey showed that the study tool motivated participants to report their psychosocial comorbidity, as well as their self-esteem status and impact of social stigma on their daily life, disease triggering factors, coping mechanisms, treatment barriers and side effects, types of alternative therapies they tried including their advantages and disadvantages. The above information may not regularly be discussed, assessed or documented during the limited consultation time, yet they are important aspects to consider before offering effective care. Equally, the tool enabled the patients to provide feedback that can help stakeholders to review, assess and improve the quality of the service.

Overall, the tool has the potential to support patients' involvement in decision making and self-management as well as offering the opportunity for regular service appraisal (Al-Abri & Al-Balushi, 2014). The tool was judged acceptable by all the interviewees, who welcomed using it on a regular basis to address their ongoing needs and self-management. Their agreement to adopt a new behaviour may reflect their desire for having a platform to voice their unmet needs (e.g. long waiting time, lack of information, education or empathy) and/or to achieve their health goals.

Although, the results in the current research echoed similar findings presented in national and international research discussed in Chapter-2 (e.g., Dubertret *et al*., 2006; Krueger *et al*., 2001; Nash *et al*., 2015; Silverberg *et al*., 2018), this is the first mixed methods research that aimed to support patients with psoriasis and eczema by exploring the possibility of a new intervention in the form of a paper or online questionnaire. The reviewed studies reported the needs and comorbidities of patients with psoriasis and eczema nationally and internationally but did not provide or assess potential options to address these and to support their investigated population.

According to the major health professionals' review of the dermatology service in the UK (The King's Fund, 2014), the dermatology service has been struggling with increasing demand particularly due to the decrease in the number of dermatologists and the increase in the prevalence of skin cancers in an ageing population that require urgent appointment and management within 62 days of their GPs' referral date (Edwards & Imison, 2014; NAO, 2016). The priority of managing skin cancers has a knock-on effect on the waiting time to review patients with chronic skin diseases such as psoriasis and eczema who require regular follow-ups and close monitoring (NHS England, 2019; Schofield *et al*., 2009).

All the participants welcomed using the tool on a regular basis. They felt it could build up a sense of relatedness between the patients and the physician and can enable them to negotiate their management preferences, report treatment efficacy and address any new metabolic or psychological symptoms. Without using the study tool, it would be challenging to assess and explore patient needs, comorbidities and feedback. Hence, the physician and the service provider may not satisfy patient needs, and such patients may continue to suffer or fail to self-manage their illness (Nash *et al*., 2015).

The majority of the interviewed participants were keen to use the online version of the study tool. The research proposed that providing an online version of the study tool that could provide digital access to comprehensive services relevant to patient needs, could improve the engagement rate of the tool, assess patients' needs and engage them in decision making of their healthcare plan, remotely (Hazara *et al*., 2020).

The proposed portal can act as interactive virtual tool and minimise the risk of assumptions by the patients and physicians (Dendere *et al.,* 2019). Face-to-face consultation can be influenced by the stereotype assumptions of the behaviour of patients and/or healthcare professionals (Keyworth *et al*., 2015). Patients may feel low or embarrassed to disclose their comorbidities or feel that some of their psychological symptoms are not important to report in a consultation (Geale *et al.,* 2017). Equally, doctors may assume that the patients do not require assessment, because they are not complaining (Nelson *et al*., 2013; 2016). The study tool could provide a platform and a regular opportunity for the patients to report their on-going needs and comorbidities.

Apart from the dermatology service, the portal has been used to support patients with other chronic conditions (Dendere *et al.,* 2019; Irizarry *et al.,* 2015). Although the study tool was not designed for research purposes, the proposed portal can be constructed to provide information for auditing and costing of each skin disease and act as a cohort study generating patients' data prospectively and provide longitudinal epidemiological data that can assist stakeholders to allocate resources where needed and to improve the quality of the service (Boylan *et al.,* 2020; Irizarry *et al*., 2015; Portz *et al*., 2019, 2020).

Many patients asked for health information, patient forums, CBT, help with healthy lifestyle changes; the proposed portal system can be designed and electronically linked to many patients' supportive services, such as online patients' forums, local mental health counselling services, and skin diseases' charities including the British Association of Dermatologists' website. The latter provides information on almost all skin diseases and allows patients to download and print handouts on skin diseases and their management in different languages. This can help educate patients about their skin diseases and enhance their autonomy, competence and self-efficacy to self-manage their chronic illness (Ebrahimi Belil *et al*., 2018; Grady & Gough, 2014). Study-3 provided positive feedback from an independent group of health experts on the benefits/risk of the proposed portal system in supporting patient care. Challenges and barriers for implementing and sustaining a new model of care were discussed in chaper-6.

