An Exploration of Life With a Chronic Skin Condition

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A thesis submitted for the degree of Doctor of Philosophy

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Dedication

To my mum, Lay Wah, and my sister, Nada. Without your love and support, I would not be here today.

Acknowledgements

It has been a great privilege to receive the support of so many amazing people in undertaking this research. Your belief sustained me when I doubted that I would ever complete it.

First and foremost, I want to thank the respondents who kindly volunteered for and contributed to this research. You were generous with your time and candid in the discussion of sensitive topics. It is my hope that the findings of this research will be of some benefit to the lives of those affected by chronic skin conditions, but without your contributions this research would not have been possible.

I must thank Royal Holloway School of Law and Social Sciences for funding this doctoral research. In addition, I would like to acknowledge the British Sociological Association for their welcome financial support at a crucial stage in the development of this work through the award of the Phil Strong Memorial Prize. I would also like to acknowledge the Psoriasis Association for advertising this research to members of their online community, as well as the National Eczema Society, an organisation through which I was able to make contact with community support groups.

I want to express my sincere gratitude for my doctoral supervisors Jon Gabe, Sarah Moore, Leah Moyle, Michelle Webster and Rob Jago. I will always be grateful for the encouragement, wisdom and care you shared with me from the inception of this project to its final submission. Each of you brought a unique perspective to the project and I absolutely could not have completed this work without each of you being in my corner. I will be forever grateful. I would also like to give thanks to David Denney, whose contributions as an advisor during my annual reviews helped greatly in clarifying ideas. I would like to express my deep appreciation to Emily Glorney, Director of Postgraduate Research Education in the School of

Law and Social Sciences. Your compassion made a huge difference in navigating some intensely challenging periods during my PhD.

I would also like to thank the many fellow PhD students and others who I had the chance to get to know along the way during my doctorate at Royal Holloway. The Doctoral Hub became a home away from home and I hold many memories of the days and nights spent working on this research in that room. This work was made far richer by the company of so many interesting and thoughtful research people along the way.

Finally, I would like to thank my examiners, Karen Lowton and Jacqueline Sanchez Taylor, for their consideration and expertise in examining my work, and Ahu Gemici, for chairing my viva.

Abstract

Despite considerable prevalence and clinical impact, chronic skin conditions have received little sociological attention. This research examines the social implications of living with a chronic skin condition, based on the thematic analysis of in-depth interviews featuring 24 adults with experiences of eczema, psoriasis or acne. Drawing on Bourdieusian field theory and corporeal phenomenology, this thesis brings new insight to the disembodying experiences of disordered skin, strategies enacted for their management, and the wider implications of disordered skin on social participation. Illustrating experiences of social dys-appearance, individuals are found to negotiate stigma, both enacted and perceived, based on normative expectations of bodily presentation. Employing the notion of aesthetic capital, disordered skin is shown to impair possibilities for aesthetic distinction and undermine a sense of capability in personal and working roles. Faced with disabling spatialities and difficulties surrounding disclosure, individuals develop anticipatory dispositions and a range of time-space tactics. The corporeal dys-appearance of disordered skin demands that individuals respond through laborious practices which often take on Sisyphean attributes. A novel concept of "containing" is introduced as a type of skin work reflecting how managing disordered skin requires attention to clearing up exudations of "dirty" bodily substances, such as skin flakes, blood, pus, and the remnants of topical treatments, to avoid soiling external environments. Pharmaceutical treatments are found to be a source of deep ambivalence. Moreover, individuals value agency in their treatment protocols and, where capital resources allow, enact resistance to medical authority through experimentation with alternative strategies and practices of self-medication. This study highlights a need to accommodate the additional labour demands of life with chronic skin conditions, and the desire for agency in treatment, through policy and practice measures. Further efforts are needed to address the impact of inequalities of access to resources on the burden of managing chronic illness.

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Introduction

This thesis attempts to develop a richly embodied understanding of the impact of a chronic skin condition on everyday life and the strategies and resources that individuals with disordered skin draw on to manage their illness. In order to develop such an understanding, what follows is an exploration of experiences and practices from across wide swathes of daily living which were often quotidian and mundane, and occasionally graphically visceral or profoundly creative, but which it is hoped will together offer a nuanced insight into the lives of people negotiating the impact of disordered skin. A particular focus for this thesis will be the material aspects of experiences, acknowledging the corporeal body as a source of both physical and social discomfort for those living with a chronic skin disorder, yet is also a source for monitoring and understanding how such discomforts may be strategically managed.

This thesis seeks to build on seminal research by authors such as Ray Jobling, whose work on psoriasis from the 1980s onwards demonstrated a wide-ranging sociological exploration of everyday experiences in living with disordered skin. It is hoped that this thesis will add to a small but valuable body of literature with an examination of contemporary experiences of management and treatment practices, in ways that reflect the sociological implications of social, technological and pharmaceutical developments that have occurred in recent years. A further rationale for the development of this thesis was my own personal experience of living with a chronic skin condition. In addition to the desire for developing the sociological body of knowledge on what it means to live with and cope with disordered skin, this thesis was born out of my ongoing questioning about my own personal experience of illness which it was clear would require a detailed, nuanced and embodied exploration to get to grips with.

Far from an inert, superficial covering to the body, the skin is a vital, dynamic interface between us and the world (Benthien, 2002). As a physical and chemical barrier, the skin serves as our immediate and most important defence against injury, infections and radiation. The skin is fundamental in our body's ability to monitor and regulate temperature and water loss, and to recognise and distinguish between sensations of touch, pain, heat, cold and itching (Schofield et al., 2009). Composed of two main layers of cells—the dermis and epidermis—the skin is host to a variety of structures including sweat and sebaceous glands, hair, blood vessels and nerves that work together to perform these functions. Changes with how these structures function, alone and together, can result in a range of chronic conditions of the skin, including psoriasis, eczema and acne. For the millions of people who have these conditions they present a significant source of physical, psychological and social difficulty for everyday life. While the burden of chronic skin conditions on people's lives remains underestimated (Hong et al., 2008) there are signs that the seriousness of dermatological issues is gaining traction in public discourse. The All Party Parliamentary Group on Skin (2013), for example, recommended that greater recognition is needed from health professionals, employers, government institutions and the pharmaceutical industry about the psychosocial impact of skin conditions and their management on people's lives.

Historical Basis for Cultural Understandings About Skin Diseases

A recent focus in anthropological work has identified the historical importance of the skin to the development of understandings of health and illness. For 'thousands of years before the birth of modern medicine', Nina Jablonski (2006, p. 21) suggests, skin 'alone testified to the state of a person's health, displaying most of the known signs and symptoms of disease'. Indeed, 'no other organ in the body can boast so many diverse and important roles' (Jablonski, 2006, p. 2). Negative connotations attached to chronic diseases of the skin have historical basis in evaluations that associate these conditions with attributes ranging from danger to disgrace.

At times when religious ideals were predominant in public understandings of health and illness, certain diseases of the skin were evaluated explicitly on grounds of religious morality. That is, the condition of a person's skin has historically been used in the evaluation of their moral standing, with disordered skin being viewed as reflective of a disorderly person.

Hebrew ideas on health and illness were influential in the development of Christian outlooks on the body and disease. Religious orientations towards sickness held that illness 'signified the wrath of God' (Porter, 1999, p. 84). Conditions such as *Zara'ath*, identified through a disputed translation as leprosy, were associated with God's punishments for sin.

To elaborate on this historical mistranslation, the condition of *Zara'ath*, based on a description of physical dermatological symptoms such as raw, scaly and scabrous skin, may not have referred to the condition of leprosy, or Hansen's disease as it is understood today, alone or indeed at all (Myles, 2013, p. 143). Rather, *Zara'ath*, translated in the second-century BC from Hebrew into the Greek word, *lepra*, and in turn into Latin, which was then used by medieval Christians (Myles, 2013, p. 144) came to embody many benign, chronic skin conditions, including eczema and psoriasis. Having looked briefly into the historical basis of stigmatisation of conditions of the skin, attention will now move to contemporary misconceptions and their impact.

The Epidemiology of Chronic Skin Conditions in Developed Societies

Skin conditions are the most common reason for people in the UK to visit their General Practitioner (GP) with a new problem (Schofield et al., 2009). Indeed, while around one quarter of the population of England and Wales see their doctor with a skin problem in any one year, surveys suggest that greater than half of the UK population experience a skin condition over this period. The majority of these people treat their skin condition themselves, with many buying over the counter (OTC) products from pharmacies (Schofield et al., 2009).

Of the approximately thirteen million people who present to GPs with their skin problems each year, just under a million are referred to see dermatology specialists for advice. The most common conditions seen by dermatologists in England are skin lesions, eczema, psoriasis and acne (Schofield et al., 2009).

Quantitative Research Understandings About Chronic Skin Conditions

There is a substantial body of literature addressing the causes, manifestations and medical treatments for these conditions. The vast majority of studies take a quantitative approach based on a biomedical understanding of disease and treatment. That is to say, there has been a great deal of research exploring how chronic conditions of the skin such as acne, psoriasis and eczema operate within the body at a cellular, hormonal or genetic level. A large body of empirical biomedical knowledge about chronic skin conditions has been developed based on this approach. I would like to briefly summarise here the current state of knowledge about three common chronic skin conditions from the biomedical literature, before addressing the development and use of quantitative instruments for assessing the impact of chronic skin conditions on quality of life.

Biomedical Understandings of Acne, Eczema and Psoriasis

Acne

Acne vulgaris, known commonly as acne, causes spots to develop on the skin, usually on the face, the back and the chest (NHS, 2014a). These spots range from the blackheads and whiteheads on the skin's surface, to inflamed pus-filled cysts that extend deeper within the skin. Individual hairs on the body grow out of tiny holes in the skin, known as hair follicles. These follicles are attached to sebaceous glands, which are tiny glands found close to the surface of the skin. Sebaceous glands produce an oily substance—sebum—which lubricates the hair and the skin, stopping them from drying out.

If the sebaceous glands produce too much sebum, as is the case with acne, the excess sebum mixes with dead skin cells, with the result that follicles can become blocked (H. C. Williams & Dellavalle, 2012). Plugged follicles close to the surface of the skin will bulge outwards and create a whitehead. If the plugged follicle is open to the skin, a blackhead forms.

Everybody's skin is home to populations of bacteria that are usually harmless, but which in the skin of someone with acne can then infect these plugged follicles, which leads to the development of deeper pustules and cysts. It has been found that the sebaceous glands are very sensitive to changes in levels of hormones. Changes in hormonal levels measured, for example, during adolescence, in pregnancy and around menstruation, have been associated with flare-ups of acne (Stathakis et al., 1997). Supporting this view, studies have also demonstrated the effects of using exogenous hormones on the development of acne, such as the use of hormone replacement therapies in women and men, and the use of female contraceptive drugs. Acne has also been found to run in families.

Eczema

Eczema is the term for a range of skin conditions that cause skin to become itchy, dry and cracked (NHS, 2014b). The most prevalent form of this condition is atopic eczema, which most commonly affects skin in areas including the hands, the cheeks, the scalp, the neck, and in the creases of the knees and elbows. It is common for people with atopic eczema to have periods when their symptoms are less noticeable, and "flare-up" periods when symptoms are more severe. As the external barrier function of the skin becomes damaged through dryness and the tendency to scratch to relieve itching, people with atopic eczema face an increased risk of developing skin infections.

While no single biological cause has been identified, there has been a significant focus within biomedical research (Sandilands et al., 2007; Irvine et al., 2011) dedicated to the contribution of a genetic component in the development of atopic eczema. Numerous studies have identified mutations in genes associated with the production of a protein called filaggrin, which is abundant in the outer layers of the skin, with a defective skin barrier and an increased risk of developing eczema (H. C. Williams & Grindlay, 2010).

Atopic eczema often develops alongside other conditions such as asthma and hay fever, as well as tendencies to having food allergies, allergic conjunctivitis and other allergenic symptoms. The predisposition to developing these forms of hyperallergenic sensitivities is known as "atopy" or "atopic syndrome" (Proksch et al., 2006). As with acne, there are often also family links with atopic eczema.

Psoriasis

Psoriasis is a condition identified by crusty red patches of skin that are covered with silvery scales (NHS, 2015). Patches can appear anywhere on the body, but most commonly present on the outside surfaces of elbows and knees, on the lower back and the scalp. For some people, these patches become itchy and sore.

In people with psoriasis, the rate of skin cell production is greatly increased. While the process of making and replacing skin cells normally takes around three to four weeks, in psoriasis this process can happen in less than seven days. This increased rate of production results in a build-up of skin cells, which form the skin patches associated with the condition. The process within the body leading to this increased rate of skin cell production is not fully understood, but it is widely believed to be related to the functioning of the immune system (Griffiths & Barker, 2007).

In autoimmune disorders, the body's natural immune defences against disease and infection mistakenly attack healthy cells. In psoriasis, a type of white blood cell called a T lymphocyte, or T cell, which travels through the body to detect and destroy foreign substances such as bacteria and viruses, attacks the body's own skin cells, as if fighting an infection or healing a wound.

Many people with psoriasis find that their symptoms emerge or become worse after a certain "trigger" event. Triggers might include injuries to the skin, a bacterial throat infection, the use of certain medications, and stress. As with both acne and atopic eczema, psoriasis has been found to run in families. The role that genetics may play in susceptibility to psoriasis is unclear at this stage, but has been and continues to be a target for research.

Quantitative Instruments for Assessing Chronic Skin Conditions

A number of quantitative instruments have been developed to assess the clinical impact of skin conditions through measurements of, in the case of psoriasis for example, the area of skin affected on the body and the severity of lesions (as measured by the Psoriasis Area and Severity Index or PASI) (Raho et al., 2012). A smaller body of literature involves the use of quantitative approaches for understanding the impact of chronic skin conditions on broader measures of quality of life (QOL). Quantitative instruments, such as the Dermatology Life Quality Index (DLQI), take into account the number of disease flare-ups, hospital admissions or extended spells of clinical remission that a person experiences (Bronsard et al., 2010). Using more generalised QOL measures, research has found quality of life implications for people who have psoriasis, for example, to be comparable with clinically severe conditions such as cancer and diabetes (Rapp et al., 1999).

Studies using such QOL instruments are based on asking a limited number of questions about daily life experience during a given period - a week, a month - prior to the assessment. While they are able to offer broad insight into the experiences of large numbers of people who live with a particular condition, they do not offer the opportunity for an in-depth understanding of multi-faceted, idiosyncratic experiences of life with a chronic skin disorder. As such, the value of research findings based on the use of QOL instruments has been called into question. (Raho et al., 2012).

Literature Review

In this chapter I will review a range of different literatures in order to build an understanding of current sociological knowledge on chronic skin conditions. In the course of this review, these conditions will come to be framed as forms of chronic illness with both biological and social contributing factors which can impact upon many aspects of individuals' daily experience, their social identity and sense of self. Based on a broad range of theoretical and empirical literature, the case will be made for an embodied understanding that acknowledges the central role of the body and its material practices to experiences of life with disordered skin.

The present study will take a qualitative approach to exploring experiences of chronic skin conditions. The remainder of this chapter will be dedicated to the current state of knowledge about what it is like to live with skin that is disordered, based on research findings on the experiences of people who have acne, eczema, psoriasis or other conditions in which there may be long-term visible disfigurement of the skin, such as burns survivors.

Findings from qualitative research investigating the experiences of people with chronic skin conditions largely demonstrate the perceived negative impact these conditions have upon the individual. On reviewing literature sourced from academic texts broadly within the field of medical sociology, it is clear that the implications of living with skin conditions such as acne, eczema and psoriasis are wide-ranging in their scope and severity, with differences between experiences of different skin conditions, as well as varying experiences among individuals who share a diagnosis. That is not to say, however, that there are no common threads in the literature. In order to make sense of this area of research, experiences of chronic skin conditions will be considered at three conceptual levels in relation to the individual, broadly addressed in the literature; firstly, how experiences of living with a skin chronic condition can impact upon social interaction; secondly, how such experiences can impact upon identity and the self; and thirdly, the material realities of treating and managing a chronic skin condition.

Chronic Skin Conditions and Social Interaction

Stigmatisation and Moral Judgement Based on Historical Mythology

Seminal work by Goffman (1963) theorised the role of stigma, which is a status or an attribute that is viewed as deeply discrediting. His work explored how stigma impacts upon the management of social interaction between affected and unaffected individuals. Goffman's conceptualisation of stigma is based on a distinction between "virtual social identity" and "actual social identity". An individual's virtual social identity is constructed from the stereotyped characterisations perpetuated in everyday life, while their actual social identity is representative of the attributes they actually have. Stigma is the result of a discrepancy between actual and virtual social identities. Indeed, Goffman (1963, p. 14) suggests that stigma is 'a special kind of relationship between attribute and stereotype'. There are a number of factors, according to Goffman, that influence the likelihood of stigmatisation.

Firstly, while some forms of potential stigma are openly apparent, others are more easily concealed. Someone with a known or highly visible stigma may be "discredited", while those whose stigma is unknown or can be concealable may be described as "discreditable" (Goffman, 1963, p. 4). This distinguishes between those attributes that are not visible and therefore hold only the potential to stigmatise and those which are in fact visible and therefore more immediately stigmatising. These distinct attributes present different problems for the people they affect. While those who are discreditable must restore their identity and status, the problem for the discreditable is to control the flow of information about those tarnished aspects of the self. Skin conditions are often particularly visible to others and in some cases continually so, but as will be discussed, can also be erratic in their presentation, and so present unique difficulties with respect to stigmatisation. A second and related factor is the extent to which other people are aware that someone has an illness, which Goffman calls the “know-about-ness”. A third factor is the degree of obtrusiveness, which refers to the degree to which the flow of interaction is impeded by the symptoms of the illness. Goffman identifies a final factor—the perceived focus—which is the perception others hold about the ability of an individual to participate normally and fully in society (Goffman, 1963, p. 50).

Stigmatisation is not always accepted by the person who holds a stigmatising attribute or status, as they may have identity beliefs which are self-protective. In many cases, however, the stigmatised person holds beliefs about identity that are in line with wider society. Sharing these beliefs, the stigmatised person is more likely to experience shame at holding the discrediting feature. Stigma such as disfigurements of the skin, particularly of the face, that are experienced by people with acne and other disorders can lead to problems in social interaction that can leave lasting damage to someone's self-identity (Murray & Rhodes, 2005, p. 184). As Jobling (1988) depicts in his work on the chronic condition, psoriasis:

> those who develop psoriasis are potentially challenged by semipermanent disfigurement, which is damaging to social attractiveness and self-esteem in the many circumstances where their lesions may be revealed to the world. Moreover the constant shedding of an unusual, unaesthetic body product, namely waste skin, which is difficult to manage, makes self-presentation and a normal everyday life all the more difficult … Additional to this comes the suspicion of culpability through poor personal hygiene; and the widespread perception of skin conditions as exceptionally infectious or contagious. (p. 226)

It is clear that the bodily characteristics of psoriasis, and other chronic skin conditions, meet a number of Goffman’s conditions for displaying a high likelihood of stigmatisation. And indeed, diseases of the skin have a long-held history of stigmatisation, as borne out strongly in the limited body of empirical qualitative literature on experiences of skin conditions. There is strong evidence documenting stigmatisation in public responses to skin disease (Jobling & Naldi, 2006). The origins of this widespread and distinctive psychosocial reaction are rooted deeply in history and culture. There have long been cultural attachments between skin disease and dirtiness, long bound to fears of contagion (Naldi & Minelli, 2007).

Contemporary Stigmatisation and Acts of Discrimination

The psychosocial functions of the skin, Jobling (1988) suggests are analogous to its physiological functions. The skin represents both a barrier between the person and the world and a major point of contact with it. Results from numerous studies have demonstrated that experiences of stigmatisation are common for people with psoriasis (Kimball et al., 2010; Schmid-Ott et al., 2007). Moreover, this stigmatisation is manifested through discriminatory practices and acts of public rejection, such as being asked to leave certain public places. These are commonly places where activities typically involve larger areas of the body being visible to others than is usual in everyday life or places where bodies come into close contact. Ginsburg and Link (1993) report that around one in five people with moderate to severe psoriasis had been asked to leave the gym, hairdresser or swimming pool. This was found to contribute to the avoidance of public places or social situations where there was a raised chance of social rejection.