It is possible that the study tool provided a potential solution for many core tensions and limitations within the dermatology service. These tensions will be discussed below and in relation to the impact of the study tool as a new proposal for a model of care to assess and support patients' unmet needs.

From the literature review, it is clear that there was an increasing number of dermatology patient referrals from primary care to secondary care which has impacted upon the health professionals' ability to provide a high-quality service, waiting time to see a specialist, number of patients complaints and number of "Did Not Attend" (DNA) patients. The DNAs often result from the long waiting time, which can reach more than a year (NHS England, 2018a). During such a period patient morbidity/comorbidity may become worse. The latter can drive some patients to suffer alone or seek alternative sources of care (Bajorek *et al.*, 2016; Balieva *et al.,* 2016; NHS Digital, 2018b; NHS England, 2019). The increasing demand on the dermatology service has negatively impacted on the quality and continuity of care as many physicians are usually under pressure to discharge inpatients and spare hospital beds for new urgent admissions (NAO, 2016; Schofield *et al*., 2009).

Discharging inpatients and outpatients may help to reduce the workloads on the health service and enable such services to accept more new referrals (von Hospenthal, 2013). However, psoriasis and eczema are incurable chronic diseases and patients with such illnesses may develop a flare of their skin rash after discharge from the hospital (Griffiths *et al*., 2017, 2020). Their GPs are usually not trained to manage such chronic conditions (Schofield *et al*., 2009). Consequently, such patients may wait many months to be referred back to a dermatologist (Borghi *et al*., 2018; Nash *et al*., 2015). Additionally, many patients have no confidence in their GPs to manage their skin condition (Monk & Hussain, 2019; Nash *et al*., 2015). This may leave them to suffer alone or to seek private healthcare or alternative therapies to manage their symptoms (Hernan *et al*., 2019).

Although GPs have a long-term role in caring for the patient, they are usually faced with longer-term management difficulties of patients with skin diseases, and they often have very limited training in dermatology to assess and manage such patients. Therefore, a referral to a psychological therapy or other supportive therapies without a specialist assessment has not always resulted in a positive outcome (de Zoysa, 2013; Lavda *et al.,* 2012). In contrast, the online version of the study tool could provide an e-visit and regular assessment for such patients remotely, without the need to occupy outpatient slots. The study tool could regularly screen and identify patients' metabolic and psychological comorbidities at an early stage, and this would alert their dermatologist to offer counselling or referral to a specialised mental health service for further support (Boylan *et al*., 2020).

Additionally, incorporating patients into the decision-making process by using the study tool on a regular basis could be regarded as a way of engaging patients to feel "related" to a caring service (Elwyn *et al*., 2012; Liewellyn-Thomas, 1995; McKinstry, 2000). It could encourage patients to take ownership and be autonomous and competent in their self-management (Bandura, 1997; Grady & Gough, 2014; Jauhar *et al*., 2019; Ryan & Deci, 2000; Vahdat *et al*., 2014). In contrast, excluding patients from the decision-making process may negatively impact upon their adherence to the treatment and their management outcomes (Burt *et al*, 2006; Monk & Hussain, 2019; Nash *et al.,* 2015).

The findings of study-1 and study-2 showed that some of the participants were often not aware of health information about their skin disease and the choice of existing treatments. Many of them asked for education and information or patient workshops. The portal system can be designed to provide online access for such supportive services. This can potentially enhance patients' competence and self-efficacy in self-managing their long-term condition (Dendere *et al*., 2019; Portz *et al*., 2019).

Literature relating to clinical formulation viewed the importance of healthcare professionals working collaboratively with patients to set therapy agendas (Elwyn *et al.,* 2012; Llewellyn-Thomas, 1995; Monk & Hussain, 2019). It has been suggested that doing so may improve patient outcomes (Ankawi *et al*., 2019). In contrast, the inability of the service provider to offer an opportunity to the patients to address their needs and to be involved in decision-making may impact upon poor treatment compliance, depression, and can generate more follow up visits in primary and secondary care (Atherton *et al*., 2019).

In this research, many patients complained of their medication side effects and others asked for an alternative therapy, yet some physicians may not be aware of their needs, they do not think that they are important or they may have no time to manage additional problems (Atherton *et al*., 2019; Burt *et al*., 2017). The lack of considering and providing holistic treatment to the patient may also relate to the fact that they do not overlap with the services' resources and/or management capacity (Nuffield Trust, 2013; Say *et al*., 2006).