Jowett and Ryan (1985) found that '[t]he extra demands that having a skin disease can impose on social life was striking' (p. 428). It is clear that the social impact of eczema - as well as psoriasis, acne, and undoubtedly other chronic skin disorders – can be substantial, and moreover, is 'at odds with the common tendency to regard such conditions as trivial' (Jowett & Ryan, 1985, p.429). Indeed, chronic skin conditions affect self-image and quality of life, lead to anxiety, depression and a reduction in social functioning (D. R. Thomas, 2005). However, despite being associated with significant psychosocial morbidity, skin diseases are often perceived as being non-serious (Hong et al., 2008). Moreover, dealing with misunderstandings from others about eczema was found to place additional strain on sufferers across many spheres of their life.

In common with experiences of other visible skin disorders, it is common for people with eczema to feel stigmatised by their condition. Many refer to the difficulties presented by socialising during periods when their skin is infected or extensively fissured (Mollerup et al., 2013). The need to clarify the nature of a visible condition like eczema can become a perpetual aspect of interactions with others. The visibility and psychological impact of chronic skin conditions often lead to feelings of embarrassment, rejection, lowered confidence and for many, social withdrawal (Ginsburg & Link, 1993).

A participant in Jowett and Ryan's (1985) study refers to the recurring difficulties of convincing people that her condition was not contagious and feels hurt when others viewed it as "something dirty". Coming to terms with these incidents with acquaintances and strangers, which often begin at school, is a significant facet of the illness experience for many with eczema. Visible damage to the skin of the those affected led to queries from some about whether they had suffered burns or some other trauma, while there were perceptions of an uncomfortable "Ugh, what's that?" reaction (Jowett & Ryan, 1985, p. 428) while in the presence of others that is dreaded by many with chronic skin conditions. Concerns about what others are thinking, their anticipated responses and uncertainty about how to respond to present the condition were key issues for many. In negotiating these concerns, it was found to be nearly ubiquitous for those with eczema, acne and psoriasis to attempt to keep affected areas of skin covered from view and to feel uncomfortable in talking about their condition (Jowett & Ryan, 1985). It is clear from Jowett and Ryan's findings relating to the impact of chronic eczema on interpersonal relationships that, due to misunderstanding and stigma, as well as the bodily impact of the condition, people with eczema face persistent social difficulties.

A study by Fortune and colleagues (1997) found that the stress resulting from anticipation of others’ reactions to their psoriasis was the most reliable predictor of disability. In line with findings about other skin conditions, fears of stigma experienced by people with psoriasis that resulted from previous negative social reactions were intense.

A widespread belief held in the social groups of adults with acne that Murray and Rhodes (2005) spoke with was that acne was a problem confined to adolescents, with the inference being that adults should have "grown out of" the condition. Daily skin care routines and special dietary adherence reported by people with acne were often found to run counter to biomedical understandings about the management of the condition. The often rigorous skin cleansing routines reported by people with acne is and may be influenced by the stigmatisation attached to this skin condition. Murray and Rhodes (2005) suggest that these practices are reflective of – and a reaction to – the ‘myth prevalent in society that acne is caused by uncleanliness’ (p. 190). In a similar vein, picking at spots, again against dermatological advice, can be viewed as an attempt both to speed the disappearance of the spots and to remove perceived “impurities” – physical and moral – from the skin. Participants' experiences of others' responses confirm that myths about the causes of acne, such as the condition being a result of uncleanliness or eating greasy food - particularly chocolate (R. Wolf et al., 2004) - remain prevalent. Corollary to these myths arguing that acne can be controlled through diet or skin hygiene is the attribution of blame to those that have it (Murray & Rhodes, 2005). As these misconceptions demonstrate, adult acne, like other chronic skin conditions, is viewed by society as much in moral terms as it is in terms of bodily disease. There are clear associations between norms for physical appearance, moral standing and social status, as will now be discussed.

Physical Capital and the Skin

The skin is a vital organ of social communication (Schofield et al., 2009), and Western society and the media place huge emphasis on physical appearance. Moreover, in our highly visual culture, concerns that people with a chronic skin condition have about facing prejudice based on their appearance are not without foundation. A visible chronic condition like acne, for instance, impacts upon the personal traits that an individual is perceived as having (Ritvo et al., 2011). It was found that young people with acne are generally perceived negatively, stereotyped as being shy, stressed, lonely, boring, nerdy unhealthy, introverted and rebellious. Clear skin was viewed positively, and this quality was associated with traits for intelligence, happiness, trustworthiness, health and creativity (Ritvo et al., 2011). Bourdieu's conceptions of the habitus, field and capital may be useful for understanding how a visible chronic condition of the skin impacts negatively upon how someone is perceived.

Bourdieu argues that people acquire a pre-reflective comprehension of the social environment and how they are positioned in it through an incorporation of the structures of the social world in which they live and practice—acting and being acted upon—since birth (Bourdieu & Wacquant, 1992). It is through their repeated exposures to a social environment that people develop a set of dispositions particularly attuned to the regularities and familiarities of their social world. Bourdieu terms this acquired set of dispositions, reflective of the differing social conditions of each person's life, the habitus. Under any given context, it is the habitus which inclines people towards particular and predictable behaviours, feelings and attitudes (Bourdieu, 1990). And these are neither automatic nor reflective responses—they are the result of the interplay between supra-individual social structures and individual decision-making.

The habitus interacts within a given “field”, and human practices are the result of this interaction. The “fields” that Bourdieu refers to are relatively autonomous ‘social microcosms’ (B. E. Gibson et al., 2007, p. 507) such as family, health care or education—each has a tacit set of rules and understandings. Each field is characterised by a juxtaposition of social positions—the distinction or mutual exclusion of people or groups from one another (Bourdieu, 2011). The position that a person or group takes up within a field is determined by the type and amount of field-specific “capital” that they can access. And “capital” is defined as a resource that is acknowledged as having value within a field (B. E. Gibson et al., 2007). As such, the field becomes a site of struggle for position or status based on the possession of capital.

In cases of disability or illness reflected in physical differences, “physical capital”—abilities and attributes judged either positively or negatively—comes into play across a variety of fields in social life (Shilling, 2012). As with other forms, the symbolic meaning that is attached to a person’s physical capital has an exchange value that contributes to their social position. It has been shown that the ways in which ill or disabled bodies are perceived as deviant from a prescribed set of social norms are related to the processes of possession of various forms of capital (Edwards & Imrie, 2003). Turning to the present research, norms about health, attractiveness and social value are heavily influenced by a visually saturated media culture which attributes a great deal of value to the appearance of skin. On this basis, living with a chronic skin condition visible to others may be viewed as damaging to the physical capital a person holds, with negative consequences for many aspects of social experience.

Shame as a Consequence of Stigmatisation

As a consequence of stigmatisation, someone with a skin disease - reflective of their physical or moral "uncleanness" - has cause to feel ashamed. The experience or anticipation of negative evaluations from others results in what many people with acne describe as feelings of shame in social situations (Kellett & Gilbert, 2001; Murray & Rhodes, 2005). Jobling's (1988) interview study provides evidence of feelings of shame and guilt in people with psoriasis.

However, the shame that people with this condition feel is not only the result of others' reactions, rather it may also stem from how the individual with acne behaves in social encounters. As Murray and Rhodes' (2005) findings suggest, self-consciousness, shyness and anxiety relating to the condition, and the subsequent avoidance of social situations, can damage an individual's social skills, increasing the difficulties presented by future social interactions. Not only do these experiences lead to feelings of being stigmatised in the moment, they have also been found to result in increased sensitivity to others' attitudes and the anticipation of future social rejection. Indeed, the psychosocial impact of stigmatisation experiences are not necessarily diminished with improvements in someone's skin over time. In a 1-year follow-up study, Schmid-Ott and colleagues (2005) found that improvements in the skin were not correlated with lowered feelings of stigmatisation, particularly in women. This long-term impact of stigmatisation or its perception can impact many aspects of someone’s life including, evidence suggests, their occupational experiences and their leisure activities, as will now be discussed.

Economic and Occupational Impact

Stigmatisation has been found to impart a tangible impact upon the social and economic lives of people with psoriasis (Horn et al., 2007). Reduced self-confidence and feelings of embarrassment can lead to the avoidance of situations where the skin is exposed, with the consequence of damaging employment opportunities and inhibiting the development and maintenance of social relationships. The probability of a low yearly income was found to be significantly higher for people with severe psoriasis than those with mild psoriasis in Horn et al.'s (2007) US study. Moreover, both absenteeism and impaired productivity have been documented across a range of chronic skin conditions (Hong et al., 2008).

Employment options were found to be limited for people with eczema in certain types of work, particularly in highly physical work that makes extensive use of the hands. One male participant in Jowett and Ryan's (1985) study had been unable to work in the building trade, while another had had to turn down work as a car mechanic. Eczema has been found to be the cause of people changing occupation, taking long-term sick leave and retiring from work (Lysdal et al., 2011; Meding et al., 2005).

The stigmatisation of visible skin conditions can also extend to the measures taken to manage them. In the case of eczema, for example, the use of protective gloves may be source of stigma in a work environment. As well as diminishing hand dexterity, particularly important in some occupations, the use of cotton gloves beneath protective gloves also drew attention to the hands (Mollerup et al., 2013), conflicting with the presentational demands of certain forms of employment, such as work as a sales representative. As one man in Mollerup and colleagues' (2013) study explains, 'Well, someone is sitting on the opposite side of the table; thinking "he's wearing gloves - this might be contagious," right. So they focus on that instead of the product you're trying to sell, right' (p. 1062). Their finding demonstrates how the need to protect the hands can interfere with many social situations, including those of occupational environments, if a person appears unable to participate normally in everyday interactions. The inability to handle certain items or the need to wear cotton gloves, for example, can also disrupt symbolic everyday acts of reciprocity (Bury, 1982) such as shaking hands when greeting.

Pallua and colleagues (2003) noted that the greater the burden of functional limitation, the increasing passivity with regards to enacting social roles that burns survivors were found to inhabit. People living with burn scars that are clearly apparent often appear less frequently in public and experience limitations in their social and occupational activities. Moreover, people living with functional impairments that affect work and social roles through the disfigurement of visible areas such as the hands and face may consequently experience socio-economic disadvantages (Pallua et al., 2003).

Impact on Leisure Activities

It is not uncommon for participation in leisure activities by people with skin conditions to be curtailed because of the physical discomfort they experience. Sometimes it is self-imposed barriers that act to limit an individual’s participation in particular activities. For some this is a result of internalising the stigma they have experienced in the past. The types of activities that people could pursue was also found to be impacted upon by their skin disorder. A third of those with eczema in Jowett and Ryan's (1985) study reported that their participation in sports activities had been curtailed by their skin, particularly so for going swimming.

Similar findings were also reported also for adults with acne, who avoided activities that had the potential to exacerbate their condition, such as sports, which would make them sweat (Murray & Rhodes, 2005). Not only are people with skin conditions limited in terms of sporting activities, however, the complex physical and social burden of eczema was also found to limit pursuits ranging from dancing and gardening to going out to dinner with friends and knitting (Jowett & Ryan, 1985).

Broadening out in terms of overall experience from limitations of the individual on pastimes and work, the impact upon interpersonal relationships with friends and family collectively may be substantial. The following section addresses how skin conditions affect social relationships and considers the roles family members and friends can play in individual illness experiences.

Relationships With Family, Friends and Romantic Partners

It is very common for the physical, social and psychological impact of a skin disorder to affect not just the individual with the condition, but those around them too. Skin conditions have been shown to put strain on interpersonal relationships with family members and partners through the disruptions to their social lives resulting from embarrassment and the time spent helping the sufferer with their treatment (Eghlileb et al., 2007). Chronic skin conditions unequivocally damage the social functioning of the individual across wide swaths of social life, from interpersonal relationships with family and friends, to the development and maintenance of romantic and sexual relationships.

Nearly half of participants with skin eczema in Jowett and Ryan's (1985) study felt that their skin condition had caused 'frictions' in their family life (p. 428). The use of messy, smelly, arduous treatments can impact upon relationships with partners and family members. From an immediate physical perspective, the "greasiness" of topical treatments for chronic skin conditions such as psoriasis and eczema emerge as a particular burden, upon both the person who has the condition and their relationships with partners and relatives (Jobling, 1988, p. 233). Greasy ointment-based treatments also reinforce the unattractiveness that individuals with chronic skin disorders often perceive about their bodily presentation. The physical act of scratching the skin can also prove difficult for others to understand and tolerate, particularly when this causes broken nights of sleep for individuals and their partners (Jowett & Ryan, 1985).

It is also quite common for chronic skin conditions to be a source of sexual difficulties with partners, with one survey of people with psoriasis finding that more than a third of respondents reporting an impairment in this area of their lives resulting from their skin condition (Sampogna et al., 2007), with another study finding that the partners of people with atopic eczema reported a negative impact on their sex life because of this skin condition, while greater than half of sufferers themselves reported decreased sexual desire.

Murray and Rhodes' (2005) study found that family and friends tend broadly to offer those with acne support and advice and attempt to make them feel comfortable using, for example empathetic humour about the condition or medication. Some respondents in their study, however, experienced a lack of support, or perhaps misdirected support from families that they felt was counterproductive. One participant found her mother's focus on taking her to get a haircut or a makeover as a way of improving her appearance - her mother "just wants her baby to be beautiful again" (Murray & Rhodes, 2005, p. 194) – to be unwelcome, despite being well-intentioned.

Due to prevalent mythology around the aetiology of acne which loads responsibility on to the lifestyle of the sufferer, any practical advice offered by friends or family to a person with acne may be inferred as blaming the individual. In addition to other social hurdles presented by the condition that lead to a general reluctance towards social interaction, such perceptions of blame cause relationships to suffer (Murray & Rhodes, 2005).

While interpersonal difficulties form a part of the illness experience for many with eczema, the supportiveness of family members and partners has shown to be important, particularly during periods when pain, discomfort or mobility are affected (Jowett & Ryan, 1985). It is also apparent, however, that in addition to support from family, people living with eczema valued support received from close friends, who could be understanding and sympathetic if they better understood the condition. While family and friends may be able to better take on positions of support or understanding over time, the reactions of strangers in everyday life towards their acne presented difficulties that Murray and Rhodes' (2005) participants found challenging, and in some instances, disabling.

Interactions With Strangers

The reactions of strangers, or perceptions of reactions, experienced by Murray and Rhodes' (2005) participants with adult acne included staring, unwelcome comments, the avoidance of physical contact and being judged based solely on appearance. One of their participants reported that during an interaction with someone who they had not met before, the stranger's gaze would inevitably be drawn to her acne. While comments from curious children were felt to be acceptable, Murray and Rhodes' (2005) participants viewed personal comments from adults, who were expected to have the ability to restrain themselves, to be unacceptable.

There were perceptions among adults with acne of people avoiding physical contact, with shopkeepers, for example, putting change on the counter rather than handing it over directly, which participants thought stemmed from misguided concerns of contagion. It was a common experience among participants in Murray and Rhodes' (2005) study to feel that they were being judged as people on the basis of their appearance. Many were self-conscious when meeting new people because of their perceptions of the negative thoughts and opinions of others. As a consequence, respondents often attempted to avoid attention and to 'blend into the background' and they refrained from going out when they perceived their acne was especially apparent (Murray & Rhodes, 2005, p. 193). Participants took care to avoid situations that might emphasise their skin condition, including taking part in activities in which their make-up may be washed off, such as swimming, as well as face-to-face conversations, and bright light. As well as avoiding particular activities, strategies were adopted to conceal or reduce the visibility of acne, such as covering the face with a hat and scarf, or long hair.

For many with chronic skin conditions, meeting new people is avoided, though some people in Murray and Rhodes' (2005) study talked of particular concerns they had with meeting people who they knew from a time before they had acne or when their skin was in better condition. Excuses were made by participants not to see people, and friends were pushed away - sometimes due to feelings of anticipated rejection. Due perhaps to this anticipation, for people with acne, meeting with people requires preparation - both physical and psychological. One of Murray and Rhodes’ (2005) female participants describes this need for preparation for social encounters: "If I’m feeling bad about my acne I won’t go anywhere, in fact I’ll tell my family to tell anyone who calls that I’m not home. And if someone stops by unexpectedly, that’s the worst, because I’m not prepared make-up wise or emotionally! I’ve actually HID in my house before when I saw a car full of my friends drive up to my house" (Murray & Rhodes, 2005, p. 194). Participants spoke of the social isolation they felt, having withdrawn from social situations, and having to 'force themselves to go out or meet people, despite experiencing discomfort' (Murray & Rhodes, 2005, p. 194) in an effort not to be limited by their skin.

The impact of living with a chronic skin condition upon the way individuals interact in the social world is substantial. As will be discussed in the following section, the difficulties faced in entering into social interactions can be related to issues surrounding identity and the self, and the presentational demands of contemporary society.

Impact of a Chronic Skin Condition on Identity and the Self

Presentational difficulties

In addition to Goffman’s work on stigmatisation being drawn upon heavily by researchers in this area, his work on the presentation of self has also been widely applied. Goffman (1959) draws attention to the seemingly paradoxical idea that it is not the innate psychobiological self-as-performer that we associate with the “true” self of any individual in our society, rather it the socially produced and performed self—the self-as-character—that represents any individual’s unique self. Indeed, it is only on the agreement of others that an individual may evaluate their own management of identity impressions. Facing such constraints in the structural features of interaction – such as the mutual acceptance that individuals must maintain any 'line' they initially present (Goffman, 1959, p. 9) – it is unsurprising that people may take steps to avoid breaching interactional bounds.

It is Kelly and Field's (1996, p. 246) view that 'to be acknowledged as competent social performers we have to be able to give the impression of some degree of control, use and presentation of our bodies'—that is, the management of bodies is also the management of meanings designed to constrain expectations about behaviour (Gagnon & Simon, 1973). A critical way by which the body in chronic illness affects the self and identity is how an individual may be let down socially—how their role performance is undermined. Indeed, the chronically ill body may to some extent inhibit the capacity to play certain social roles entirely.

Many of the participants in Nørreslet et al.'s (2010, p. 101) study of people with atopic dermatitis, for example, stated that they 'had to rely on AD medicines in order to cope with their condition and fulfil their cultural and social roles'. In addition, the identities of people with chronic skin conditions may require a particular form of management sensitive to the form the condition takes. Conditions that affect the appearance of the face or hands, or that have symptoms that are visible publicly, such as the shedding of psoriatic scales or heavy dandruff or cause cracks in the skin that may bleed into clothes, may require sufferers to manage their identities carefully. Identities may be managed differently depending on the severity of symptom. That is, individuals must take into account the potential cost of these signs of illness to their public identities – a cost which is experienced or perceived as stigma. Ultimately, the ingrained stigma attached to skin conditions and the physical signs they display result in diminished social attractiveness, damage to the self that is displayed to the world and evaluations of blame being attached to the individual (Jobling, 1988).

Because of the visibility of their conditions to the world, in Goffman's (1963) terms people with skin conditions are, as discussed previously, readily ‘discredited’ by their disease. As such, personal presentation is clearly affected in the daily lives of people with skin disorders. It is very common, for example, for people with chronic skin conditions to feel that their choice of clothing is restricted due to their reluctance to reveal areas of affected skin, with the imposition of such limitations felt more severely by women than by men. Moreover, self-constraints on clothing and use of cosmetic products may also be based on how someone's skin reacts to the materials and substances used in these items. Some people find that their skin is irritated by synthetic fibres and so may choose to wear only cotton next to the skin (Jowett & Ryan, 1985). Furthermore, findings in a study on psychosocial impairment in women with acne by Mulder and colleagues (2001), in which participants were given a course of treatment with oral medication found that while acne severity was reduced, this dermatological improvement was not related to an improvement in appearance-acceptance or self-esteem.

Attending to the broad social impact of burns injuries, Noltensmeyer and Meisenbach (2016) note that changes in the physical appearance of the body, such as a burn scar, can lead to challenges with the discursive management of stigma in interpersonal encounters. Moreover, the work of Scambler and Hopkins (1986) argues that while instances of enacted stigma are often rare, the experience of felt stigma can be highly disabling, demanding constant attention to presentation and avoidance of disclosure.

The ability to fulfil social roles is in an important aspect of a person’s functional status (Pallua et al., 2003). E. Williams and Griffiths (1991) showed that burns survivors who were functionally impaired by their physical trauma often avoided personal contact with others, experiencing debilitating social isolation and feelings of marginalisation. Burn victims have been found to feel that they have lost a sense of control over their environment (Pallua et al., 2003).

Impact of Disordered Skin on Emotional Wellbeing

As discussed earlier, with misunderstanding rooted in historical perception, the discreditation of the individual with a skin condition is couched in moral terms. The experience of stigmatisation can lead to feelings of shame and embarrassment that have a lasting impact on perceptions of the self. Shame and embarrassment are feelings that are common in people with chronic skin conditions, but as Jowett and Ryan's (1985) study suggests, not necessarily universal. Age of onset of the appearance of a person's eczema or psoriasis was found to be an important consideration in the extent to which these feelings were reported. Those whose experiences of eczema or psoriasis began from birth or late in life did not report these feelings. While related to concerns about appearance, the emotional wellbeing of people with eczema is also compounded by the practical frustrations of their condition, particularly when their skin disorder affected their independence. As one woman with eczema reported, “I used to cry when my hands were bandaged. I couldn’t accept being dependent on people. I liked to be independent.” (Jowett & Ryan, 1985, p. 428). The authors found that these feelings of frustration in eczema sufferers often caused changes in demeanour, and in particular, a general 'irritability'.

Conditions that cause physical disfigurement often have substantial and wide-ranging effects on mental wellbeing, causing anxiety, depression, and damaging self-esteem (Kent, 1999). Burns survivors may face devastating physical, emotional and social consequences (Noltensmeyer & Meisenbach, 2016). It is known that people living with burns injuries face issues regarding their body image that often lead to states of depression (Corry et al., 2009). Emphasising the profound impact that bodily disfigurement can have on psychological wellbeing, Pallua et al. (2003, p. 143) found that ‘patients in the aftermath of burn trauma with aesthetically disfiguring and functionally limiting scars are predestined for mental dysfunction'.

Studies examining the psychological impact of psoriasis have found prevalence of anxiety and depression to be significantly higher than found in the general population, particularly among younger adults. Depression was reported by more than half of adult respondents under the age of thirty-five in one study (Krueger et al., 2001), while suicidal ideation prevalence was reported to be around seven percent in those being treated as hospital inpatients for their psoriasis (Gupta & Gupta, 1998).

The psychological impact of acne has also received attention in the literature. Findings have indicated higher levels of anger and anxiety in those with more severe acne (Wu et al., 1988). Associations have also been found between adult acne and psychiatric morbidity (Picardi et al., 2000), and notably high levels of depression and clinical anxiety among this population. Emotional functioning has been found to be damaged by experiences of adult acne over long periods (S. C. Kellett & Gawkrodger, 1999). Research participants with adult acne have been shown to evaluate their body-image more negatively and to have lower self-esteem than a control group (Murray & Rhodes, 2005).

The bodily location of a socially discreditable attribute is also important in understanding both stigmatisation and the impact it has upon the self. Acne, psoriasis, eczema and other chronic skin conditions can be highly visible and, particularly when they affect the head and neck, difficult to conceal from others. In a review of the problems experienced by people with facial disfigurement, Clarke (1999) finds social interaction to be one of the most common areas of difficulty. The face, in particular, is imbued with social meaning, and contributes greatly to social identity. As such, social experiences may be especially problematic for people whose conditions that present on the skin of the face, and any form of facial imperfection or disfigurement can be experienced as disabling (Murray &

Rhodes, 2005). Moreover, in addition to the evaluations made by others, those made by the individual of themselves are particularly sensitive to conditions affecting the face. Picardi et al.'s (2000) study, for example, found those with facial acne to ascribe lower self-evaluations than those whose acne is on their trunk.

Pallua and colleagues (2003) found an increase in depression among people who had burns to areas of the body that are normally exposed compared to those with burns in areas that are typically less visible. These findings echo those of others, including E. E. Williams and Griffiths (1991), who demonstrated the significance of disfigurement to hands and faces in the impact they have for damaging emotional wellbeing. Findings from a variety of studies have suggested that the relationship between the clinical severity of a disfiguring condition, such as a burns injury, and its effects on the distress of the individual is not strong (Malt & Ugland, 1989; Patterson et al., 1993). However, Noltensmeyer and Meisenbach (2016) point out that for burns survivors, the total body surface area that has been burned and the bodily location of the burn can affect experiences of stigma. While a burn that is easily hidden by clothing may allow an individual to live a social life that is relatively free from stigmatising communication, someone with burns to their face or genital area may experience more stigmatising situations in their social life.

Long-Term Illness Management and its Impact on Identity

The impact of living with a chronic skin condition on identity has been discussed in a number of studies. Long-term self-management is imperative for the management of many chronic skin conditions, whether through the application of creams and greasy emollients or oral medications. However, for many people, the often unpredictable nature of the illness course over time gives rise to feelings of fighting an intangible enemy, resulting in experiences of biographical disruption (Bury, 1982). Indeed, writing about experiences of psoriasis, Jobling (1988) emphasises the point that the condition ‘is not only a "biological" disorder, it is (in common with other skin disorders) a social and cultural phenomenon of considerable complexity' (Jobling, 1988, p. 242). For participants in Mollerup et al.'s (2013) study into hand eczema, some of this complexity is based on the difficulty of avoiding exposure to specific allergens and irritants, including nickel or particular chemicals that cause the skin to flare up. The necessity of taking measures such as the use of protective gloves to avoid contact with potential irritants or wearing additional cotton gloves underneath their gloves, in addition to the perpetual need for using emollients, without the certainty of a successful outcome, all added to the perceived complexity of their condition.

Murray and Rhodes' (2005) study demonstrates how unpredictable fluctuations in the severity of their condition led to uncertainty and disruption of the lives of people with acne. This was found to result in the development of a fluid identity highly dependent upon the current state of the skin. This unpredictability affects the potential to make plans, and requires people with acne to adapt constantly to changes.

'Bodies change in chronic illness', Kelly and Field (1996, p. 247) write. These changes come in the form of self-conceptions that are reciprocal to bodily feelings, experiences and actions. They also emerge in how others perceive and define the sufferer as chronic illness progresses – that is, how an illness identity is constructed. Albeit it must be acknowledged that these processes of change in self-conception and public identity, as has been shown, fluctuate and vary. Changes are neither coterminous, nor simultaneous, nor deterministic (Kelly, 1986).

The unpredictable progress, fluctuations in the intrusiveness of symptoms and uncertainty of prognosis for many chronic skin conditions means that they may move between these extremes of public visibility at different times and in relation with a wide range of circumstances. As such, consequences for self and identity can vary greatly. Someone with psoriasis (Jobling, 1988) or other chronic skin disease with erratic presentations must perform continual routines of care at the level of the self. As such, their illness becomes highly salient on this level.

Living with the uncertainties presented by a chronic condition of the skin, the impact upon the foundations of understanding can be stark. Referring to the unreliability of the body in chronic illness, Kleinman (1988) writes that the sick body:

> is out of control…. The fidelity of our bodies is so basic that we never think of it – it is the certain grounds of our daily experience. Chronic illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair. (pp. 44-45)

People with chronic illnesses commonly adopt coping strategies in order to maintain the 'maximum relative normality in the face of incapacitation or stigmatization' (Gerhardt, 1989, p. 139). While we all consider the potential consequences of our decisions about how to approach tasks, this process, which Pinder (1998) refers to as "balancing", is more precarious when faced by a chronic illness such as psoriasis or eczema which for many is characterised by unpredictability. People with chronic conditions often have to weigh up the pros and cons of using medications which may alleviate symptoms, but which carry the risk of unpleasant side-effects. The balancing process associated with the potential consequences of undergoing particular forms of treatment is made increasingly complex when facing uncertainty about the onset of symptoms of the illness itself, which may appear and disappear inexplicably. These concerns about the trajectory and physical realities of bodily illness serve to compound the difficulties faced in managing the social consequences and the impact upon identity and the self of living with a visible chronic skin condition.

Powerlessness in Treatment and Fears of Deterioration

A predominant theme emerging from Nørreslet et al.'s (2010) accounts of atopic eczema experiences centres on how concerns about the risks associated with the long-term use of potent medications acted as a strong incentive to seek alternative forms of treatment. Indeed, informants were found to be 'extremely concerned about AD medicines especially topical corticosteroids', to the extent that they 'would have preferred to avoid using these medicines entirely' (Nørreslet et al., 2010, p. 101). Despite making efforts to find different ways of treating their eczema, however, they 'were eventually forced to return to and rely on conventional medicines because of their efficacy in alleviating and treating symptoms' (Nørreslet et al., 2010, p. 91). Such findings exemplify how the choices of available treatments for certain chronic skin conditions are limited, which may limit the opportunities for adopting a position of contemporary reflexivity in managing the illness. It is clear that for many people with eczema, there exists an apparent, but always illusionary, choice or hope for alternative treatments. Treatment regimens ultimately lead back to a reliance on the same conventional treatments – dependable in the moment but characterised as filled with uncertainty over the long term – and a continued sense of powerlessness over their skin.

For Murray & Rhodes' (2005) participants, even when their acne symptoms improved, they were fearful of the threat of an imminent deterioration in its condition. Facing the persistent need to adapt to a changing body-image was experienced as a cause of great disruption to life. The chronic experience of these conditions which are often erratic in their symptoms, often leads to feelings of a loss of control over the state of the skin. With fluctuations in their condition that they feel unable to account for, people with acne have been found to experience a lack of control over their illness trajectory as a form of powerlessness (Murray & Rhodes, 2005). Moreover, it was shown that the daily regimen around personal hygiene and food require a substantial commitment of time and effort that may not ultimately yield relief from the condition.

Preoccupied with thinking about the state of their skin, treating their skin and washing their skin, the identities of Murray & Rhodes' (2005) participants were often based largely on being an acne sufferer. Comparably, the drive for clearance of symptoms 'dominates the lives of many (perhaps most)' people with psoriasis, despite the unlikelihood for many of achieving this. Indeed, Jobling (1988), p. 241) refers to the prospect of symptom clearance as 'one of the fictions of dermatological practice'.

PUVA treatment, involving the oral administration of a drug psoralen and exposure to ultra-violet radiation, was relatively new when Jobling (1988) writes about the impact of its wide-scale and rapid introduction on the lives of the psoriasis patients to whom the new treatment was administered. PUVA, the "cleansing fire" (Updike, 1976), signalled the possibility of freeing people with psoriasis from the daily routine of ointment-based regimens and was understandably greeted with widespread enthusiasm. Some people experienced dramatic and sustained improvements in the condition of their skin and were freed from the demands of daily topical ointment regimens.

For others, however, results with this treatment were less successful and PUVA also had a number of potential side-effects, both immediate and long-term. Moreover, people for whom PUVA treatment was not successful commonly experienced uncertainty, anxiety and depression at the failure of what they had hoped represented a bright prospect of relief from their condition. To "fail" on PUVA was perceived by patients as both a therapeutic and personal regression (Jobling, 1988, pp. 236–237). The denial of access to PUVA when it did not show signs of success in visibly clearing psoriasis symptoms, or even when it made a person ill or exacerbated their condition, was still seen as a blow by patients who had to return to conventional ointment treatments.

In addition to experiences of deterioration, improvements in the condition of the skin brought about through treatment has also been found to impact upon the self. People for whom PUVA treatment is effective for their psoriasis, also experienced changes in their self-identity (Jobling, 1988). John Updike (1976) experienced a sense of alienation caused by the changing relationship with his skin, with any improvement always being tempered by a fear the symptoms would return. The clearance of symptoms of a chronic skin disorder like psoriasis, for however long its improvement lasts, undoubtedly changes the relations an individuals have with themselves, others and their wider environment.

These findings may be viewed in the light of Charmaz's (1983) work which demonstrated the attempts people with chronic illnesses make to maintain positive and valued definitions of the self. It could be argued, however, that in the case of experiences with chronic skin conditions, findings suggest at a persistent drive to remove associations between identity and the condition rather than a positive attempt to maintain the self.

Fluid Identities and Comparisons of the Self

Experiences of chronic acne have a clear impact upon individuals' sense of identity. Identities have been found to take on a fluid quality relating to fluctuations in the severity of the condition. The 'fluid identity' associated with acne, Murray and Rhodes (2005, p. 191) find, describes the process in which someone's 'outlook and behaviour became a product of how visible and unappealing they experienced their acne to be, and where both their identity and skin condition were in a constant state of flux'. There is clearly a complex set of relations between the person and their acne, with the acne acting as both a separate entity and as a part of the person. That is, the acne both imposes itself upon the individual who actively tries to combat it; and the acne is woven into the person's sense of identity, 'continually revising and moulding' (Murray & Rhodes, 2005, p. 191) their expression of self. Participants' descriptions of current experiences were often juxtaposed with previous experiences, and comparisons were made between themselves and other people without acne.

Comparisons were made in terms of equality and self-worth. One male participant in Murray & Rhodes' study suggests that his acne marks him out as being abnormal, "damaged" and of lesser value than others who are "unblemished": "I don't feel equal to them because they are normal and I am not. Would you rather buy an unblemished apple or an apple that has lots of dents and bruises? Nobody likes damaged goods" (Murray & Rhodes, 2005, p. 191).

A second point of comparison lay between participants' perceptions of themselves in the present and with themselves before they had acne or when their acne was less severe. Respondents often used such comparisons in evaluating their current self-worth, and talked of their life before acne with a sense of nostalgia, highlighting what had been lost, personally and socially (Murray & Rhodes, 2005). Conversely, Murray and Rhodes' (2005, p. 192) participants whose skin conditions had improved were found to recall their previous self-image in a negative light, conveying 'a devalued and objectified former self, consumed by their acne... from which they were constantly striving to distance themselves'. Those that Murray and Rhodes (2005) spoke with did not feel that appearances held greater importance than a person's character or intellectual ability, yet they felt unable to escape the primacy of appearance in their self-image. As one of Murray and Rhodes' (2005, p. 192)participants explained, while her "intellectual confidence is very secure" her "shaky confidence in my appearance weakens me as a whole".

Having addressed the ways in which the concepts of identity and the self are developed in the literature, the final section will explore the impact of managing the everyday bodily realities of life with a chronic skin condition and negotiating individual and professional understandings.

Managing the Burden of Illness Work

As the literature around experiences of chronic skin conditions demonstrates, a dominant finding in many accounts of life with a chronic illness is the disruption of normal everyday routines, and the ways in which experiences are reconstructed and given meaning both by sufferers and their social contacts (Anderson & Bury, 1988; Radley, 1995). Within these accounts however, a principal concern has been the coping behaviours people employ towards their illness (Moos & Tsu, 1977). '(C)entral to the coping task', Kelly and Field (1996, p. 247) argue 'is dealing with the physical manifestations of illness, and that coping with the physical body has to precede coping with relationships, with disruptions and indeed with any social reconstruction of events'. They suggest that the management of the physical problems generated by the chronic illness is '(a)t the very epicentre of the coping experience and from which other social coping processes flow' (Kelly & Field, 1996, p. 247).

The burden of work required in persevering with the "ritualised" tasks involved in managing the treatment of a severe chronic dermatological condition can be overwhelming (Jobling, 1988, p. 234). Psoriasis treatment involves a number of physically demanding ritualistic practices for topical treatments and UV light therapies that take up hours each day. For some people such treatments bring little physical relief, and so lead to their questioning of the value and meaning of undertaking these arduous practices. Perceptions develop among those with psoriasis of the management of their condition as a Sisyphean task that is exhausting and unsatisfying on a number of levels. That is, the illness work associated with psoriasis and other chronic conditions can be 'physically, psychologically, and socially burdensome' (Jobling & Naldi, 2006, p. 1438)

It is clear that experiences of treatment regimens for the skin can be a major source for feelings of powerlessness or a loss of control. It is not uncommon for people with skin conditions to feel that treatment regimens directed by dermatologists do not give enough consideration to how they will be applied on a day-to-day basis. That is to say, medical treatment regimens may not fit well with the practicalities of daily life, or problems that arise in the course of treatment may have psychosocial impact upon the individual being treated.

Personal and Professional Understandings About Chronic Skin Conditions

In their focus group study, Mollerup et al. (2013) found that sufferers experienced a paradox between the lived complexity of managing this condition and the apparent simplicity of preventative solutions offered by dermatologists, and were ultimately left feeling ambivalent. While the advice given to them to avoid exposure to irritants and to undergo ongoing measures to manage their skin participants was understood as being straightforward, the disparity between the simplicity of this advice and the unpredictability of their condition led participants to use metaphors such as "it's like a jungle" to describe the information grey zone they were experiencing (Mollerup et al., 2013, p. 1059). What appeared to be simple advice was felt to be uncomfortable or impractical for application in the real world. Emollient regimens, for example, were found to be unfeasible for some because they caused hands to be slippery and greasy. For others the use of creams prescribed by doctors caused discomfort and seemed to provoke their eczema. As one woman explains, "Sometimes when it's bad and I put on my cream, it becomes ... even if there's no water in the cream, it still feels dank and provocative in a way, so it only gets worse. So mostly, actually, I only put on the cream when my hands are not so bad. Because when they're itchy and have blisters and all that, I just think it gets worse then I put on the cream' (Mollerup et al., 2013, p. 1062). These practical problems and issues of bodily discomfort were found to hamper the intentions of individuals to engage in the continuous preventative behaviours advised by health professionals (Mollerup et al., 2013).

Even when taking preventative measures to avoid known allergens or irritants, the condition of the skin does not necessarily improve. The difficulty in identifying irritants in the first instance, and finding that the skin does not necessarily improve even with attempts at avoidance can result in a ‘knowledge gap’ (Mollerup et al., 2013, p. 1062) and feelings of frustration at the lack of predictability. This is complicated further as in spite of the specific allergenic cause of a person's contact dermatitis, including hand eczema, once the skin is damaged other irritants can cause deterioration. As such, the mechanisms of cause and effect can become unclear and people with the condition then face further psychological and social strain in 'combating an intangible enemy' (Mollerup et al., 2013, p. 1062). Mollerup et al. (2013) draw on Bury's (1982) work on chronic illness and his concept of "biographical disruption" to explain this strain. That is, those first developing symptoms of hand eczema, the individual is faced with a struggle to repair the biographical disruption they have experienced and adapt to a new understanding of their skin and the required treatment regimen. The intangibility of identifiable cause-and-effect characteristics to eczema exacerbation, in addition to the psychosocial hurdles sufferers face mean that the individual may experience great difficulty in establishing a place for their new life condition that is acceptable and legitimate (Mollerup et al., 2013).

Research by Ersser et al. (2002) demonstrated differences between the criteria applied by psoriasis patients and dermatologists to what it means for treatment to be successful. Dermatologists were found to focus primarily on the physical appearance of the skin. In addition to appearance, people who have psoriasis place emphasis on numerous other criteria. For example, people referred to their bodily experience, including skin sensations such as whether their skin feels sore or itchy. Reference was made to levels of comfort in terms of the suppleness and the "feel" of the skin to touch. Issues of timing, such as the speed with which a treatment produces changes and the duration of any positive effects, were also important. Moreover, for patients, the effectiveness of treatment for their psoriasis also rested upon changes in the 'desirability' of their skin, referring to its smell, consistency and colour, how a treatment disrupted daily activities, their awareness of risks associated with the treatment, whether they faced difficulties in adapting to a treatment regimen, and the issue of combining a new treatment with other treatments.