Patients may actually become worse if they receive less effective treatments, which often negatively impact upon their self-esteem, interest, motivation and adherence to their treatment (Devaux *et al*., 2012; Monk & Hussain, 2019; Nash *et al.,* 2015). This therapeutic approach also has implications on the quality of the service and the budget of the patient and healthcare provider (Schofield *et al.*, 2009). Inappropriate treatment can lead to more morbidity, more follow-up visits and more consultations as well as more psychological stress and anxiety to the patients (Cohen *et al*., 2007). The latter may aggravate patients' skin conditions and impact on their work, career or social life (de Zoysa, 2013). The vicious cycle between stress and disease aggravation can continue and may place more financial strains on the service and more pressure on the patients to purchase over the counter commercial skin products to ease their symptoms (Barry *et al*., 2019; Krueger *et al.,* 2001; Lim *et al*., 2017; Steen *et al*., 2017).

The research however, proposed that providing a patient portal system with access to patient information about the choices of the available therapies has the potential to help to alleviate some of the above challenges and encourage, engage, involve or motivate the patient to self-manage their illness (Hazara *et al*., 2020). Likewise, the portal system could offer the opportunity to the physician to assess vulnerable patients regularly and to ensure that their treatment pathways are efficient and responsive to their needs (Laukka *et al*., 2020). Hence, the study tool envisages encompassing patient engagement and a holistic treatment approach.

8.2 Recommendations and future research

Policy makers and stakeholders need to assess and review patient feedback, manage the gaps in patient care, and take more account of patient decision-making and management preferences (Atherton *et al.,* 2019; von Hospenthal, 2013). This could include conducting a regular patient needs assessment by using the study tool or any other alternative intervention (APPGS, 2013). Utilising the generic NHS patient satisfaction questionnaires or other dermatology tools discussed in chapter-2 and 3 alone may not be enough to assess patients' comorbidities or their self-management barriers, on a regular basis. It cannot explore areas that require improving where patients report that their clinical and psychological needs are not being met (Boylan *et al*., 2019, 2020; Hernan *et al*., 2019).

Many managers and leaders in the NHS follow a rigid financial or bureaucratic pathway without offering a vision for a long-term plan to ease the demands on the NHS such as providing preventable approaches and campaigns to reduce the prevalence of many preventable skin diseases and skin cancers by promoting healthy lifestyle campaigns (Atherton *et al*., 2019). Campaigns are also needed to increase public awareness about skin diseases and the harmful impact of their stigma on sufferers (Mannion & Davies, 2018; Oliver, 2017; NAO, 2016). Such campaigns can help to prevent rejecting, abusing or stigmatising people with disfiguring skin conditions in public places or at work (Alpsoy *et al*., 2017; van Beugen *et al*., 2017).

Efforts are needed to manage the increasing demands on the dermatology service and to reduce the waiting time to see a dermatologist. The delay in the management of patients with chronic skin diseases can have a negative impact on their morbidity and comorbidities and impose a potential strain on service resources and on patients' mental health (Bajorek *et al*., 2016; Balieva *et al*., 2016; Finlay, 2009). Prioritisation of measures with a wider scope beyond symptoms, which may include individualised self-report measures in the evaluation of services, may help to better reflect patients' needs and perspectives (BAD, 2014; NHS England, 2019; Nuffield Trust, 2018).

There is a need to solve the difficulties facing the health service when making decisions or adopting an individualised approach, which may conflict with local healthcare resources and national health policy guidelines (APPGS, 2013). Research is needed to consider new ideas and innovations to solve many limitations within the dermatology service at primary and secondary care levels. GP dermatology training should be provided and designed specifically around managing common chronic skin diseases and their associated psychological comorbidities. This may partly alleviate the pressure on secondary care and improve the appropriateness of GP referrals of common skin diseases such as psoriasis and eczema (Atherton *et al.,* 2019; Schofield *et al.,* 2009).

Large multi-faceted organisations such as the NHS are regarded as complex systems and may benefit from alternative management strategies, informed by complexity theory (Tuffin, 2016). More theory based research is needed to explain and explore how to solve the gaps in patient care. NHS management has continued to focus primarily on evaluating income and outcomes with less attention to the mechanisms by which these outcomes are produced (BAD, 2014; Nuffield Trust, 2018). Integrating theory into health services research can improve research methodology and encourage stronger collaboration with decision-makers (Brazil *et al*., 2005). Using theories in health services research can also provide a framework to understand the relationship between program inputs, program activities and their output or outcomes (Appleton & King, 2002).