It is important to acknowledge, however, that through the experience of engaging in the work demanded by medical regimen, people build knowledge about their chronic condition and develop sophisticated skills for its management. Gaining such knowledge and skills may enable people with chronic illnesses to question the roles traditionally assigned to health care professionals in the treatment of their condition (Nettleton, 2013). As they gain experience in the work of managing illness and so become to an increasing extent independent of health professionals, people are able to make decisions and practice treatment regimens that apply “social logic” in addition to “medical logic” (Herzlich & Pierret, 1987). While the application of a medical logic requires strict adherence to a therapeutic regimen based solely on a patient’s physiological condition, pursuing a social logic would imply a treatment for their skin condition that would accommodate all the other demands of daily life.

Embodied Experiences of Chronic Skin Conditions

The concept of embodiment is rooted in the phenomenonological sociology of theorists such as Maurice Merleau-Ponty (1962), whose work developed the idea that all human perception is embodied. That is, we unable to sense or perceive anything, whether consciously or not, independently of our bodies. Human beings, then, are “embodied” social agents (Nettleton & Watson, 1998).

Few contemporary studies have explored the unique sensory experiences of people with chronic skin conditions and the meanings attached to these embodied phenomena in detail. Yet it is these sensations and bodily experiences – of itching, pain, inflammation, scaling and flaking skin – and their management, that are the most tangible aspects of the experience with a chronic skin disease and which can become central to the identities of sufferers. The phenomenologist Edmund Husserl described the body as the “zero point of orientation” (Scanlon, 1974), referring to the way in which all perception begins from the body of the individual oriented in space.

Of the limited body of literature documenting the impact of bodily or sensory experiences of skin conditions, (Jowett & Ryan, 1985) study is perhaps distinctive in capturing a sense of the imagery conceived in attempting to explain their bodily experiences. While around a third of those among Jowett and Ryan’s participants with eczema experienced pain in relation to their condition, the physical sensation of itching was ubiquitous. Describing the experience of itching, one woman explained, "it's like when you have an itch and scratch it but doesn’t relieve it. It’s raw with eczema, you can’t feel the soreness just the itching, the blood runs and you still scratch.” (Jowett & Ryan, 1985, p. 426). Indeed, the constant irritation of the skin was likened to "sitting in a bed of ants or spiders". A female participant in Jowett and Ryan's (1985, p. 426) study suggested that "people don’t realise how uncomfortable it is. If it looks bad they sympathise, people don’t realise unless it looks bad. It can look okay but be really painful.”

The fact that the sensation of physical discomfort - itching and pain - is not necessarily reflected in the appearance of the skin, means that people experience misunderstanding from others about the impact of the condition on their lives. Moreover, the relationship between sensations of pain and itching, and the reaction of the individual to the physical result of scratching to relieve an itch – such as the appearance of blood - reflect something unique in the way someone with a chronic skin condition experiences their skin. As I will expand upon in the discussion, there is clear scope for advancing the limited body of research into experiences of living with chronic conditions of the skin, but particularly in developing an understanding of life with these conditions that returns to the body as its central focus.

Conclusion

The purpose of this chapter has been to review a range of relevant existing literature that comprise the current state of sociological knowledge about experiences of living with a chronic skin condition. It is clear that the impact of living with a skin disorder can be wide-ranging and substantial, affecting many aspects of life, from interpersonal relationships to occupation opportunities. While conditions such as psoriasis, eczema and acne have differences in their biological aetiologies, their symptoms and how they are treated and managed, from a sociological perspective they share many similarities.

The visible nature of these diseases of the skin is an important aspect in the ways in which they impact upon social relations for affected individuals. It is based on this visibility that stigmatisation and its consequences – feelings of shame, damage to identity and the self – emerge as central to experiences with a skin condition. The stigmatisation of individuals with chronic skin conditions, based on historical and cultural mythology, impacts upon many areas of life. This stigmatisation transposes a negative physical evaluation of the health of the skin into a negative moral evaluation of the characteristics and qualities of an individual. Across a range of visible skin conditions, a broad range of social interaction settings can be damaged, and particularly so when the skin of the face, imbued with social meaning, is affected.

A second key component found across this area of literature concerns the impact of negotiating the practical realities of managing and treating skin conditions. The work involved in managing the use of medications to treat conditions that are erratic both in their presentation and in their response to treatment was often found to be arduous. Again, the impact upon identity is important here, as sufferers undergo perpetual work to manage the course of their illness. The unpredictability of conditions such as eczema, acne and psoriasis leads many to feel a sense of Sisyphean powerlessness as the actions they take in trying to take control of their skin may not be met with results they consider to be successful. Moreover, the apparent simplicity of guidance from dermatologists, and metrics of success in treatment, are often felt to be at odds with the complexity of lived experiences and the desire for skin that meets outcomes beyond simple visual improvement to take into account a more holistic understanding of how skin feels.

Despite the prevalence of chronic skin conditions, the overall body of qualitative research into experiences of living with these conditions is small. It appears that chronic skin conditions share with other common conditions – such as back pain, stroke and bronchitis – the phenomenon, noted by Kelly & Field (1996, p. 243) that illnesses which ‘in terms of incidence, prevalence and caseload are those which preoccupy most general medical practitioners are less well represented in the sociological canon’ than more exotic illnesses.

There is a need for research which better addresses embodied understandings of life with a chronic skin condition, where bodily experiences are a central focus. In this regard, the work of theorists of the body such as Turner (1992, 2008) and Shilling (2004, 2011, 2012), and theorists of emotion, notably Freund (1982, 1988, 1990, 2006), may be of great value. Turner (1992, 2008) work combines views of the body as both biological organism and as a part of “lived experience” contributing to social relations. However, he also aims to analyse the body discursively as a system of representation. While Turner argues that there are organic foundations to the body and human activity, he sees ‘no reason to doubt the proposition that the body is socially constructed’ (B. Turner, 1992, p. 16). Similarly, Shilling (2012) views the body as a material object that is located in nature, but which is subject to social change and is both constructed by and constitutive of social relationships. Understandings about the body can be viewed as products of economic, political and cultural factors that have developed historically.

Peter Freund (1982, 1988, 1990, 2006) has written extensively on "the emotional body". Freund suggests that bodily well-being is found to be related intimately to our social existence through what he terms "emotional modes of being", that is, the mind/body experience of being either assisted in, or facing obstruction towards, achieving our aims. arguing that emotion is fundamental to human life. Emotions develop through social interaction with other people. A 'mode' of feeling unpleasant can arise from experiences of encountering resistance in relations with others, of being subdued and of being injured (P. E. S. Freund, 1990, p. 461), or indeed, facing illness. Common to all of these experiences is that they are ways of being "disempowered" that occur through interaction with an external, social world. This disempowerment can impinge upon the "interior" of our bodies through its effects on our neuro-hormonal system, damaging our ability to reach a state of bodily well-being. That is, the ability to achieve bodily well-being is shaped by the ways in which our emotional modes connect the embodied self to social relationships.

Finally, the work of Norbert Elias (1939/2012) establishes a long-term historical tendency towards internalising bodily controls and for the movement of bodily functions to the "back regions" of social existence. This has occurred as part of a general "civilising process". A focus on the locations and settings used for the application of skin ointments and creams or the administration of oral medications, and other interactions with the skin, would enable an understanding of what actions may be moved to such "back regions". In this vein, more could be understood about the practices of scratching the skin or picking at spots or scales, and the settings where these practices – which could be considered functions of the body in people with skin disorders – take place. Taking an embodied approach to exploring experiences of life with a chronic skin condition that centralises a focus on the interaction between an organic body and the external social world would help to better contextualise such actions and experiences.

Methodology

Chronic skin conditions such as atopic dermatitis and psoriasis (Gelfand et al., 2005) together affect greater than 1 in 20 people in the UK, while acne is almost universal in young people and remains very common in adulthood (Bhate & Williams, 2013). These conditions have significant effects on self-image and quality of life, lead to anxiety, depression and a reduction in social functioning (D. R. Thomas, 2005). Yet despite the difficulties chronic skin conditions cause, they are often perceived as non-serious (Hong et al., 2008). A report by The All Party Parliamentary Group on Skin (2013) recommended that greater recognition is needed from health professionals, employers, government institutions and the pharmaceutical industry about the psychosocial impact of skin conditions and their management on people's lives. The aim of this research project is to build an understanding of life for people with a range of chronic skin conditions, which, considering their prevalence, are under-represented in sociological literature. Working with a sample of adult participants who have a chronic skin condition, a qualitative approach was taking using semi-structured interviews to build an understanding of experiences of living with a chronic skin condition.

In this chapter I will outline the methodological approach taken towards this research. I will first broadly outline a number of principles for the qualitative approach being used. The criteria for sampling and process of recruitment for the study will then be discussed. I will then discuss methods for conducting interviews with participants. Next, procedures used for working ethically and attaining ethical approval will be outlined, followed by a discussion of how research quality was maintained. Finally there will be an indication of the analytical process and findings developed in this thesis.

A Qualitative Research Paradigm

This study was conducted based on the principles of qualitative research. This study was exploratory in that the research was conducted in order to generate theory on a topic on which there is currently very little empirical knowledge, rather than testing existing hypotheses. The research aims to build understandings of life experiences for people who have a chronic skin condition. The meanings participants give to their experiences form valuable data about their unique situations (Mason, 2002). My role as a researcher and the actions I take were reflexively taken into account and the process of undertaking this research was recorded with notes throughout. Within a qualitative paradigm, the subjective voice of participants within the research is valued (Silverman, 2013). The analysis of data produced in the course of this research was in-depth and iterative in its approach, with all theory being generated inductively and remaining faithful to the data collected within the study.

An Embodied Approach to Research

Chronic conditions of the skin, categorised by particular disturbances in the physical structures and functioning of this organ, give rise to a range of particular sensory, emotional and social experiences, which may affect how someone is perceived and treated by others in the social world. Reciprocally, the medical signs and symptoms of many chronic skin conditions have been shown to be affected by factors including a person’s physical environment, their daily practices, as well as psychosocial issues such as stress.

To understand experiences of living with a chronic skin condition, an approach was used that acknowledged the importance of the skin-covered body as being inextricably linked to self-conception and social identity. Contemporary society places a great deal of value on visual appearance in relation to norms about health, capability and physical attractiveness. The individual with a skin condition is faced with the continual and mutual management of both their social conception and their bodily reality of pain, discomfort, itching and oozing. Bearing the interdependence between the physical and the social in mind, and taking into account the ways in which meaning is constructed by the individual through this contextualised interaction, the methodological approach taken to this research focused on facilitating an embodied exploration of life with a chronic skin condition, open to the construction of meanings and understandings by participants.

Research Design

Sampling and Recruitment

The sampling frame for this research consisted of people aged 18 and over who have a chronic skin condition. Recruitment for this study was mainly carried out through regional groups based in London and the South East of England of a range of national patient support organisations representing people with different chronic skin conditions, as well as online. I met with a regional group linked to the National Eczema Association, informed them verbally about this study, provided information sheets with further information about the research and interest from a number of members, who went on to become respondents in the study. It was also valuable to seek other forms of recruitment. As such online advertising was used in order to try to recruit participants as I was unable to recruit the desired sample size through support groups alone. Information about the project was reviewed by the Communications team of the Psoriasis Association, who agreed to advertise the project through their social media. Recruitment continued until a total of twenty-four participants was reached.

Semi-Structured Interviews

Semi-structured, in-depth qualitative interviews were conducted with participants who live with a chronic skin condition. This form of interview offers the flexibility (Fielding & Thomas, 2008; Mason, 2002) to adapt to any unplanned shift of topic. Taking a more structured qualitative method may restrict the extent to which unexpected avenues might emerge. There has been little research into understanding chronic skin conditions from a sociological perspective. Adopting a semi-structured, in-depth interview approach offers the opportunity for a detailed exploration of an under-researched area (Bryman, 2008).

Differences in the nature and severity of skin condition faced by the participants in my study, in forms of treatment and impact on living will affect their experiences and the meanings they ascribe to their experiences. The adaptability offered by a semi-structured interview approach enables the researcher to be reflexive to the complexities of experience in individual narratives while also being guided by the overall aims of the research.

Semi-structured interviews allow an interviewer to probe a participant to expand on their views and opinions in response to questions. This is critical for research aiming to explore subjective meanings participants ascribe to concepts and events in their lives. Probing may also allow an interview to be diverted along new pathways (Gray, 2009), which, while unforeseen, aid in meeting research objectives.

Interviews took place either at the homes of respondents or another place suitable for a private conversation. Interviews were aided by a topic guide [see Appendix 2], based on findings from the literature review (Arksey & Knight, 1999), that acted as a prompt for the researcher to develop interview discussions with participants according to the overarching lines of inquiry for the research and to address any important topic areas that the interviewee may not have touched upon. It is important to note that the topic guide did restrict the researcher from responding to shifts of direction in an interview discussion that were unforeseen but which might add to the richness of understanding.

Interviews with respondents took place between September 2016 and February 2018. In total, 24 respondents were interviewed [see Appendix 4]. Of the respondents, there were 17 women and 7 men. The mean age was 40 years and respondents ranged in age from 18-65. 12 of the respondents identified as having eczema (8 women and 4 men). 8 respondents identified that they had psoriasis (7 women and 1 man). 2 respondents identified as solely having acne (both of whom were women). Identifying as having experienced combinations of different skin conditions, 1 man participating in the study had lived with eczema and acne, and 1 man had experienced both acne and psoriasis.

Interviews with 15 of the respondents took place by video call using computer software (either Skype or FaceTime), 5 interviews were conducted in person, 3 were voice-only interviews by phone or using the voice call function on WhatsApp, and 1 took place first by phone and then in person at a later date. Of the total respondents, 20 were living in the UK, 2 in the US, 1 in Italy and 1 in Canada. The in-person interviews were conducted either in respondents' homes or in quiet areas within public houses or cafes. The majority of interviews had a duration of between 60 and 90 minutes.

Data Analysis

It is central to analysis that the researcher has an intimate knowledge of the data. To achieve this, the researcher made repeated listenings of interview data and personally conducted a verbatim written transcription, aided by audio playback manipulation software called ExpressScribe. Undertaking an inductive analysis, codes were developed and refined following immersion in the data (Patton, 2002). While being informed by theory, engaging in this iterative process was chosen to enable the analysis and subsequent findings to be guided by the data. To demonstrate the rigour of my analytical method, it was crucial to keep records of the steps taken (Seale, 1999) in the development of a coding framework.

Computer-assisted qualitative data analysis software (CAQDAS) offers the advantage of speed for the analysis of large quantities of data. As Seale (2013) advises, CAQDAS also assists in improving the rigour of qualitative research by offering powerful tools for searching across the data and for counts of codes assigned by the researcher. The qualitative data analysis software NVivo was used to aid in organising and analysing the interview data.

Ethical approach

The research design for this project has been guided by principles outlined in the British Sociological Association Code of Ethics (2002) and the Social Research Association ethical guidelines (2003). Guided by these ethical codes, I did my utmost to ensure that I observed guidelines relating to my professional integrity, and my relations with and responsibilities to my research participants, as well as taking appropriate measures to observe the anonymity, privacy and confidentiality of my participants.

To ensure participants' security, all data was anonymised and held in a password-protected computer in the form of electronic recordings and transcripts, accessible only by me as the researcher. Consent forms containing personal details such as participants' names were held separately from any data produced with them in the form of interviews in the course of the study. Data will be held for a maximum period of five years following completion of this research before being destroyed.

This project required ethical approval from the Royal Holloway, School of Law, Research Ethics Committee. After ethical approval for the research has been granted, I was in a position to be able to recruit participants. I provided an information sheet for respondents that gave details about the purpose of the research and what their participation would involve [see Appendix 1]. An assessment of potential risks and benefits arising from the research was undertaken and included in this information sheet about the study provided for respondents. Participants were informed of the principles of confidentiality under which the research was being conducted, as well as their rights to anonymity, and the security of their data.

After respondents had been informed and had the opportunity to ask any further questions they have about the purposes of the research, what participation would involve and how their data would be used, they were then asked to complete a form consenting to their participation in the research and return this to the researcher [see Appendix 3].

It was important to consider the possibility that discussion of personal experiences of life with a chronic skin disease in interviews may have led to psychological distress for participants in this study. Participants were made aware on the information sheet and informed verbally before the start of interviews that they had the right to end an interview at any point. The researcher provided participants with contact details for psychological support services if required. There was also a small possibility that the researcher may suffer some psychological distress as a result of interviews. The researcher had access to the Wellbeing Service at Royal Holloway in the event of any psychological distress that resulted from the research and also reported back regularly to the project supervisors about any difficulties that emerged during the research. For the safety of the researcher, a friend was informed of the time and location for which any in-person interview was scheduled. The friend was informed that the researcher would make contact by text message upon completion of the interview, that they should call the researcher if no contact was made by an agreed time and to call for help if they were unable to reach the researcher.

Research quality

It is hoped that the findings from this research will ultimately add new insight to existing knowledge about life with a chronic skin condition. One of the driving forces behind the design of the research must be the search for credibility by ensuring that the findings can be trusted (Gray, 2009). In order to achieve this, issues relating to the quality of the research such as validity and reliability be considered.

Validity refers to whether an instrument is measuring what it is aiming to measure, whereas an instrument is reliable if it produces the same results every time it is employed (Sarantakos, 2013). While these issues are important, they must be conceptualised in a way that is appropriate for qualitative research, which, unlike quantitative research, has an in-depth focus on the meanings individual participants give to their life-experiences and an inductive approach to generating theory (Gray, 2009).

The validity of the study benefited from the use of a digital voice recorder for interviews as this form of recording allowed the researcher to hear data multiple times in the course of analysis, benefitting the research through the development of a deep familiarity with each piece of data. Validity in semi-structured interviews was strengthened by using interview techniques that gave participants the scope to express themselves. Steps were made to engage in a process of building trust and rapport throughout the recruitment and research process. Interviews were scheduled to give sufficient time for an in-depth exploration of participants' experiences of life with a chronic skin condition. And during the interviews, participants were be prompted to expand upon their initial responses. External validity refers to the extent to which findings from a study can be generalised. Interviews are well-suited to in-depth qualitative research studies with small samples, but this can restrict external validity. The generalisability of findings was increased by aiming to select a varied sample of participants that allowed a topic to be explored from a range of different perspectives (Arksey & Knight, 1999).

A number of other steps were taken in order to improve the overall quality of this research. The analysis of a relatively large volume of data from twenty-four participants assisted with the validity of findings. Findings from data were discussed with academic supervisors experienced in designing and undertaking qualitative research.

Conducting in-depth interviews with each participant and then reviewing this interview data involved a prolonged engagement with the fieldwork process. This immersion in fieldwork applying the proposed methodology resulted in increasing the reliability with which I was able to collect and analyse data. In addition, the overall reliability of this study was ensured through a process – fulfilled in part through this chapter – of clarifying the research context, how and why participants were selected and how data was collected and analysed (Sarantakos, 2013).

Reflexivity

Reflexivity, in this context, involves the provision by the researcher of a methodologically self-critical account of how a piece of research is done (Seale, 1999). My reflexive evaluation will function at a number of levels - both “descriptive” and “analytical” (Letherby, 2011). The first level is “descriptive reflexivity” (Letherby, 2011), which refers to reflections I as the researcher made about the research process, such as the effectiveness of the chosen methods for answering research questions. To fulfil the second level, “analytical reflexivity”, I evaluated both my own and my participants’ experiences, as well as my own understandings and theorising, located within the theoretical framework adopted for this piece of research. In this case, I made an evaluation about whether my analysis and the way I conducted the research meets the principles of a rigorous qualitative research framework.

Part of being analytically reflexive is ensuring that the analytical procedures are made transparent, which requires an acknowledgement of the processes of data selection, interpretation and theorising (Letherby, 2011). Making my experiences, values, prejudices and social position explicit has it is hoped, help respondents and readers understand this research to frame the motivations behind the work and puts them in a position to make judgements about both the approach taken and findings that are presented. That is, the adoption of a reflexive approach to research makes clear the role of the researcher in actively constructing knowledge (Letherby, 2011), as well as that of the participant.