Researchers need to look beyond SDT, SRT and SET to identify the diverse sources of engagement or motivation for health-related behaviours. They may need to identify different theories and methods to explain patient engagement, motivation, self-management and decision-making, or how they can be ameliorated as well as evaluate the effectiveness of different ways of making decisions (Pinder, 2008). Emphasis within practice is required to ensure patients’ expectations and their understanding of care are better addressed, and to explore ways of making more patient-centred assessments of outcome that still function in the context of a system like the NHS (Say *et al*., 2006; Vahdat *et al.*, 2014).

Research is also needed for the planning and development of a holistic service, such as the proposed portal system, and to assess what impact, risk, benefits, and resources are required to provide confidential, effective and sustainable services. The holistic approach should include primary prevention, patient education, healthy lifestyle advice, regular metabolic and psychological comorbidities assessment and improving patient accessibility to the supportive services including counselling or psychotherapy when needed (APPGS, 2013).

8.3 Final conclusion

Skin is an important part of human identity, immunity, homeostasis and wellbeing. Skin has been subjected to appraisal and criticism socially and politically because of its colour, age, and cosmetic status. Chronic skin diseases such as psoriasis and eczema can significantly impact on patients’ quality of life including their daily performance, education, career, life goals, confidence, self-esteem, private and intimate relationships. In addition, patients with psoriasis and eczema have a high risk of developing long term metabolic and psychological comorbidities that are often not regularly assessed, discussed or managed by the health care provider.

After reviewing the literature on the impact of psoriasis and eczema on quality of life and health service limitations, the research identified 3 knowledge gaps in managing patients with such skin conditions and adopted a conceptual framework from multiple theories aiming to develop a new intervention that can fill the gaps in the above patients' care. The research proposed a novel intervention (study tool), in the form of a paper questionnaire which contains open-ended questions and DLQI. It proposed that the tool could regularly engage/involve patients in decision making and self-management of their care and enable them to express their unmet needs, comorbidities and feedback about the service they received.

The research assessed the acceptability and the potential of the study tool by conducting a novel mixed method study and obtained participants' points of view from different sources and perspectives. All the participants in this research were adults with either psoriasis or eczema. Data was collected by means of a patient survey (study-1) and semi-structured face-to-face interviews (study-2) with the participants. Data analysis of both studies was divided into figures, tables, themes, and subthemes to make sense of the size and the constructions of the participants' challenges, needs and feedback.

The participants in this research reported diverse unmet needs and hidden psychological comorbidities reflecting their undertreatment or failure of offering them an effective assessment and management plan. The participants disclosed gaps in their management at primary and secondary care levels, including problems with the appointment systems and with their physician, poor education about their diseases and limited consultation time and resources that can restrict physicians from assessing patient needs or offering a holistic health care package to their patients.

The research provided unanimous approval of the participants on using the study tool on a regular basis to support their unmet needs and to improve the quality of their care. The majority of them preferred using the online version of the tool for convenience. Considering patients unmet needs expressed in both studies, the research provided a proposal of an online version of the study tool which can be electronically linked to many medical and psychological services and charities relevant to patient needs and self-management.

The proposed portal gained positive feedback from an independent group of health experts in a pilot study (study-3). Locally, our local dermatology team and service managers welcomed the proposal. However, within the ongoing demand on the dermatology service, there were systemic, financial and logistical barriers that need to be discussed and resolved before piloting such a proposal. Future research could focus on piloting and testing of the paper questionnaire in different healthcare settings to assess its reliability, validity in achieving its aims and objectives and to evaluate its impact on patients’ care, medical staff’s activities and on the quality of the health service.

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List of Appendices

Appendix - I Patient information sheet/consent for postal survey

Research title: Have patients with chronic skin diseases needs been met?

Dear Participant,
You are invited to take part in a survey, which asks for your feedback on the treatment you have received for your chronic skin disease.
Chronic skin diseases such as psoriasis and eczema are associated with distressing skin symptoms such as disfiguring itching skin rash and bleeding spots. There is no cure yet for psoriasis and eczema. Managing such chronic skin diseases can be challenging for the doctor and for the patient. We aim in this survey to find out your feedback on the treatment you have received, and the challenges you have experienced in managing your skin disease.

Why have you asked me to take part and what will I be required to do?