Throughout the process then, it was important to recognise that as the researcher I am not a neutral observer and the questions posed or guidance given to participants had both direct and indirect effects on the participants and the research. I kept a reflexive journal throughout the process of engaging with participants on my role in the research process and the ethics of my research practice. Acknowledging my own personal experiences with a chronic skin condition, a position of analytical reflexivity allowed me to acknowledge and try to account for the effects of being a researcher who has an illness experience shared with the respondents in this study.

This research seeks to build an understanding of what it means to live with a chronic skin condition. As has been outlined in this chapter, the research takes an embodied approach that seeks to acknowledge the material and social realities of life for people with these forms of chronic illness. Through the production of in-depth semi-structured interviews the research aims to benefit from a rich source of qualitative data that will shed light on the impact of having a chronic skin condition on past experiences, current practices, future plans, conception of self and public identity.

The findings of this research will be differentiated into three sections that each represent a thematic area of experience. These findings will represent experiences of Being, Living and Treating for people who have a chronic skin condition. The first section, ‘Experiences of being’, will focus on aspects of identity and engaging in relationships with respect to the social importance that is attributed to the skin, and how this is affected by a chronic skin disorder. In the next section, ‘Experiences of living’, there will be a representation of findings that explore the material realities of living with a chronic skin condition, with a focus on the everyday impact and practices required to manage the body through chronic illness. In the final section, ‘Experiences of treating’, will address how people living with chronic skin conditions relate to the treatments which are used as part of their regimens for managing illness.

Findings: Experiences of Being

This findings chapter will explore how living with a chronic skin condition affects experiences associated with identities and relationships. A particular focus will be to examine the impact of living with and managing disordered skin on experiences of personal relationships, such as connections with family, friends and intimate partners, as well as the impact on experiences of working roles and relationships in employment. This chapter will draw on the work of Goffman (1963) and others focusing on how stigmatised identities can lead to stereotyping and discrimination. Scambler's (2004) work on stigma and chronic illness provides insight into experiences of both "enacted" and "felt" stigma. Furthermore, as illustrated in the work of Munir and colleagues (2005), perceptions about risks to productivity at work can attach stigma to people who live with chronic illness. Owing to such perceptions, those who are ill often have concerns about maintaining the appearance of competence in the workplace, which can make decisions about the disclosure or concealment of illness complicated (Beatty, 2018). It will be demonstrated that for many people who have a chronic skin condition, interpersonal experiences are imbued with the problematisation of their embodied identities, creating a sense of what Leder (1990) refers to as social dys-appearance.

T. L. Anderson et al. (2010) conceptualise "aesthetic capital" as a means for understanding the societal value attributed to physical beauty, the labour expended in attempts to meet normative aesthetic ideals and the costs of divergence from appearance norms. Drawing on the work of Anderson and colleagues, a focus of concern will be to address how disordered skin relates to acts of stigmatisation and concerns about aesthetic presentation. Moreover, this chapter will explore how living with a chronic skin condition affects the embodied capabilities that respondents feel they can draw on in the course of daily life. Efforts will be made to understand how these concerns about identity relate to issues of disclosure.

Based on findings around identity and relationships, the chapter will then explore how participants responded to these experiences. Crossley's work (2001a, 2001b, 2006) addresses how reflexive habits become embodied in order to conceal illness. Drawing on the work of Hawkesworth (2001), it will be demonstrated how people use temporo-spatial tactics in order to avoid stigmatisation in social circumstances that provoke concerns about unwanted disclosures of illness. It will be shown that respondents often developed what can be described as habitual reflexivity about their embodied presentation. A range of strategies that emerged in response to habitual reflexivity, helped respondents to manage the presentation of their bodies and minimise the undesirable impact of chronically disordered skin on identity will be addressed. It will be demonstrated that people living with disordered skin employ strategies of passing and disclosure in ways that are nuanced and creative, and aid them in maintaining and developing identities which they value.

In the final part of the chapter, the role of social networks as sources of support for people living with a chronic skin condition will be explored. Research by Charmaz (2010) and Munir and colleagues (2005) demonstrates the value of disclosure for gaining access to support across social contexts, but also the difficulties which disclosure presents for people living with chronic illness. The work of Vassilev et al. (2011) aids an understanding of the complex matter of support in the self-management of chronic illness. Vassilev and colleagues build a nuanced picture of how people who are living with illness engage with a range of social networks, both in real-world settings and online. It will be shown that social networks provide support for a range of valued identities, practically and emotionally. However, it will also be demonstrated that support is often a complex issue, with limitations on the support that any network could offer. It will be demonstrated that while family, friendship networks and work environments are often supportive, the needs of people living with skin conditions can add strain to relationships in these networks. Indeed, access to appropriate or welcome support may not always be available from these social networks. The use of real-world and online illness support groups will also be explored in terms of the value they offer their users for managing illness, and how respondents engage with these forms of illness support.

Presentational challenges

The presentational challenges which resulted from their illness formed an important part of the experiences of living with a chronic skin condition for the respondents in this study. These challenges often centred around notions of stigma, in ways that reflected the unique impact of disordered skin in relation to aesthetic appearance norms and their management across everyday life.

Goffman (1963) observed that notions of what is “normal” originated in large-scale bureaucratic structures of the nation-state and the clinical perspective of medicine. However, as Morris (1991) notes, “normal” is a concept loaded with values and judgements that may not be achievable, as well as pressures to be like other people. Drawing on Goffman’s (1963) work, it is known that stigmatised groups are discredited and viewed as inferior by majority groups who are considered to be normal. As a consequence of stigma, the stigmatising characteristic may be given priority over all others in how a person is perceived. Furthermore, as Charmaz (2010) has demonstrated, assumptions of moral failure can fuel enacted stigma.

The disclosure of a stigmatising characteristic can lead to stereotyping, shaping what others notice about an individual and how they are evaluated. Moreover, people with less visible social identities must choose whether they reveal or attempt to pass (J. A. Butler & Modaff, 2016).

Much work in sociology has demonstrated how the body is central to identity (Featherstone, 2010; Goffman, 1959; Leder, 1990; B. Turner, 1992). There are pervasive reasons why people may not disclose their illness to others, given that chronic illnesses often confer stigmatised identities (Scambler, 2009). While Young's (1990) work draws attention to how every social group has differences within them, it has been shown that people with stigmatising conditions may be reluctant to disclose their illness through fear of stereotyping and discrimination (Munir et al., 2005).

As the findings in this chapter will demonstrate, it was clear that people living with chronic skin conditions shared worries about social encounters and fitting in, recognising the social pressures placed on physical presentation that are derived from the appearance and performance of the skin. Where acts of stigmatisation occurred, respondents often framed this stigmatisation as being the result of ignorance of understanding about what was causing the visual appearance of disordered skin. Despite this framing of stigmatisation as the product of ignorance or misunderstanding, such acts brought concerns that respondents held about illness and identity to the centre of their attention in unwanted ways.

Enacted Stigmatisation

In accordance with much of the prior work on experiences of chronic illness and stigma drawing on the seminal work of Goffman (1963), a number of respondents had experienced acts of overt stigmatisation in relation to their disordered skin. Speaking about an incident from her adolescence, Jennifer, who has psoriasis, says:

> I remember being in Turkey when I was, um, about 15 and I had some on me at that point…. And I remember a Turkish man shouting leper at me, and I thought it was really funny. It didn't really hurt me. It didn't hurt me. I thought it was funny. But I think there's just something about skin diseases…. there's like a horrible stigma and it's like, goes back a long way, and there's just something about the skin that… if it's

> not clear and healthy then it indicates something worse inside. And obviously with psoriasis, eczema, acne, it doesn't, but it does give that really strange impression of people, instantly [clicks fingers], that, um, “oh god, what's wrong with them” like. 'Cause it's the first thing you see. It's our exterior.

The way that this stranger responded to Jennifer’s appearance was an act of stigmatisation that made an association between the appearance of psoriatic plaques affecting her skin and the condition of leprosy, a disease long stigmatised historically (Grzybowski et al., 2016). Reflective of prior work in the sociology of dermatological conditions by Jobling (1988) and others, Jennifer’s experience illustrates the continuing presence of a historical discourse that associates disordered skin with shamed identities.

Jennifer is aware of this historical precedence that draws on a discourse of the skin as being a highly visible “exterior” which represents the state of health of an “interior” of both the corporeal body and of the moral standing of the self. Based on this discourse, a diseased exterior is seen to embody an identity that is discreditable. It is notable that in this example, Jennifer responds to - and resists - the stigmatisation of her identity enacted by the shouting man by dismissing the validity of his comment as being uninformed and finding humour in his prejudice.

The stigmatising comments that Patricia received from ‘the occasional ignorant person’, a group that included former stock market colleagues, typically focused on the appearance of visible scars on her skin. Speaking about these comments, which likened the appearance of her hands to those of an older woman, Patricia says:

> there's all these men on the stock market floor in the 80s, all these wide boys and old Etonians and things, you know, and my scars would show up quite a lot and they'd make comments…. And I've had adults say about my old lady hands.

These comments portrayed aging skin pejoratively, denigrating Patricia's identity based on gendered cultural discourses which valorise the youthful appearance of the skin while depreciating skins that show signs of aging, particularly for women. This finding was consistent with work by authors including (Featherstone, 1982, 2010) who have pointed out the prevalence of gendered and ageist discourses in consumer culture.

While they could be hurtful, it was Patricia's experience that these acts of enacted stigma had been relatively infrequent in adulthood. 'It's not even once a month anymore, you know, it's just occasional. You might not even get a comment for a year', Patricia estimates. Children, however, are quick to make stigmatising comments about appearance, and for Patricia, 'at primary school it was every single day'. This was a theme that emerged the across experiences of many respondents, with experiences of stigma being enacted reported as occurring far more rarely as adults than during childhood. Indeed, for those respondents whose skin disorder developed early on, as Patricia and others found, there was often a stark difference in the incidence of stigmatising interactions between periods of youth and adulthood.

Many of the respondents whose condition was apparent during childhood or adolescence, including Patricia, above, as well and Helen, spoke about their experiences of stigmatisation at school. Helen and others pointed out that children and teenagers are often quick to comment on signs of physical difference or of illness, such as the appearance of disordered skin. Recalling her discomfort around an incident of children commenting on the blood marks which stained her school blouse, Helen says:

> I remember things like having like a long sleeve white blouse on and having blood on it and everyone going URGH what's THAT? And it's like 'cause I've been scratching my arm through it, and you, kids would just go urgh what's that? The WORST…. So

> people notice. Kids, kids are very cruel. They're not cruel. They don't like people who are different from them. They're very quick to pick up on differences.

As this extract illustrates, in voicing these perceptions of difference, children's comments about the appearance of disordered skin were often found to be particularly direct in ways that respondents had found hurtful. These results reflect those of McNiven (2019), who found that adolescents living with acne had often been the focus for teasing, if not bullying, about their disordered skin.

Helen recalls an experience of stigmatisation from prospective employers when she applied for a part-time job at a supermarket when she was a teenager. The job involved serving customers at a deli food counter. Speaking about the interview, Helen says 'they took one look at me and said we couldn't employ you, it would be off putting…. or, my feeling was that customers would find it distasteful as I'd be handling food'. This act of stigmatisation appears consistent with conceptualisations in the work of Sartre (1943/2003) on the development of abject feelings of revulsion, as well as notions of dirt as matter out of place in the work of Douglas (1966) and fears about "leaky" or "unruly" bodies (as developed in the work of Hodge (2014)) breaching boundaries of physical integrity.

While incidents in which disordered skin became the unwanted focus of attention were relatively uncommon, when they did occur such reactions from others were found to be more prevalent for respondents if the skin of their hands or their facial skin was affected. As Helen's experience of the gaze of others illustrates, people tend to focus on appearance of skin on her face and both the appearance and texture of skin on her hands more than other areas of the body:

> that's what people look at, it's whether you've got eczema on your face or not. Hands they'll sometimes look at, and you see people doing a double take at your hands if

> they're bad, especially if they shake your hands and they're very dry. And you'll sometimes see them look at them again.

For people whose bodies and appearances differ from what is normative, public attitudes about physical attractiveness may present obstacles to social participation. These attitudes may be particularly relevant for people whose substantive bodily differences are located in their faces, as there is particular aesthetic aversion to facial disfigurement. As Hawkesworth (2001, p. 300) puts it, ‘nothing is more visible than the face’. In Western culture, the face is accorded particular aesthetic value, separate from the body overall. Sontag (1989, p. 125) writes that the face ‘influences every aspect of manners, fashion, sexual appreciation, aesthetic sensibility – virtually all our notions of appropriateness’. The privileged aesthetic influence of the face gives facial disfigurement unique weight in its effects on evaluations of appearance. In addition to the skin of the face, another important focus for bodily attention is the skin of the hands. Connor (2003) conceptualises the hand as a “homunculus” in the way that this corporeal structure can represent the entirety of the body. The hand is not merely a limb or an organ, but may be viewed as a faculty capable of representing the individual. As Connor (2003, p. 266) puts it, ‘the hand (like the face) can be an alternative body, a second skin’. Moreover, as Helen’s extract illustrates, the face and hands are areas of the body which are more likely to be exposed to the view of others and used in daily interaction, through acts of social reciprocity such as shaking hands with another person.

Felt Stigmatisation

A notable aspect of contemporary culture, Hughes (1999) argues, is the “oppressive gaze”. This part of modern visual culture is disfiguring as it seeks to assess and eradicate every anomaly and imperfection of the body, according to an image based on ‘mythologies of normality, truth, beauty and perfection’ (Hughes, 1999, p. 164). Young (1990) argues that the effectiveness of the oppressive gaze is strengthened by the internalisation of aesthetic standards of oppression, as individuals will then consistently scrutinise themselves through the eyes of others according to such standards. This tallies with Scambler and Hopkins' (1986) conceptualisation of "felt stigma", which acknowledges the fear of stigma being enacted but also crucially the internalised shame associated with the possession of characteristics viewed as socially unacceptable.

It was of interest to find that across respondents' experiences that could be considered stigmatising, predominant among these were experiences of felt stigmatisation rather than enacted stigma, particularly in adulthood. While respondents were aware that others may notice their disordered skin, it was most respondents' experience that as an adult, few people had commented pejoratively about their skin condition or otherwise enacted stigmatisation relating to their disordered skin. Despite the visibility he perceives of psoriasis on the skin of his hands and fingers, for example, Theo has not experienced stigmatising reactions or questions from others as an adult in daily life. 'And it is kind of annoying me', he says, 'but no one really tells you "oh your hands look weird!" or "what do you have?". People don't tell you that'. Rather, it emerged that for Theo and many others, it was much more often self-perceptions about bodily presentation and its effects on identity that had a more telling impact on the everyday experiences of respondents than explicit stigmatisation by others.

Discussing the difficulties presented managing both appearance and comfort caused by her skin condition in high temperature weather, Tanya speaks about how during a recent spell of hot weather she chose to wear a dress that revealed affected skin on her arms and legs. It has been Tanya's experience that other people either do not react to or do not stigmatise her skin through their comments. However, Tanya feels that her self-perception about the severity of her pompholyx eczema does not match what others perceive about her. Despite her experience that others generally do not react to her disordered skin, it is Tanya's own knowledge of its presence that affects her self-image and leads to discomfort with revealing areas of visually disordered skin in public. She says:

> when it was really hot last week obviously, I wore a dress in school and my legs were visible and my arms but it was so hot but nobody really mentioned it then, so I think it's probably worse than it actually is. I know it's there. And I know my skin's dry, but other people probably can't see it as much as I can, as much as I think they can see it. I think I've maybe been slightly paranoid about it, because I know how bad I think it is… It's when I have to have any skin showing really. If I've got to have my arms or my legs showing. But I think it's more my problem than other people in that other people, they don't say anything.

The physical sensation and appearance of her skin condition constantly reinforce her sense of illness and the implications such illness has for her identity, particularly by comparison with her self-image before the development of her skin disorder. Tanya says:

> I think I feel that it's bad. And it isn't that bad, but I can see it and I can feel it and know it's there. And it does- I've always had really good, smooth skin usually so it has affected my confidence really I suppose, in that way.

These perpetual embodied reminders of illness reinforce Tanya’s feelings of stigma, bolstering a sense of unease about presenting her body in public.

Theo was aware about the pejorative terms that other young people he knew growing up in France often used to describe people who had acne on their faces, such as the use of an analogy comparing facial appearance with the buttons of a calculator. Theo says:

> at that time people were not making fun of me or you know, sometimes you hear things when kids are talking they are, kids can be, kids, teenagers, young adults can be tough to each other or when they're talking about a third person who is not there they might say bad things, comments, you hear things like “oh this girl is like a

> calculator”…. she's got so many buttons, spots, so that's the analogy we use sometimes here between kids or some kids are so nasty that they might say that in front of the person as well…. I've heard those comments, but never told those comments pointed at me directly. So I shouldn't have necessarily felt that you know I was not accepted, it was not the case.

In the absence of direct acts of stigmatisation to demonstrate a lack of social acceptance, Theo feels that his ongoing presentational concerns, and the social limitations he experiences because of these concerns, emanate from within himself as part of a broader set of social apprehensions. As Theo puts it:

> a lot of my anxiety or stress is coming from me in general. It's about work, it's about my look…. my friends were not telling me “you've got plenty of spots, we don't want to go out with you”. No that was not the case. It's more like it was coming from me…. And I'm putting some barriers myself.

In accordance with the work of Scambler (2009), many of the respondents’ experiences alluded to the power of stigma they felt in relation to their illness to constrain their actions in real-world public environments, without stigma being enacted towards them by others. Theo’s experience suggests that the discourses stigmatising disordered skin are pervasive and impose unfavourable identities which become incorporated by people whose presentation is affected by a skin disorder, even in the absence of direct stigmatisation. This means that while stigmatisation may not necessarily be enacted, Theo and other respondents experience the social consequences of stigmatisation through their concern to avoid taking on discredited identities.

Consistent with the experiences of felt stigmatisation shared by many other respondents, James has felt a need to cover up his body when his symptoms of psoriasis were more visible. James says:

> I think the psoriasis is like, you have to cover up I know there are some people, very few people, I don't see many, will you know show off their legs or their arms, I wouldn't…. Any skin disease. No. You know, it's just not- People just don't do it, do they? I mean I wouldn't do it.

James makes clear that these feelings were not a result of any negative comments directed towards him by others. Rather, as James puts it, 'people haven't said anything'.

In line with the findings of Hawkesworth (2001) about the experiences of people with acne, these extracts from James, Theo and Tanya illustrate an imperative encountered universally by respondents to conceal their illness in public spaces, absent of the necessity for experiences of explicit stigmatisation.

Jennifer is ambivalent in her feelings about the presentation of disordered skin in public. While she believes that someone who has psoriasis should not have to conceal their skin in public, she maintains a feeling that it is not appropriate to 'put it on show'. Jennifer says:

> I do believe that if you want to walk out covered, um, then you should. And there's a model, isn't there, a female model, who's got really severe psoriasis and I think that's great. But at the same time it really doesn't look... it doesn't look right.

Jennifer values positive representations of people with psoriasis in wider society but she also feels that psoriasis portrays a "horrible negative impression" of a person, particularly when psoriasis affects the skin of their face, and if they are able to conceal it then they 'probably should'. On this basis, Jennifer feels that people with psoriasis have a responsibility to hide their skin disorder in order to manage the impression that is portrayed, but that this is a responsibility to themselves. As she has experienced very few stigmatising reactions from others in her adult life, Jennifer is unsure about the source of the necessity she feels to cover up her psoriasis in public spaces:

> I've never really ever had anyone say to me, 'oh god'. Like I've never had that reaction. So I guess, you can almost say, well why do you think it? You're assuming something negative's going to happen and it might not. But I know what it looks like, and, I just.... I don't really know why I think it's inappropriate, but I wouldn't feel happy, I wouldn't feel comfortable knowing that people would be able to see it and wonder what it is. People might not ask me or be rude, 'cause I honestly don't think people are, but I just think I don't want people to think about-, even in their own head, 'cause I would, if I saw it. So I just think keeping it hidden is the best thing…. When I was at school, I remember I had some, only some names called at me, but ever since secondary school I've had nothing, not a single detrimental nasty comment. Nothing. Which is good. But I still think I need to hide it and I don't feel comfortable. I feel very insecure and it makes me, like, go in on myself a little bit…. It's-, I can't explain it. It's so difficult to explain, because even I don't know what it is in me that makes me want to hide it.

Jennifer’s position reflects the complex challenges agents face as part of being embedded within social networks that enforce norms about bodily presentation. The need to embody norms about what is acceptable for bodily appearance in public spaces conflicts with values about rights to personal expression, the acceptance or embracing of personal difference, and increasing visibility and understanding of illness in society. Negotiating the challenges of reflexive embodiment here, even in the absence of enacted stigma, produces an understandable sense of ambivalence about the management of appearance in public.

Challenges of Aesthetic Distinction

The results of this study indicated that many of those living with a skin disorder had felt concerned about the impact of their illness on their aesthetic presentation. T. L. Anderson and colleagues (2010, p. 564) address how sociology can ‘forge an understanding of how value associated with beauty returns some forms of individual wealth' and suggest "aesthetic capital" as a tool for doing this. Aesthetic capital refers to 'the privileges and wealth people receive from aesthetic traits, such as their face, hair, body, clothes, grooming habits and other markers of beauty'. Such privileges include 'the kinds of perks, and penalties, people receive from being deemed beautiful'. T. L. Anderson et al. (2010, p. 564) find that 'visually appealing traits greatly impact our lives, in matters of modest importance (friend selection) to great importance (e.g. getting a job and career mobility)'. The wider implications for thinking using this concept of "aesthetic capital", may be found through 'enabling sociology to better understand inequality and the socially based forms of wealth available to individuals in modern society' suggest Tammy Anderson and colleagues (2010).

The work of Bourdieu (1991) reveals that symbolic forms of capital establish hierarchies of discrimination, or distinction. Aesthetic capital can be located as part of what Bourdieu refers to as cultural capital, which is largely symbolic. Cultural capital represents non-financial assets that involve educational, social, and intellectual knowledge. Because cultural capital functions symbolically it often makes it seem like there is something "natural" about those who possess it. As Moore (2008) puts it:

> Each type of symbolic capital achieves its effect by virtue of the contrived and sustained "illusion" of the autonomy of its field as constituted by what is claimed to be its intrinsic principle – its own particular, disinterested, sacred, consecrating principle (beauty, truth, altruism, etc.). (p. 105)

Like others forms of capital, 'cultural capital has market value in the constant struggle for privilege. It can also be used to obtain other resources… because people believe it should be rewarded' (Kingston, 2001). Drawing on Bourdieu's conceptualisation, T. L. Anderson and colleagues (2010) suggest that beauty is perceived to have intrinsic worth through what they term "aesthetic capital" that may be considered alongside other forms of symbolic capital. In proposing their concept of “aesthetic capital”, Anderson and colleagues (2010, p. 566) outline a range of ‘traits of beauty that are perceived as assets capable of yielding privilege opportunity and wealth’. To delineate the features of aesthetic capital, T. L. Anderson et al. (2010) note that:

> At a minimum, they are located in the face and hair (e.g. symmetry of the face and other facial features and hair colour, texture and style), body or physique (waist-to-hip ratios, body mass indices, height and weight etc.), clothes and fashion (style, presentation of self and trendiness) and accessories (makeup, tattoos, handbags, belts, shoes etc.). (p. 566)

Importantly, like other types of capital, aesthetic capital can be construed as ‘a relational construct that taps how the assets one has return wealth and opportunity’ as T. L. Anderson and colleagues (2010, p. 566) outline.

Featherstone (2010, p. 193) notes the prevalence of beliefs ‘that a person’s inner character or personality will shine through the outer appearance’ both the through the appearance of the body generally and particularly that of the face. Of particular relevance to the present study, as Borgerson and Schroeder (2018, p. 104) argue in their study on consumer culture imagery, ‘the skin forms one of the major features of the body’s “outer” appearance, or exteriority’ – a feature that is often highly visible and is subject to scrutiny and judgement.

Exploring society’s reactions to and regulation of people who have facial acne, Hawkesworth (2001, p. 300) develops the concept of “disabling spatialities of disfigurement”, defined as ‘the normalising and pejorative discourses [of acne] which perpetuate disabling attitudinal barriers and position “disfigured” people in their occupation of social space at the margins because they do not exactly fit in’. The concept of “spatiality” conveys the idea that as well as having a physical form, space also has strategic, temporal and political qualities that are constructed through social relations (Lefebvre, 1974/1991). This means that there is a direct relationship between living bodies and their occupation of space. Moreover, the experience and interpretation of a space differs for each individual and reflects the social positions they hold as part of this space (Massey, 1994).

Young (1990) maintains that oppression is not necessarily the product of purposeful acts by a ruling group, but as structural or systematic constraints that are the result of everyday social relations. This oppression in everyday life emerges from a system which Young (1990, p. 41) identifies as ‘unquestioned norms, habits, symbols, in the assumptions underlying institutional rules and the collective consequences of following those rules’. Hawkesworth (2001) argues that the representation of facial acne as an experience that is common and relatively benign during adolescence has normalised the condition for this phase of life. However, this selective representation of acne can have powerful effects on the lives of people both during adolescence and in adulthood, whose experiences diverge from this norm. Misrepresented by dominant perceptions about the impact and trajectory of acne, people may feel unable to acknowledge to others the effects that acne has on their lives. Viewed from a social disability perspective, as demonstrated by (Hawkesworth, 2001), it is owing to misrepresentations and stereotypes about their condition that many sufferers experience acne as a ‘visible secret’ which affects their participation across much of social life. This is particularly notable in spaces where established norms of self-presentation are strongly “classified” – that is to say, wherever “looks” are considered important.

Unable to meet the rules of visibility attached to social situations where there are particular demands about presentation – at job interviews or at work, at parties, weddings or on romantic dates, for example – individuals may feel, Hawkesworth (2001) argues, that their disordered skin becomes an unwanted defining feature that engenders shame about being seen in these spaces. Embodying an identity that is conferred through a reflexive awareness that (Sartre, 2003) terms the “look” of the Other, an individual may experience a loss of assurance in their appearance that compels a need to hide or flee from this sham. Social imperatives about how a person should appear contribute to the regulation of what Sibley (1995) calls “purified identities” which marginalise bodies that do not meet given conceptions of aesthetic appeal.

There are often particular pressures for women to be visually appealing. Spatialities are produced with demands for the display of heterosexual desirability and other hegemonic images of femininity. Women living with facial acne, for example, are known to experience their condition as a physical disfigurement that damages their perceptions by others in terms of both normality and desirability (Hawkesworth, 2001). These demands are often reproduced materially through media sources such as advertisements for make-up and skin products and linked to economic imperatives for appropriate presentation through employment. Moreover, the perception of the body that is promoted through the media often concentrates on appearances of youth, physical beauty and fitness (Featherstone, 1982, 2010). These idealised images of attractiveness provide a means to regulate what is viewed as acceptable or desirable skin, which does not include skin that is disordered or visually blemished. Goffman (1963) observed that notions of what is “normal” originated in large-scale bureaucratic structures of the nation-state and the clinical perspective of medicine. However, as Morris (1991) expounds, “normal” is a concept loaded with values and judgements that may not be achievable, as well as pressures to be like other people.

Helen’s concerns about her appearance had affected her self-image and her experiences of social networks from the time she was a child. Helen expresses some reluctance to acknowledge the validity of how her perceptions about her appearance affected her social experiences. However, the effect of eczema on her aesthetic presentation meant that, from early on, Helen ‘didn’t feel pretty’ and felt like ‘an outsider’. Helen says:

> it made me feel a bit of an outsider, I think…. little girls are supposed to feel pretty, and I didn't feel pretty. God it sounds pathetic, doesn't it, but you know, those kind of things are important. So I didn't feel, yeah, I didn't feel that.

Helen’s experience demonstrates the social imperative demanded of girls and women, in particular, to feel attractive through their physical appearance, and the consequences for self-image and social embeddedness of failing to meet these demands. While she is reticent to attach such value to aesthetic appearance, she acknowledges the impact that her disordered skin had on her own self-image and her social position among her peers.

Heather feels that it is unavoidable that others will see her acne and as the following extract makes clear, she finds this deeply upsetting. Heather says:

> To go out, when I turned 18 and stuff, was quite upsetting when I used to get ready. I used to always cry before I went out because obviously you've got your nice outfit on, your hair's nice and everything, but it was just always there, on my face... all I could see when I looked in the mirror, no matter if I looked nice, that's all I could see.

Heather’s concerns about her aesthetic presentation are centred on the intractable impact of her skin condition on the appearance of her face. Even after the aesthetic labour (Bordo, 2003) which Heather puts into her appearance before a night out with friends results in other areas of symbolic importance such as her clothing and hair styling appearing as she would wish, it is her face that draws all of her focus. Heather’s experience highlights the importance of the skin for considerations about appearance and identity. Her skin disorder presents an image in contrast to the outcome of all her other beauty work and in Heather’s perception, negates all her efforts. Heather’s skin disorder creates a sense of what Leder (1990) terms “social dys-appearance”. Drawing on Leder’s (1990) conceptualisation, Heather’s disordered skin has become an object that she feels is “other” - her skin is outside of herself and removed from her desired identity. However, the aesthetic burden Heather feels through its permanent visibility means that the impact of her acne on her self-image is deeply embodied, and profoundly influences the identity that Heather believes she portrays to other people.

Reflecting on how wearing make-up would be followed by an exacerbation of her skin condition, Monica's experience alludes to how the ability to shape self-presentation through appearance feels important for managing identity. Monica found that she needed to be very selective about using make-up, choosing to wear make-up only for special occasions where she felt particular value was attributed to appearance. While she experimented with different forms of make-up, including those advertised as being "hypoallergenic", Monica found that there were few options that did not exacerbate her skin condition. However, a recent development in her treatment regime to include the use of more potent medications has opened up options for wearing make-up that were not available to her when she was younger.

One issue that Monica had faced with using make-up is that was often been unable to enact looks or styles that fit with how others presented themselves in particular social settings. During her teenage years, Monica limited in her capacity to look 'dressed up' for school social events:

> Whereas most teenage girls at sixteen, seventeen, eighteen, want to do their best to look good at school and events and dances and all these things… I was never able to do that. Because even just putting any sort of stuff on my skin, especially my eyes, even you know the nice, hypoallergenic make-up, I would break out. So that was something that was kind of completely out of my options. So I'm already being defined by the disease, I guess. But not being able to even try to enter the category of, ok, you know, in high school, where there's like, ok, the girls that like to be dressed up or pretty or popular or whatever else. Not that I couldn't hang out with them, but when you look at me, physically, I'm going to be different, you know?

Monica felt different to the others and limited from embodying social identities among her peer group that were associated with particular styles of aesthetic presentation. Monica’s awareness of the social value of these aesthetic differences from her peers illustrates the notion of a “beauty premium” (Mobius & Rosenblat, 2006) that is prevalent across broad spheres of social life. Moreover, the efforts made by Monica in her experimentations with make-up exemplify the idea that beauty is accomplished, a point made by Bordo (2003) through her work on aesthetic labour and echoed by Anderson and colleagues (2010) in the development of their concept of aesthetic capital.

As an adult, the restrictions that psoriasis placed on her use of cosmetic products meant that Monica was unable to use make-up techniques as part of presenting a professional image as a music teacher. Monica says:

> If I'm going for my first job interview and I want to look my age, clothes help a lot but so does make-up. I already have a face that I could probably pass for twenty, you know? Where I'm twenty-five. So especially when you're trying to teach kinds who are eighteen, it's hard, because you realise, I look almost the same age as you. Other women would be able to do the eye liner thing and the fancy- whatever, to add three years or five years to their look.

Monica was only a few years older than some of her students and felt that if she was able to apply eye-liner and other make-up to her skin, like other women can, this would allow her to appear more mature at job interviews and while teaching. She felt that the option to use make-up to create the impression of being older would have helped her embodiment of her professional role as a teacher in relation to her students.

Doing what is “best” for managing her disorder skin is demonstrated through Pavana’s discussions about the limitations she has found her disordered skin place on clothing style choices, including the fabric and the cut of garments. These limitations are highlighted by Pavana's description of the process of making decisions about what to wear for attending the special social event of a wedding. While other guests wear embellished, fitted clothing, Pavana makes a series of compromises for her eczema which result in her outfit being 'so far from the norm and style' of what others are wearing and what she used to be able to wear before eczema:

> whereas before I would have bought something that was fitted, now I go for loose, you know, 'cause it's more comfy, 'cause I don't itch in it. And I don't for beaded, I go for the simple satin because it's not itching. And so you get to the point where you look at the outfit and it's just so not what you like anyway but it fits with the eczema that you give up. You just think, oh I've compromised that far, who gives a monkey's, you know. It looks alright. It'll do. And you go into that mode, you know. Whereas before you would have chosen based on style, based on- and it's so far removed. And 'cause Indian weddings, and especially ones which are like this, the clothes are really, really stunning. They're really beautiful. And the one you choose is so far from the norm of what people are wearing that you kind of think it doesn't really matter what shade of rubbish I get, because it's still [laughs], you know, what shade of this moderate one I'm getting anyway. It doesn't matter what shade. And you kind of give up a little bit on making the effort to faff around on the choices, 'cause you think it's so far from the norm and the style of thing people are wearing.

Making these decisions about what outfit to wear to a wedding involves a series of concessions to the management of her skin that affect the identity that Pavana feels she portrays to the other wedding guests, some of whom she has established relationships with but others who she has not met before. Moreover, Pavana feels that the compromises she makes with her presentation affects how others treat her:

> it brings you down a little bit and makes you think, um, you're less important than you are I suppose…. I think it affects maybe more what people you don't know think of you…. the other side of the family might think of you as a dowdy, old, you know, older person…. may not treat you as well, because they might not think of you as important were you better dressed and better-. from the new family if you like, sort of thing. And when you're meeting new people, um, they may look down on what you're wearing and stuff like that. Whereas I think the people I know, know me well enough to not I suppose make that judgement as much…. 'cause that can be a little upsetting. 'Cause I suppose initially, when you don't-, you will judge by appearance. That's what you- Initially, that's all you've got to go on I suppose when you first meet people. I think it's more a case of, feeling like you're ignored more. Whereas, people would go up to you more and you feel like they would maybe communicate more as you're slightly more sidelined. But maybe, I think, as not being one of the fashionable ones.

Illustrative of an argument made by T. L. Anderson et al. (2010) on the importance of aesthetic capital, this extract shows how being unable to present herself according to the norms of aesthetic distinction that are observed at these grand social events means that Pavana feels that she is ‘sidelined’, ‘ignored’ and looked down upon by others.

Embodied Capability Challenges in the Workplace

Another important finding was that respondents frequently experienced their disordered skin as challenging how they perceived their capability in the workplace. Perceived pressures of maintaining competence, credibility and reliability at work can make someone less likely to disclose their illness (J. A. Butler & Modaff, 2016). This can be attributed to the stigma attached to groups who risk being perceived as a burden to the productivity of the workforce (Munir et al., 2005).

Heather was reluctant to pursue work that she may have aspired towards because of her perception that her aesthetic appearance did not meet with her expectations of what someone doing that job should look like. ‘Well I didn't feel brave enough to go for a very good job. I didn't feel like I'd LOOK the part’, Heather says. For Heather, a ‘very good job’ demanded an aesthetic appearance which because of her acne she was unable to embody, and on this basis meant she was precluded from fields of work she may otherwise have interest in pursuing:

> HEATHER: Well I used to work as a personal trainer in a gym. But obviously I was faced with the problem of being around good looking people, and then I had to leave because my skin was bad and it looked awful
>
> INTERVIEWER: So you said that you'd be around good looking people. Do you mean the other personal trainers?
>
> HEATHER: No, customers that would come in and I would have to personal train them, and I felt like they were just looking at my skin. They probably weren't, but-

Heather’s experience represents the impact of felt stigma that had become attached to her acne in the course of her illness trajectory. Her experience also represented a self-consciousness about how the appearance of acne meant that she could not embody normative images of health and desirable aesthetic presentation that she associated with being a personal trainer working with clients in a gym environment.

Heather’s extract also illustrates concerns about maintaining credibility at work that are common about people living with illness (Beatty, 2018). Heather’s concerns about the exposure of her acne in her role as a gym instructor reflect the demands of work in a space where beauty is strongly classified (Hawkesworth, 2001). Despite enjoying other aspects of the job, Heather’s concern about her appearance meant that she no longer wanted to continue to work as a personal trainer, and had taken up a job as a carer in a nursing home. She went on to say that she would ‘definitely’ prefer to be working at a gym than this carer position. However, the importance that Heather attributed to physical appearance within the role of personal trainer, and her negative perceptions of her own appearance, meant that it did not feel possible to pursue a career in her preferred field.

Patricia talks about how she feels a need to hide her scratching and the management of her eczema from other people in the context of her work life to manage the impression she makes with colleagues. Taking on work in a number of new freelance jobs meant that Patricia would work with many new colleagues and face challenges in adapting to the demands of these work roles. The demands of learning her new job were compounded to a level of exhaustion by the demands of trying to conceal bodily practices, visual presentations and experiences of discomfort that would reveal Patricia’s skin disorder to her new colleagues. Having completed the freelance work and endured the difficulty of negotiating the management of her exacerbated eczema alongside new colleagues, Patricia had hoped that going on holiday would feel rejuvenating. However, spending this holiday with friends who she did not know that well meant that she felt she had to “negotiate” the management and presentation of her skin with these people as well:

> I think that's probably why I had to come back from my holiday this year, because I literally had had two or three new jobs as a freelancer, with terrible skin, absolutely sore and itchy, really severely itchy, and then trying to learn your new job and contain your skin so they don't know what you're going through, 'cause you don't want them to, and by the time I went on holiday I was just so exhausted. I needed to be on holiday in comfortable surroundings…. and not have to negotiate my skin with people I didn't know, and not negotiate with anyone about anything really.

Patricia’s experience reflects a concern that the exposure of the manifestations of her disordered skin to new colleagues may demonstrate problems with her ability to cope with the demands of her job, and in so doing would affect the professional identity she hoped to embody. With similarities to Heather's experience at work, Patricia's wariness of how her new work colleagues may view her reflect findings that people living with illness often have concerns about their credibility in the workplace (Beatty, 2018). In addition, such results are in line with those of Munir et al. (2005) who found that concerns held by people with illness that they may be viewed as a burden at work can make it difficult to disclose their illness, with the consequence that accommodation of their illness needs is not made possible.

Barbara explains that her image is important as part of her work as a solicitor, with her hands being visible to clients every day. Moreover, the need to use her hands to type on a keyboard became incredibly difficult due to the pain affecting her fingers as her nail psoriasis developed. Barbara says:

> Oh god, at that point it was sore. I started being unable to use my fingers. I write a lot with my job, I'm taking instructions from clients, and I'm using the computer. My fingers are on show all day long because I'm seeing people, you know I'm on show basically, I've got to look a certain way and my fingers.

The physical changes that were occurring as part of the manifestation of nail psoriasis affected Barbara's physical appearance to clients in an area of the body that was not only highly visible, but which was also important in doing the practical and symbolic work of being a solicitor in a work venue where aesthetic appearance is strongly classified (Hawkesworth, 2001). Barbara was understandably concerned that this may negatively impact the image of professional capability that as a solicitor she felt it was important to embody.