As a member of the clinical team, the researcher doing this study is allowed to access the database of patients with chronic skin diseases at Queen’s Hospital in Romford. By using this database, you have been chosen randomly to participate in this survey.
It is a voluntary survey and you are free to not participate without having to provide a reason for doing so. Your participation in this survey will not affect your medical care as it is entirely separate from your medical care.

Your confidentiality is protected in the survey by writing a study number on the feedback questionnaires instead of writing your personal details i.e. you do not need to write your name or any personal details on your questionnaires.
If you agree to participate in this survey, please fill in the attached questionnaire and send it back using the enclosed self-addressed envelope. By posting back your questionnaire you are providing your consent and agreeing to have your data used in the survey.

What if I do not wish to take part or change my mind during the study?

Your participation in the survey is entirely voluntary. You are free to withdraw from the research without having to provide a reason for doing so.

What happens to the research data?

The answers in your feedback questionnaire will be transferred on a spreadsheet and the information (data) obtained from participants’ feedback questionnaires will be analysed and assessed by the University of Cumbria. At the end of the survey your feedback questionnaire will be kept in a secure place at Barking, Havering and Redbridge Hospitals (BHRUH) for 5 years and in line with to the Data Protection Act 1998.

How will the research be reported?

The results of this survey might be published in a medical journal, but without using patient’s personal details i.e. the published report will not include your name or your personal details.

How can I find out more information about the study?

You can contact Dr Taha Aldeen by Email: taha.aldeen@bhrhospitals.nhs.uk or contact Elisa Visentin (Senior Research Nurse) on 01708435000 ext. 6128.

Since the survey is anonymous, we would not be able to identify you when you contact us, therefore if you have any concern on your current medical treatment, you can discuss this directly with your GP or with your dermatologist at the hospital.

What if I want to complain about the research?

Initially you should contact Dr Taha Aldeen, directly as above. However, if you are not satisfied or wish to make a formal complaint you should contact Diane Cox, Director of Research Office, University of Cumbria, Bowerham Road, Lancaster, LA1 3JD. diane.cox@cumbria.ac.uk
If any of the issue in this questionnaire were distressing or if you want to discuss any concern with somebody independent from the study, please contact the Research and Development (R&D) Department at Queen's Hospital in Romford on 01708435000 ext. 4956 or contact Patient Advice and Liaison Service (PALS) at Queen's Hospital in Romford on 01708435454 or email PALS at PALS@bhrhospitals.nhs.uk

Thank you for taking the time to participate in this survey.

Appendix - II Postal questionnaire (Study tool)

Research title: Have the needs of patients with chronic skin diseases been met?
Participant questionnaire Participant No------------------------

Please circle one of the answers below: -
1-Do you use skin topical treatment such as ointments, creams, or shampoo for your skin?
Yes
No
If so, do you think one or more of your topical treatments: - (circle all that apply)

1- Are ineffective.
2- Make your skin rash worse
3- Are not convenient to apply as frequently as recommended
4- Require a repeat prescription which is not easily accessible
5- I don’t know which one to use and how frequently

Other---

Which ointment(s) or cream(s) were helpful? --

Which ointment(s) or cream(s) were not helpful? --

-- ---
What are the side affects you have experienced? Please give details------------------------------
----

2-Your general health. Do you suffer from? (Circle all that apply)
1-Joint pain or arthritis
2-Poor mobility
3-High blood pressure
4-Diabetes
5-Obesity
6- High cholesterol
7-Anxiety, social anxiety or panic attacks

8- Insomnia or difficulty sleeping
9- Depression or suicidal thoughts
Other--

3-Have you tried one or more of the following? (Circle all that apply)
1-Antidepressants
2-Cognitive behaviour therapy (CBT)
3-Chinese herbs
4-Acupuncture
5-Homeopathy
6-Special diet e.g., dairy free, gluten free
7-Mindfulness sessions
8-Yoga/meditation sessions
9-Positive thinking sessions
10-Hypnotherapy
Other--

If so, which of the above were helpful in tackling your skin problems ----------------------------
----

4-What are the trigger(s) for your skin rash flare? (Circle all that apply)
1-Stress
2-Cold weather
Other ---

-- --
5-How do you cope with stress? (Circle all that apply)
1-Comfort eating
2- Watch TV or listening to music
3-Working late hours
4- Practicing hobbies
5- Practicing religion or praying
6- Taking antidepressants
Other ---

6-Do you feel you are able to cope alone with your chronic skin disease?

Yes No

If your answer is no, what are the factors preventing you from coping alone.

1-Lack of family support

2-Inablity to deal with the stigma of the skin disease

Other --

7-How do you rate the service you received in the following places: -?

Primary care (GP) very poor----poor------satisfactory----good----very good-----excellent

Secondary care (Hospital) very poor----poor----satisfactory----good-----very good----excellent

8-In order to manage your skin symptoms, do you think that you need: (tick all that apply)

1-Support at home

2-Support at work

3-More health information

4- More / longer appointments with the GP

5-More / longer appointments with the dermatologist

Other---

Any other comments or ideas that you feel would be helpful for managing your skin problems--

----

The final questions are based on the national DERMATOLOGY LIFE QUALITY INDEX (DLQI), which aims to measure how much your skin problem has affected your life **OVER THE LAST WEEK**.

Please tick or circle **one** answer for each question below.

1. Over the last week, how itchy, sore, painful or stinging has your skin been?

Very much

A lot

A little

Not at all

2. Over the last week, how embarrassed or self-conscious have you been because of your skin?
Very much
A lot
A little
Not at all
3. Over the last week, how much has your skin interfered with you going shopping or looking after your home?
Very much
A lot
A little
Not at all
Not relevant
4. Over the last week, how much has your skin influenced the clothes you wear?
Very much
A lot
A little
Not at all
Not relevant
5. Over the last week, how much has your skin affected any social or leisure activities?
Very much
A lot
A little
Not at all
Not relevant
6. Over the last week, how much has your skin made it difficult for you to do any sport?
Very much
A lot
A little
Not at all
Not relevant
7. Over the last week, has your skin prevented you from working or studying?
Yes
No
If "No", over the last week how much has your skin been a problem at **work** or **studying**?
A lot
A little
Not at all
Not relevant
8. Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?
Very much
A lot
A little
Not at all
Not relevant
9. Over the last week, how much has your skin caused any sexual difficulties?

Very much
A lot
A little
Not at all
Not relevant

10. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?

Very much
A lot
A little
Not at all
Not relevant

In order to check which ointment or cream is helpful or unhelpful for your skin problem, please bring all the medication you are currently using, with you in the next follow up visit.

'© Dermatology Life Quality Appendix. AY Finlay, GK Khan, April 1992'.

Thank you for your feedback and comments. We wonder if you are interested to participate in similar research or interviews that could help to improve the management of patients with chronic skin conditions. Yes No

Appendix – III Patient Information sheet for interview

Research title: Have patients with chronic skin diseases needs been met?

Dear Participant,

Thank you for retuning the dermatology feedback questionnaire, which was posted to you a few months ago, regarding the management of your skin disease. You have indicated in your answers that you are happy to participate in further research and we would like to invite you to a short interview at Queen's Hospital in Romford. The aim of the interview is to find out your opinion on using the questionnaire like the one you have already completed, for the management of your skin disease.

Chronic skin diseases such as psoriasis and eczema are associated with distressing skin symptoms that can affect a patient's quality of life. In primary care (GP setting) and secondary care (Hospital setting) there is limited time for the patient and the physician to discuss the challenges in managing your skin diseases during the short consultation.

We think that using the above feedback questionnaire in each follow-up visit can give patients the opportunity to address their needs in managing their chronic skin disease and to have answers to their questions. Filling the questionnaire at each follow up visit can also update patients' treatment record and keep them engaged with their physician in a more informative way. In the long term the questionnaire can help your service provider (dermatology service) to tailor their service according to patient needs.

The last page of this letter (Appendix-IV) contains the questions that you will be asked in the interview. This is a voluntary interview, and you will have the freedom to not answer any question you feel is not clear for you. The interview is confidential and for your security the interview will be audio recorded. If at any time you want to stop, you can let us know and we will stop the interview.

Why have you asked me to take part and what will I be required to do?

You have highlighted in your answers that you are happy to participate in further research. If you agree to attend the interview, we will ask your view on whether or not using a patient feedback questionnaire, like the one you have already completed, will be helpful to address your needs and the challenges you face in dealing with your skin diseases.

What if I do not wish to take part or change my mind during the study?

Your participation in the interview is entirely voluntary. You are free to withdraw from the interview at any time without having to provide a reason for doing so, or your care being affected.

Where and what happens to the interview data?

The interview will be conducted in the Dermatology Department at Queen's Hospital in Romford RM7 0AG. In the interview you will be asked the questions in the enclosed Appendix-IV. Your answers in the interview will be documented and analysed by the University of Cumbria (UoC). All the material used in the interview will be kept in a secure place at Queen's Hospital for 5 years after the study has finished and in line with to the General Data Protection Regulation (GDPR) of 2018.