Habitual Reflexivity in Response to Presentational Concerns

It was apparent that respondents had often developed a range of habitual practices in response to specific presentational concerns. It emerged that respondents were often continually aware of how they perceived their body appeared to others in terms of the visibility of their disordered skin. Butler and Modaff (2016) found that people living with chronic illness demonstrate a range of tactics for passing as normal, which the authors identified as “fabrication”, “concealment” and “discretion”. People engage in fabrication when they give false information about themselves. Meanwhile, concealment involves taking steps to make sure no one finds out about their illness. Finally, tactics of discretion entail the avoidance of questions about the stigmatised characteristic posed by others. Each of these tactics may be deployed by a person who hopes to pass as both typical and competent. Discretion can be used when a necessary social exchange, such as negotiations around employment, requires a level of disclosure of illness, such as instances when the accommodation of illness needs or perceptions of competence are needed (J. A. Butler & Modaff, 2016).

Presentational concerns faced by those living with disordered skin were found to be guided by apprehensions about identity within the context of a range of social relationships. Such identity apprehensions often appeared in relation to a habitual reflexivity. That is, feelings of concern about how disordered skin affects aesthetic qualities and embodied capabilities related to a range of social settings were associated with a perennial monitoring of embodied self-presentation across a broad range of social contexts. Speaking about the impact of psoriasis on his everyday practices, Theo says, ‘I’m very concerned about my presentation, how presentable I am, so you know every day I'm thinking about this and every day I'm trying to sort of trying to hide’. As illustrated in Theo’s extract, based on presentational concerns, respondents engaged in a habitual process of self-monitoring. These findings around the need for individuals to monitor their bodies are consistent with the ideas of Crossley (2001b) who suggests that contemporary, late modern societies tend to call for and generate more reflexive habits among their members (Crossley, 2001b, p. 114).

Respondents were highly sensitive to the potential for unfavourable appraisals of identity, such as stigmatisation based on appearances associated with illness. Moreover, respondents felt a pressure to be perceived in ways that were both socially acceptable and which they considered desirable, meeting social norms for bodily capability as well as aesthetic qualities.

Guided by a habitual reflexivity of both skin and social setting, respondents were found to use a range of strategies that helped to manage the presentation of body and self in social space, attuned to the presentational sensitivities of their disordered skin and how such sensitivities relate to issues of identity. Drawing on conceptualisations in the work of Hawkesworth (2001), it was found that respondents managed the presentational concerns associated with their illness through the use of a range of strategies for passing as someone who does not have disordered skin. Aesthetic strategies were employed, where stylistic practices involving clothing and cosmetics helped to conceal the appearance of disordered skin from external view at a level immediate to the physical contours of the body. Temporo-spatial strategies took into account bodily presentation in broader dimensions, such as how the sensory qualities of particular spatial settings, or the timing and social context in which activities take place, can aid or complicate attempts at passing. Socialising under the cover of darkness, avoiding activities where disordered skin may be exposed to others, or events where photographs are likely to be taken, and positioning the body with care in the presence of others, are all temporo-spatial strategies that help to manage bodily presentation and are indicative of a reflexive outlook (Crossley, 2001b). However, the perennial call for such self-monitoring, shaped in part by the bodily demands of skin disorders - demands which may be complex and erratic – produce a habitual need for this reflexivity. Moreover, the demands of responding to such habitual self-monitoring, and the limitations these responses may produce, can profoundly impact experiences of everyday life.

Passing Strategies

Respondents used a range of tactics to manage the appearance of their disordered skin to others. These tactics focused around the application of cosmetics and preferences for clothing styles and colour-ways which aided passing. Respondents cited a range of concerns they had about the appearance of their skin in the context of social interactions. A number of respondents spoke about how their use of make-up related to their skin disorder. This was often associated with feelings of necessity to conceal their skin disorder from others because of concerns that their skin would convey an undesirable impression of their skin and themselves. Based on these feelings of need, respondents often alluded to their use of cosmetics as a way to manage the appearance of their skin when they knew they would be in the company of other people.

People have an ‘understanding about their own aesthetic traits’ (Anderson et al, 2010). Moreover, as Anderson and colleagues put it, ‘beauty is accomplished’. The work undertaken for the accomplishment of beauty has been explored sociologically from a range of angles. Research has examined the purchase of beauty products (Peixoto Labre & Walsh-Childers, 2003), as well as notions of body work (Wacquant, 2004) and aesthetic labour (Bordo, 2003; Dean, 2005), which encompasses the responsibility that individuals, particularly women, take on to scrutinise and manage their appearances from an early age. Naomi Wolf’s work (such as The Beauty Myth, 1990) denounces the “holy oil industry” of cosmetics which, she argues, reduces women to being merely a lustrous surface. The value of physical beauty and its associations with wealth has been recognised in empirical work since the early 1970s (Dion et al., 1972), and more recent work in the social sciences (Mobius & Rosenblat, 2006) has explored the notion of a “beauty premium”.

In addition to its value as a tool for concealment, a number of respondents spoke about the use of cosmetics for self-expression. While the use of make-up and other beauty products was possible for some, a number of respondents spoke about the difficulties of finding make-up suitable for use with their skin, given the particular nuances of their skin disorder. Some respondents had experience of make-up exacerbating their skin condition. Others had found that make-up did not work effectively with the form or texture of their skin. For many of the respondents who used or had tried make-up there had often been a trial-and-error process of testing different products for effectiveness and compatibility with the nuances of their disordered skin. Such issues with the practical use of make-up in the context of negotiating the health and illness of their skin, as well as its material qualities, meant that some respondents felt limited in their aesthetic expression.

Use of Cosmetics

Heather distinguishes a difference in the meaning she attributes to make-up compared with the meaning make-up holds for her friends. ‘It's taken away the like luxury of- when my friends get ready to go out and they put make-up on it's to make themselves look pretty. Mine is just to make myself feel normal’, she says. In her utilitarian relationship with cosmetics Heather feels that has lost a component of the experience of using these products that hold value for her - a sense that using make-up can be used to add to qualities of beauty in ways that offer freedom of aesthetic expression and possibilities for social distinction and not merely concealing her disordered skin. Such limitations sometimes became apparent through respondents’ comparison with past selves before the development of disordered skin, or with the aesthetic choices afforded to friends and peers who did not need to consider the management of disordered skin.

As her illness has progressed, Pavana has found that can no longer wear perfume without exacerbating her condition. It is known that fragrances can be the cause of adverse dermatological reactions and the exacerbation of disordered skin (de Groot & Frosch, 1997). Unable to wear fragrances as she used to before she developed eczema, Pavana now feels that has a scent that is ‘antiseptic… rather than smelling nice’. She alludes to the value that wearing perfume holds aesthetically, reflecting on the importance of fragrance for her self-image before she developed eczema and laments the cosmetic limitations she now faces.

Pavana has found that attending to her aesthetic presentation through the use of make-up adds an additional burden to the labour of managing illness and its effects. She expresses a changed relationship with her self-presentation caused by her eczema, some of which is related to the difficulty and effort required in finding make-up that does not exacerbate her skin:

> Yeah, I mean, there's one brand which seems to be ok at the moment, a foundation. Um, and whereas before the eczema I would have tried to make a bit of an effort before you go to something, now, making that bit of effort on top of everything else you have to do becomes a bit of-, and I do make a bit of an effort.

A dichotomy of before- and after- the development of illness is clear in how Pavana experiences the feasibility of managing aesthetic presentation. Where before eczema, the effort required to engage in beauty work was available, with eczema Pavana has found that it is effort enough to attend a social event and manage the sensory discomfort and material needs of her illness. Keeping up with the overwhelming demands of managing the skin to avoid exacerbation sometimes means forgoing presentational efforts that complicate this management. For Pavana, giving priority to managing exacerbation and doing what is “best for eczema” means compromising on the time, effort and aesthetic expectations that she can dedicate to styling her hair, using make-up or choosing clothes in ways that she would prefer. Pavana says:

> But the problem is that, like, you do your hair, but I can't leave it out too much, 'cause I get too much and I'll scratch too much, and then then flakes fall out. Whereas if I keep it tied up-…. And you get to the point where you're doing so much to avoid the

> eczema making things worse that I kind of give up sometimes. I just kind of think, well ok that's best for eczema, just tie it up. Um, if I do wear foundation, oh it's a bit rough today, I won't risk putting it on, better to leave it…. you just give up and then you don't want your photo taken at events. You don't want your picture taken because you've decided to go with the "this is best for the eczema" approach.

Doing what is "best" for managing disordered skin compromises the identities that a person can embody. The strategies Meghan learned for using make-up in the context of her acne involved developing a knowledge of the mechanics of make-up and applying the creative use of make-up protocols posted by members of online acne communities. These communities were comprised of people who lived with acne and had shared tips online in order to help others lessen the impact of disordered skin on their lives using cosmetics. Meghan says:

> the make-up look at the moment… if you have acne it just doesn't work… the make-up just doesn't sit on your face like it does if you've got clear skin. I can never do the like proper look 'cause… you have to have like really smooth skin for it to lie properly… so I do my make-up like differently, and I've got… a colour correction palette. So you put green on top on top of the red to mute a colour, so yeah… it takes longer and you have to do it differently, and you have to get like different products as well.

This strategy for lessening the visibility of acne using arduous make-up protocols highlights the knowledge and labour involved for people living with acne in concealing their skin to approach normative ideals for aesthetic appearance. Moreover, even with the cosmetic tools and resources she has assembled, Meghan acknowledges that the texture of her skin makes it impossible to achieve the "look" that is currently in fashion.

Grounded in Foucauldian notions around biopower and resistance, Rabinows's (1996) conceptualisation of "biosociality" enabled the development of understanding about the formation of collectives based on shared biological conditions. Moreover, authors such as Vassilev and colleagues (2011) have argued that virtual communities function in translating abstract knowledge into practical knowledge which can then reshape everyday practices. Drawing on these ideas, Meghan's extract illustrates how the sharing of cosmetic strategies online for concealing acne empowers a collective sense of resistance against the challenges presented by this illness and fosters possibilities for developing nuanced and creative practices of aesthetic expression. This finding resonates with Bradley's (2021) ideas around the relationship between these forms of online biosociality and the development of what she terms "biosolidarity", through which acts of advocacy can improve the public recognition of the needs of illness groups.

Jennifer is particularly bothered by the appearance of psoriasis on her face because of how visible the face is to others, as the skin on the face cannot be covered up as easily as other parts of the body using clothing. Drawing on a perspective that illustrates Cooley's "looking glass self" (1902/1983) she feels that if she saw someone whose psoriasis was visible, she would wonder what was causing their 'unsightly' disordered skin. On this basis, Jennifer would understand others reacting with shock in this way at her visibly disordered skin:

> And I think the face thing is the one that's most shocking. I really wish it didn't come on my face because I think, to look at me, I get that. I always put myself in other people's shoes and I would think, 'oh my god, what's wrong with that person?', like, 'what have they got?'. 'You know, it's really unsightly. Skin conditions haven't got great press, going back way back when. Like it gives you the impression that someone's ill, someone's poorly, someone's got a disease, someone's contagious. And having it on your face is the worst part of it because you can't cover up.

Jennifer believes that the ways that people react to the appearance of someone with a skin condition are in line with and stem from historical perceptions of disordered skin signifying infection or disease. Indeed, when her psoriasis is visible on her face, Jennifer herself perceives that she looks ill. 'I think, 'god I look poorly'. I look like there's something not quite right with me’, Jennifer says. Jennifer uses specialist make-up that she has found to be effective both in terms of producing aesthetic coverage and in being compatible with the sensitivity of her skin to exacerbation. She has found that she must take the textural qualities of her skin into account when she decides to use make-up to 'cover up' the psoriasis on her face. Jennifer has developed a strategy for the effective use of make-up that involves the pre-emptive preparation of the skin on her face with steroid cream. Jennifer explains that, ‘Now, I've got, I've bought a special make-up and I have um, like, I do that regime on my face with the steroids to make it as flat as possible so I can actually cover up’. This strategy was developed based on Jennifer’s embodied understanding of the effects of medication on the aesthetic qualities of her skin. Jennifer has found that the steroids help in this process in how they affect the texture of the skin, priming the skin by flattening its surface so that it becomes amenable to coverage with make-up. While Jennifer has developed a practice of timing her use of steroid cream medication to be able to use her specialist make-up effectively, so that now she ‘can actually cover up’, it is clear that this management of aesthetic presentation for the face is as Jennifer describes, a ‘regime’, and requires significant planning and knowledge to perform.

Leder’s (1990) concept of “social dys-appearance” acknowledges the increased vulnerability and alienation some bodies face through objectification produced by discrepancies of power. Leder recognises, for example, how historical and cultural power discrepancies associated with constructions of gender mean that the bodies of women do not disappear in the same ways as the bodies of men. “Social dys-appearance” can limit access to tacit embodiment for women (Leder, 1990, p. 99), who as a result of gendered expectations about beauty (N. Wolf, 1990) are faced with particular societal demands to give scrupulous attention to their external appearances.

While Matt has not tried using make-up extensively, he found that applying a “cover-up” stick of concealer was not effective for his skin during a flare-up. When his skin condition was exacerbated, his skin would become inflamed and ooze fluid which meant the concealer product would not adhere to the surface of the skin. However, through his illness treatment practices Matt developed a strategy for adding coverage to the skin that did not involve the use of make-up:

> To be honest I do have a cover-up stick, but I found that it does not really work that well. Because usually when I have a flare-up, the skin is inflamed and red and like, it's not dry, you know? So it's more oozing and a bit more wounds, so if you try to apply it then it will not stick. It won't work very well. But what I do is… when my nose is red or my temple is red I apply calamine lotion, which has two effects. First of all I apply it because it helps me deal with the itching again. It somehow calms down the skin, I've noticed, but it also leaves like a fine white chalky film that works a bit like a cover-up. But I've never used make-up or anything. I don't think it works so well for my skin condition.

Matt realised that the calamine lotion which he applied to his skin to help manage itching also has textural properties that, unlike the cover-up stick, allow it to adhere to his skin during a flare-up. He found that calamine lotion leaves a chalky film on the surface of his skin which, unexpectedly, helps to conceal his condition. While further demonstrating the perennial necessity that respondents felt to manage their aesthetic appearance, Matt’s inadvertent finding illustrates the creative possibilities that can emerge from the embodied experience of habitual practices in managing illness such as creating the dual-purpose of cosmetic enhancement to this everyday use of a cream intended to treat itching skin.

Barbara, who has nail psoriasis, runs her own practice as a solicitor. She spoke about the daily regime of treatment for her nail beds and the application of artificial nails as being ritualistic and an important element of preparing herself for work. ‘It's a necessity, as far as I'm concerned it's a necessity anyway’, Barbara says. Barbara’s use of false nails helps to minimise the aesthetic impact of psoriasis and consequently helps to manage the impact on her professional identity (Beatty, 2018). While the effort and time required to prepare her hands each day for work is substantial, she contrasts her own position with others who she feels may not be able to regain control over the aesthetic impact of their condition to the same extent, impacting their work identities and all facets of their lives. As Barbara says:

> I’m looking forward to the day when I don't have to do that but you know in the same breath I'm glad I'm able to find a solution because some people can't, you know if they got psoriasis on their body, or on their face, I'm lucky enough to be able to put nails on and hide it so that's how I look at it. I think I'm one of the lucky ones.

Given her ability to cover up her nail psoriasis, owing to the availability of artificial nails and the relatively small area affected, Barbara feels that she is fortunate in comparison to others whose condition affects their face or other larger areas of the body, despite the labour involved in her coverage regime. Like Barbara, many respondents spoke about the need they felt to conceal any visual signs of their skin disorder that might be noticed by others, particularly in public spaces. Concealing visual signs of their skin disorder meant covering up the appearance of disordered skin, but also involved concealing other material aspects of their conditions that might be perceivable by other people, such as flakes of skin that may have shed from psoriatic patches on to their clothes.

Temporo-Spatial Strategies

Another important finding in relation to the management of identities involved the use of temporo-spatial strategies for passing. Charmaz (2010) demonstrates that relationships with space, time and timing change with illness. These changes produce obstacles that require problem-solving if they are to be overcome. Such experiences are dislocating and fracture connections with people, places and spaces. As Charmaz (2010, p. 12) puts it, upon the development of illness, individuals ‘occupy a liminal space where earlier rules, routines and meanings do not apply. In this space of ambiguity, ‘they likely lack a language through which to understand and express their changed lives’ (Charmaz, 2010, p. 12).

Drawing on Bourdieu's (1977) notion of bodily hexis, which describes the embodiment of learned dispositions, parts of the body, such as hands and hair, could be used to cover the face from view, while turning the body away from other people or creating physical distance from others are also practices used to avoid close scrutiny, as noted also in work by Hawkesworth (2001).

Cover with Darkness

A strategy cited by a number of respondents involved the careful selection of environments for socialising which had lower levels of illumination. Dark or dimly lit venues were preferable as there was less of a likelihood that respondents’ disordered skin would be noticed by others. Strategies for passing often involved the negotiation of control over activities, over environments and over timing. That is to say, as well as considerations about who would be present for social encounters, strategies for managing impressions of identity took into account the material context of interactions, including what kinds of activities would be involved, where they might take place and when they would occur. These contextual elements of social interaction were framed by embodied knowledge about ways that skin disorders might impact impression management within an interaction.

As appearing in environments highly classified by aesthetic norms could be experienced as disabling, many acne sufferers in Hawkesworth's (2001) study used time-space tactics to avoid social events. Goffman's (1959) conceptualisation of the "backstage" is valuable for understanding the time-space tactics used by people whose skin is visibly disordered. Applying this concept to the experiences of people with acne, Hawkesworth (2001) identifies how "backstage" spaces represent 'safe terrain' where the visibility of acne is not a central concern. Backstage spaces were often those where there was an absence of light. Indeed, Hawkesworth (2001, p. 311) finds that many people with acne 'preferred working and socialising in literally dark spaces' while brightly lit places were experienced as problematic. In the "safety" of backstage spaces, individuals are less intensely aware of their appearance. As a consequence, in these backstage spaces, Hawkesworth (2001, p. 311) writes, 'they are not forced into the position of feeling self-conscious about their facial skin, nor are they disadvantaged by the norms and conventions of bodily presentation'.

By inhabiting settings shielded from an emphasis on the rules and values imposed on bodily presentation, there is less concern about the potential for the stigmatising remarks, bodily reactions or attitudes of others which reinforce the hegemony of normalcy around the body (N. Hansen & Philo, 2007) and through which a sense of social competence or acceptability may be undermined (Wendell, 1996). In accordance with the work of Hawkesworth (2001), there was a common preference among respondents for socialising in settings where lighting was less intense, as a dark atmosphere helped to conceal the visual appearance of their disorder from the people around them and lessen the likelihood of unwanted exposure. This proclivity to socialise in settings where there is less vivid light and more darkness meant that some respondents felt more comfortable socialising in the evening and at night-time than during daylight hours, while respondents sometimes took steps to manage the levels of light and create darkness in their environments, particularly for intimate encounters. This was, in turn, helpful for managing tendencies for habitual reflexivity about social appearance. It emerged that this was particularly important for respondents going out to meet people for romantic dates, especially in the early stages of relationships. As Melanie puts it, ‘darkness is my friend’. She speaks about how she used the dark conditions of a night club environment, a convivial atmosphere in which others had been drinking, as an opportunity to socialise in a space where she was able to feel the freedom to reveal areas of her body that in everyday life she felt a strong need to keep covered with clothing:

> MELANIE: I was somewhere really dark and I've done some preparation, like say I was going on a night out and the fashion was a boob tube so you know they’re the tops with no straps, I'd soak myself in moisturiser and I get in the bath and I just gently rub my skin so there was no scaling on the plaques and then when I got out I put moisturiser straight on, I put my boob tube on, my cardigan, and then when I was in the club and it was really dark I take my cardigan off and just pretend I had normal skin a while, cause people tended to be a bit drunk and it was quite dark and because there was no scaling some people might not notice the contrast differences. But then as soon as we went into like a bar area where the lights were on or we went outside like my cardigan would go straight back on again
>
> INTERVIEWER: So the idea of darkness… as being something that can be really helpful
>
> MELANIE: Oh yeah. Darkness is my friend [laughs].