UoC is the sponsor for this study based in the United Kingdom. UoC 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 UoC are responsible for looking after your information and using it properly. Your data is only identifiable to Dr Taha Aldeen as the lead researcher. 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. You can find out more about how we use your information https://www.cumbria.ac.uk/research/research - support/or by contacting the research officer or data protection officer at UoC. The Queen's Hospital will keep your name, hospital number, NHS number and your contact details confidential and will not pass this information to the UoC. Certain individuals from the UoC and regularity organisations may look at your medical and research records to check the accuracy of the research study. They will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, hospital number or contact details.*

How will the interview be reported?

The results of the interview might be published in a medical journal, but without using patient's personal details i.e., the published report will not include your name, age, address or your personal details or anything which might identify you.

How can I find out more information about the interview?

You can contact Dr Taha Aldeen by Email: taha.aldeen@bhrhospitals.nhs.uk or contact Elisa Visentin (Senior Research Nurse) on 01708435000 ext. 6128.

What if I want to complain about the interview?

Initially you should contact Dr Taha Aldeen, directly as above. However, if you are not satisfied or wish to make a formal complaint you should contact Diane Cox, Director of Research Office, University of Cumbria, Bowerham Road, Lancaster, LA1 3JD. diane.cox@cumbria.ac.uk

If you find any of the issues in the interview distressing or if you want to discuss any concern with somebody independent from the study, please contact the Research and Development (R&D) Department at Queen's Hospital in Romford on 01708435000 ext. 4956 or contact Patient Advice and Liaison Service (PALS) at Queen's Hospital in Romford on 01708435454 or email PALS at PALS@bhrhospitals.nhs.uk

If you agree to participate in the interview

Please sign the enclose consent form if you wish to take part in the interview. You may post this form back to us, using the enclosed self-addressed envelope.

Thank you for taking the time to participate again in our dermatology research.

Appendix – IV Patient consent form for interview

Research title: Have patients with chronic skin diseases needs been met?
Please answer the following questions by circling your responses:

Have you read and understood the information sheet about this interview? YES NO

Have you been able to ask questions and had enough information? YES NO

Do you understand that you are free to withdraw from this study at any time, and without having to give a reason for withdrawal or your care being affected? YES NO

Your responses will be anonymised. Do you give permission for members of the research team to analyse and quote your anonymous responses? YES NO

Do you agree to your interview or focus group to be audio recorded? YES NO

Please sign here if you wish to take part in the research and feel you have had enough information about what is involved:

Signature of participant:.. **Date:**................

Name (block letters):...

Signature of investigator:.. **Date:**................

Name (block letters):...

Appendix – V Patient interview questionnaire

Title: Have patients with chronic skin diseases needs been met?

1. **How did you find filling in the questionnaire?**

2. **How easy did you find answering the questions?**

3. **Do you think a questionnaire like this one would be useful before each visit? (YES/NO)**
   If yes…
   3a) In what ways might it be useful?

4. **Is there anything else you would have liked me to ask you about that was not on the questionnaire?**

5. **Do you think this questionnaire could help to address your needs in terms of managing your treatment? (YES/NO)**
   If no….
   5a) Please explain why you do not think it will help
   Can you think of anything that might help…?

6. **What circumstances might stop you from completing the questionnaire?**

7. **Would you recommend the opportunity to use this questionnaire (on a regular basis) for all patients with chronic skin diseases?**

8. **What other tools (if any) do you think could be used to help the patient to be actively involved in the management of their skin problems?**

9. **Do you have any other comments or ideas that may help you to manage your chronic skin diseases?**

10. **Do you think people might be more likely to use this questionnaire regularly if it were available in an electronic form e.g. website or app?**

Do you have any questions for me?

Appendix - VI Dermatology Life Quality Index

Hospital No: …………………………………… **Date:** ……………………
Name: …………………………………… **Score:** ……………………
Address: ……………………………………
……………………………………
Diagnosis: ……………………

The aim of this questionnaire is to measure how much your skin problem has affected your life
OVER THE LAST WEEK. Please tick (ü) one box for each question.

Please tick or circle **one** answer for each question below.

1. Over the last week, how itchy, sore, painful or stinging has your skin been?
Very much
A lot
A little
Not at all

2. Over the last week, how embarrassed or self-conscious have you been because of your skin?
Very much
A lot
A little
Not at all

3. Over the last week, how much has your skin interfered with you going shopping or looking after your home?
Very much
A lot
A little
Not at all
Not relevant

4. Over the last week, how much has your skin influenced the clothes you wear?
Very much
A lot
A little
Not at all
Not relevant

5. Over the last week, how much has your skin affected any social or leisure activities?
Very much
A lot
A little
Not at all
Not relevant

6. Over the last week, how much has your skin made it difficult for you to do any sport?
Very much
A lot
A little
Not at all
Not relevant

7. Over the last week, has your skin prevented you from working or studying?
Yes
No
If "No", over the last week how much has your skin been a problem at **work** or **studying**?
A lot
A little
Not at all
Not relevant
8. Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?
Very much
A lot
A little
Not at all
Not relevant
9. Over the last week, how much has your skin caused any sexual difficulties?
Very much
A lot
A little
Not at all
Not relevant
10. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?
Very much
A lot
A little
Not at all
Not relevant

DERMATOLOGY LIFE QUALITY APPENDIX (DLQI) - INSTRUCTIONS FOR USE

The Dermatology Life Quality Appendix questionnaire is designed for use in adults, i.e. patients over the age of 16. It is self-explanatory and can be simply handed to the patient who is asked to fill it in without the need for detailed explanation. It is usually completed in one or two minutes.

SCORING

The scoring of each question is as follows:
Very much scored 3
A lot scored 2
A little scored 1
Not at all scored 0
Not relevant scored 0
Question 7, ‘prevented work or studying’ scored 3
The DLQI is calculated by summing the score of each question resulting in a maximum of 30 and a minimum of 0. The higher the score, the more quality of life is impaired.

HOW TO INTERPRET MEANING OF DLQI SCORES

0 – 1 no effect at all on patient's life
2 – 5 small effect on patient's life
6 – 10 moderate effect on patient's life
11 – 20 very large effect on patient's life
21 – 30 extremely large effect on patient's life

REFERENCES

Finlay AY and Khan GK. Dermatology Life Quality Index (DLQI): a simple practical measure for routine

Appendix - VII Final version of the study tool

Chronic skin diseases questionnaire

Skin disease diagnosis (code) ----------------------------- (to be filled by the physician)

Please answer the following questions: -

1-Please list all the medication you are currently using ---

2-If you are currently using topical treatment; list the drugs that you find helpful
----

3-Do you suffer from? (Circle all that apply)

1- Allergy
2- High blood pressure
3- Diabetes
4- Obesity
5- Joint pain
6- Stress
7- Poor sleep
8- Depression
9- Suicidal thoughts
10- Cancer

Others, please specify ---

4-How do you rate the service you received in the following places (circle one that apply)
Primary care (GP) very poor-------poor------satisfactory----good----very good-----excellent
Dermatology service very poor-------poor-----satisfactory----good-----very good----excellent

5- Are you coping with the management of your skin disease (circle one that apply)

No Yes

If you are unable to cope alone, what are the factors that can support your skin self-management.

The final questions are based on the national DERMATOLOGY LIFE QUALITY INDEX (DLQI), which aims to measure how much your skin problem has affected your life **OVER THE LAST WEEK**.

Please tick or circle **one** answer for each question below.
1. Over the last week, how itchy, sore, painful or stinging has your skin been?
Very much
A lot
A little
Not at all
2. Over the last week, how embarrassed or self-conscious have you been because of your skin?
Very much
A lot
A little
Not at all
3. Over the last week, how much has your skin interfered with you going shopping or looking after your home?
Very much
A lot
A little
Not at all
Not relevant

4. Over the last week, how much has your skin influenced the clothes you wear?
Very much
A lot
A little
Not at all
Not relevant

5. Over the last week, how much has your skin affected any social or leisure activities?
Very much
A lot
A little
Not at all
Not relevant

6. Over the last week, how much has your skin made it difficult for you to do any sport?
Very much
A lot
A little
Not at all
Not relevant

7. Over the last week, has your skin prevented you from working or studying?
Yes
No
If "No", over the last week how much has your skin been a problem at **work** or **studying**?
A lot
A little
Not at all
Not relevant

8. Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?
Very much
A lot
A little
Not at all
Not relevant

9. Over the last week, how much has your skin caused any sexual difficulties?
Very much
A lot
A little
Not at all
Not relevant

10. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?
Very much
A lot
A little
Not at all
Not relevant

DERMATOLOGY LIFE QUALITY INDEX (DLQI) - INSTRUCTIONS FOR USE

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