Illustrating a clear temporo-spatial awareness in relation to her skin, Melanie’s moisturising regime for preparing the texture and appearance of her skin worked in concert with this dark environment to lessen the visual contrast between patches of psoriatic plaque and the surrounding areas of unaffected skin to an extent that Melanie felt her psoriasis could pass without being noticed. Until she and her friends left the club area for lighter surroundings and she put her cardigan back on, Melanie's use of darkness relieved to an extent her concerns about bodily presentation and enabled her to enjoy the embodied experience of dancing with her friends.

Deploying this strategy in other arenas, Melanie had continued to use the cover that darkness can enable in other settings where the exposure of her skin makes her feel uncomfortable. She spoke about how the diffuse illumination and 'flattering' atmosphere of candlelight is helpful during intimate moments with her husband as it allows her to maintain a sense of confidence when her body is exposed. Melanie says, 'even now, when it comes to like sex and things it's obviously a massive problem, like I have psoriasis everywhere and everyone looks better in candlelight anyway but it's just much more flattering. I just feel more confident'. Melanie talked about how her husband is emotionally supportive and gives no indication of being 'put off' by the appearance of psoriasis on her body during moments of intimacy, and indeed does not appear to notice her skin condition in daily life. She says:

> Like it makes no difference to my husband. He doesn't even notice. I showed him a picture. We were going through my photos on my phone the other day and there was one of me, and it's horrific, nearly my whole body is covered, he went "wow that's awful!" And I was like "you took that picture last year!" And he went, "did I?" He went "I just don't notice that about you". So he is really good like he said when he looks at me it's not what he sees.

However, it is when Melanie herself sees areas of her own body that are affected by severe psoriasis that intimacy is affected during sex:

> it's just me like during sex I'll look down and I'll see it and it'll put me off a little bit. So if it's quite dark it just makes me feel a bit better and I can stay in the moment in terms of like the sex life and all of the sensory parts of that kind of intimacy.

Despite the concerns that she experiences about her body, through the strategic use of candlelight and darkness Melanie is better able to remain embodied in these moments of intimacy.

In a similar vein, the dark atmosphere of a bar was found to be particularly helpful for one respondent in relieving some of the presentational concerns associated with dating, where there is a level of intimate interaction that adds further difficulty to avoiding the unwanted exposure of disordered skin. Christopher, who has experience of both acne and eczema, talked about his understanding and use of the inherent spatial and sensory qualities common to social environments like bars as places for romantic meetings. Further illustrating the strategic use of darkness in managing the appearance of disordered skin as noted by Hawkesworth (2001), Christopher's extract elaborates on how he used the cover of darkness as a way of avoiding the close scrutiny possible in brighter settings, without the person he was meeting being aware of the strategic nature of this choice. Christopher says:

> I did go dating quite a lot… the worst of the eczema was still there, but I still had traces of it still on my hands, and I think that did make me self-conscious of it before I was going on dates. Maybe wear sort of long-sleeve shirts…. I tend to go to darker places to meet girls. Gloomy bars…. I had a tendency to go to these places and I was certainly aware of my hands and maybe I would be less self-expressive, I would maybe keep my hands sort of to myself more.

Christopher used the combined effects of low light environments common in bar settings and clothing choices that provided greater coverage of disordered skin to avoid exposure during romantic dates. Christopher also monitored postural elements of his body such as the gesticulation of his hands while talking. Each of the reflexive bodily strategies that Christopher developed helped to assuage his appearance concerns. However, the consideration of how each element of interaction on a first date affected the likelihood of unwanted exposure highlights the need for acute reflexivity that Christopher experienced in relation to interpersonal presentation.

Avoiding Events Where Exposure is Likely

A notable strategy that respondents deployed to manage valued identities involved limiting the possibility of unwanted exposures of their illness to others by avoiding collective social events entirely. The likelihood that photographs would be taken at an event was often a factor that respondents took into account in their decisions about whether to attend social events.

Work by Valentine (1999) has shown that as part of an “imaginative spatiality”, people situate themselves in a material space that is constituted by an awareness of “self” and “other”. As Hawkesworth (2001) found, for people with acne, their spots can become a focal point for their sense of self, and in turn a source of concern for their imagined perception and social exclusion by others. The layout of spaces such as train carriages where seats are arranged for sitting face-to-face fuelled an “imagining” of perceptions by others that produced concerns for individuals which focused on their acne and desires to find ways of limiting the visibility of their spots.

Hawkesworth (2001) identified a range of “time-space tactics” that people with acne employed to manage their appearance concerns. These are tactics of escape, withdrawal and the avoidance of crossing geographical and social boundaries. They are used when individuals are faced with the risk of being reminded of their own appearance. They are also used when an identity associated with the image of their skin – an identity that is disfiguring or embarrassing – may be imposed. Acutely aware of the appearance of their skin, and with a belief that others may view them critically, participants in Hawkesworth’s (2001) study were found to delay or postpone meetings when their disordered skin was especially noticeable.

The movement across boundaries from social spaces where a person feels a sense of ease to spaces where there is a sense of discomfort can arouse feelings of self as outsider, as the border between self and other becomes exposed, suggests Sibley (1995). Moreover, the breach of temporal or spatial boundaries with the potential for harm can damage feelings of control and may disturb a sense of ontological security (Giddens, 1991). It has been argued that ontological security is important for the ongoing development and maintenance of self-identity and has been found to shape the practices of managing chronic illnesses (Lawton, 2003).

G. Laws (1994, p. 7) observes that ‘fear reflects an oppressive social structure to which people respond in a variety of ways’. Examining the impact of such fears in those living with a skin condition, Hawkesworth (2001, p. 312) found that deep concerns about the appearance of their facial acne, driven by the social denigration of acne in adulthood, led people to ‘disappear’ into the safety of their homes and other specific local contexts. For someone whose social experience has been spatially limited to the home and other safe places by their appearance concerns, practices of leaving the relative safety of home and stretching outwards through newly emerging spatialities may represent an increased sense of autonomy over their condition and a greater sense of being ‘psychically secure’ (Hawkesworth, 2001, p. 313) in their willingness to cross geographical boundaries.

Hawkesworth (2001) identifies difficulties that people with acne face in their attempts to plan public “front stage” appearances or work meetings for times they hope the presentation of their acne will be less severe. This is often complicated by an uncertainty about when their condition will be exacerbated. In agreement with Hawkesworth’s finding, many of the respondents in the present study found the prospect of going to places or doing activities that would expose their skin to the view of others to be frightening, despite the measures they often took to conceal their condition. Heather explains how there were many daily activities and places that she avoided through the fear of her acne being seen by others. ‘Everywhere, to be honest, used to be quite scary to go’, she says. Heather is reluctant even to leave her house to retrieve items from her car because of her concern that neighbours may see her if she is not wearing make-up to conceal her acne. As such, Heather has tried to avoid attending any event or activity where exposure is likely, which has limited her social participation and everyday practices in many ways. The concern she feels about her appearance means, for instance, that Heather avoids sunny days at the beach where her acne would be highlighted to others, even while wearing make-up. Indeed, sunny weather generally is a concern that disrupts her experience of everyday actions. Heather is uncomfortable when driving when the sun is shining, for example, because she feels the bright light makes her acne more visible to people in other cars. The possibility of her acne being exposed to the gaze of other people without make-up coverage is a profound concern for Heather. Sports and fitness activities present issues for Heather of make-up being either washed off or being lost from the skin through sweating:

> The gym. Swimming pools. I used to go to boxing, but obviously I wear make-up there and then you'd sweat and your make-up would come off…. Yeah, even like if all my friends are going camping, I would not go there. Because I would not want to wake up there in the morning, with new spots on my face.

The incompatibility of doing sports while maintaining make-up coverage meant that there were a number of physical activities that Heather had valued but felt uncomfortable to return to. As Heather explains, the fear of her acne being exposed without make-up coverage has meant that Heather has avoided camping trips even with her friends.

Moreover, Heather’s experiences of relationships have been profoundly affected by her skin condition since it first presented as a child. While she has developed strategies to manage the impact of her acne, these strategies also appear to limit the development and maintenance of intimate social relationships. Heather says: ‘I used to sneak out of boyfriends' houses at four o'clock in the morning just so I didn't have to wake up next to them in the light’. Such was her feeling of unease, the steps that Heather would take to avoid her acne being exposed even included ending relationships through arguments that Heather says she purposefully created during acne outbreaks.

Theo created reasons to turn down invitations from friends because he felt was ‘not presentable enough to go out’, despite wanting to spend time with his friends. Speaking about the need he felt to avoid socialising, despite his desire, Theo says:

> I shouldn't have necessarily felt that you know I was not accepted, it was not the case. I think I was putting those limits myself like my friends called me and I'm like yeah I'm not feeling well I'm not going to come out tonight. The real reason was I probably wanted very much to come out but I didn't feel like it, I was thinking oh I'm not presentable enough to go out and I would just stay home.

Theo’s experience illustrates how a need to avoid exposure emerged from his fears about being stigmatised on the basis of his disordered skin and his reflexive desire to present himself in ways that he found socially acceptable. However, these habitual concerns to avoid exposure of his acne meant that Theo felt the necessity to impose such limitations on his social experiences.

While Helen speaks about the visual appearance of her exacerbated skin condition being a primary reason for deciding not to attend social events, a particular focus for her discomfort is appearing in photographs taken at these events. Helen speaks about how she avoided attending a wedding, an event where photographs are very likely to be taken.

> I've not been to events 'cause my skin is bad. I've not been to, I mean it has been a while, but I have not been to somebody's wedding because I couldn't bring myself to go. Complete vanity. I just didn't look very nice and I was covered in it, and I just

> thought I don't wanna go…. something that I regret not going to. It was a damn fine wedding apparently, but…. I just felt too uncomfortable, I felt, I don't want to look like that in the photographs. I don't wanna, you know, it's that kind of last thing, 'cause you know that they'll be taking pictures.

Helen's feeling that she simply "couldn't bring myself to go" further illustrates a reflexively ingrained necessity for enacting strategies that help to maintain a valued self-image and resist unfavourable appraisals which may be further challenged by such photographs.

In a similar manner, Matt does not want to be photographed when he has a flare-up of his dermatitis. A particular focus for Matt in avoiding being photographed during an exacerbation is that seeing these pictures later on will present an unwelcome reminder of his disordered skin. Matt says:

> it does not look ok, you know, once you're really red…. You don't want to take a picture…. To be honest, I don't care so much about other people. I care about my own face. When I see myself and I feel "eugghh, that looks horrible"…. I don't care too much what others think about me. In that sense, I'm more concerned about myself…. I don't like having pictures taken, you know, for example, a photo or something like that when I have a massive flare-up, then I will not want my picture taken. I want to forget about that.

Matt's emphasis that it is his own perception of his appearance that concerns him rather than how he appears to others suggests that he experiences a sense of felt stigma about his skin condition rather than stigma being enacted by others. Capturing an image of his disordered skin at a social event produces a record of Matt's illness, reifying an unwelcome, stigmatised identity. To avoid this reification, Matt avoids having his picture taken.

Reflexive Bodily Positioning

Several respondents had developed habits for positioning their bodies in ways that made their disordered skin less visible to others in their immediate environment. Respondents spoke about how they would hold the position of their body in ways that they felt would make their skin condition less apparent to other people, illustrating Bourdieu's (1977) notion of bodily hexis, which describes ways in which bodily dispositions become integrated into habitual action. The conscious positioning of the body often focused on areas of skin that were not commonly concealed with clothing and in particular social contexts. These were often contexts where interactions happened with another person at close distances. The hands were frequently mentioned as areas of the body that respondents were careful to position and to use in ways that could help to minimise attention from others.

Using public transport in London, Theo is concerned with avoiding disclosure of his nail psoriasis to passengers nearby. Theo talks about trying to conceal his nails from the view of others through the positioning of his hands while in public, because of the importance he feels his appearance holds to his perception by others. Theo says:

> but it's essentially my nails. And when I'm taking the Tube and taking the DLR…Then I'm trying to somehow to put my hands may be in a certain position so that people will not see my nails or things like that so I think I'm very aware of that and I don't want people to think that you know my nails don't look nice or what are people going to think about my look… I guess for me it is something important to the way people perceive me….I might put my hands in such a position that it's not going to be straight in someone's face or you know things like that, or at work, or I see myself trying to somehow hide you know one of those bad nails with the other fingers, things like that. I'm very conscious that I've got that and again I'm very concerned about my presentation, how presentable I am, so you know every day I'm

> thinking about this and every day I'm trying to- sort of trying to hide or if I'm at, you know, having a beer with my friends or with my coworkers I know that drinking and very very clearly they will see my nails, but that’s it. I don't see a way to drink my beer without holding the glass [laughs while speaking]….

Reinforcing experiences common to many respondents however, despite the visibility he perceives of his skin, Theo has not experienced stigmatising reactions from others in work or leisure settings. ‘And it’s kind of annoying me’, he says, ‘but no one really tells you “Oh your hands look weird!” or “What do you have?” People don't tell you that’, he says.

Similarly, Brooke says she is hyper-aware of her hands. There are numerous practices of bodily positioning that Brooke uses to avoid unwanted disclosure of the appearance of disordered skin on her hands. Speaking about her considerations of bodily positioning, Brooke notes:

> Depending on what stage it's in and how bad it looks, like now I wouldn't try and hide it, 'cause it's barely visible even to me and I'm well aware that it's there. But when it's red and really, really bad, yeah absolutely, I'll keep my hands balled up or try and keep my hands in my pockets as much as I can running after a toddler. I'm definitely hyper-aware of my hands and trying not to put 'em up towards, you know, use my hands to talk or draw attention to 'em. Looking at 'em though, it's frustration.

Brooke reflects that the use of these tactics of positioning is dependent on what “stage” her condition is in and consequently on how disordered her skin appears. That is, when she feels that her skin is less visually disordered Brooke is able to relax some of these elements of reflexive body positioning, yet it is clear that the habitual self-monitoring of her appearance continues.

Disclosure

While strategies for passing without illness are commonly deployed, the management of identity also often involved the disclosure of illness. It is through disclosure that accommodations can be made to support a person in living with their illness. Charmaz (2010) illustrates how people disclose their condition at work, for example, so that accommodations can be made. Charmaz noted that remaining in employment can be an 'identity anchor' that enables stability and continuity. Disclosure was used by respondents in several related ways. By revealing illness, disclosure makes the practical accommodation of illness possible where employing strategies for passing would not be feasible. Self-disclosure may be necessary for managing treatment regimens that would be difficult to conceal (Charmaz, 2010; Munir et al., 2005). Self-disclosure makes it possible for employers to be able to provide tangible support that helps with practical self-management. Adjustments can be made, for example, to working hours, the pace of work, workload, or the physical working environment.

Disclosure for Practical Accommodation

The pressures of a heavy workload contributed to Barbara's illness. As a way of managing this workload, Barbara took on further employees within her solicitor's office to help maintain the practice. Barbara is open with her colleagues her about her nail psoriasis and about the importance of practices she uses for managing the aesthetic impact of her condition. Speaking about the support she feels from colleagues to whom she has disclosed her condition, Barbara says:

> I've taken more people on to work for me, you know, and they are very supportive, and they don't really, you know they know about my nails but they've only ever seen it when things are getting better and you know I come in sometimes and I've just put my nails on but not painted them and I'll say I've just got to paint these nails before I see my clients. And they are great about it, you know, they are very supportive.

As a result of her openness in disclosing her psoriasis to her colleagues, and their positive responses to her disclosures, Barbara feels a level of added support from within the work environment in managing her illness. Dynamics of power and discourse in the workplace have consequences for the person managing their illness. Charmaz (2010) identifies how disclosure at work often depends on the type of illness, the culture and tradition of a workplace, the social values and norms in operation, hierarchy and workplace policies. A person's respective situation is also key, including their status at work, the amount of support available to them, and their work opportunities. A strategy of disclosure may be related to self-efficacy and outcome expectations with managing their illness. That is, how confident a person is in their ability to be able to manage their illness and the outcomes that they expect from their self-management actions (Munir et al., 2005). While Barbara's position of power as the employer in her working environment might moderate the likelihood of responses of stigmatisation, the ingrained importance of aesthetic presentation as a solicitor means that the support of her colleagues in undertaking this aesthetic labour is important for her professional identity.

Although she did not often make requests for accommodation for her illness at the school where she taught, Melanie did ask her managers for freedom over clothing choices in order to help manage her psoriasis while teaching, as Melanie found that many items of more tailored clothing that were the norm for other teachers to wear exacerbated her condition. Melanie was concerned that the looser, less formal clothing she wished to wear might not be considered appropriate for a teacher to wear, as her perception was that this was 'not very teachery, I looked a bit like a student', and that her footwear choices might fall foul of safety regulations for teaching in a science laboratory. However, Melanie found that raising the issue openly with her managers was met with support through accommodation:

> I rarely asked for support. The only things that I asked for them was freedom to wear what I needed to wear so sometimes I would wear things that were not conventional for a teacher, so I might wear leggings because the waistband on my trousers is just causing too much friction on my stomach or wear like really loose, baggy tops. You know, it's not very teachery, I looked a little bit like a student, but they were happy for me to basically wear what I wanted to wear. And then at one point I couldn't wear shoes, so I was in flip flops. And I taught science, so that's technically against health regulations [laughs while speaking] I'm pretty sure, but they let me wear flip-flops.

Melanie suggests that the clear visual exacerbation of the skin on her feet meant that school management could not fail to understand her need for freedom over footwear choices. Indeed, Melanie was met with reactions of shock at work at the condition of the skin on her feet, with some people seeming ‘a bit afraid when you start showing them skin’. Speaking about this reaction, Melanie says:

> Well they could see it, that's the benefit of psoriasis in terms of that. like I'm wearing flip-flops and I'd point to my feet and then they'd go oh my goodness that's fine! That's absolutely fine! You know like it's not like it was a hidden thing and they could doubt what I was talking about. You could see my feet were like insane, they were like bright red you know, shiny, they looked like very unhappy feet! I think people are just a little bit afraid when you start showing them skin, like no! That’s enough! Do what you want! [laughs while speaking].

The visual appearance of severely exacerbated skin on Melanie’s feet confirmed to her managers in uncertain, material terms her need for some freedom over clothing choices while teaching at school. This visual demonstration of the disorder removed the potential for ambiguity about the seriousness of the disorder, while her request for autonomy over her clothing at work made known how these modifications to her working conditions would allow Melanie to continue teaching. Working in an environment where her employers were amenable to these accommodations meant Melanie was enabled to maintain some control over her working identity despite the challenges presented by her illness.

Disclosure to Control Discourse

The negotiation of control over disordered skin at work was often attempted through acts aimed at managing discourse. One such tactic was in the pre-emptive disclosure of a skin disorder as a way of shaping discourse about the nature of a skin disorder to avoid the potential for unwanted appraisals later on.

Brooke, who has dyshidrotic eczema and works at a day-care centre for children, talks about how she provides some information about her skin condition to parents pre-emptively as a way to allay a number of potential concerns they may have. The concerns she anticipates are based on the appearance of her skin and her practice of wearing gloves while cleaning the toys that the children play with. First, she informs parents about her skin disorder to assure them that the condition is not contagious. Second, speaking with parents about her condition allows Brooke to explain that the reason she wears gloves while using cleaning products on the toys is not because ‘harsh chemicals’ are being used but because of the increased sensitivity to such products that she experiences with dyshidrotic eczema. Brooke says,

> People don't kind of say anything on their own, you know, if we get into a conversation about it. Because I get self-conscious of it when it's really bad, and my fingers are all red and nasty looking, and I'm working with people's kids, you know? Who knows what they think? So I draw attention to it before they can, even though they probably wouldn't notice, just so that I can be like "hey! It's not like a contagious thing”. It's, you know, I would just mention, you know, I've got this condition, but I'm using gloves to clean the toys with. It's not that we're using harsh chemicals. We use a

> really gentle chemical on them. But I can't touch it. So I bring it up before somebody else can.

By speaking to parents at the day-care centre where she works about her skin condition, Brooke hopes to limit the development of discourse based on misperceptions about her illness, and in so doing, gain control over her identity and avoid stigmatisation. Employees choose to disclose information about their illness at work in exchange for workplace relationships and job security (J. A. Butler & Modaff, 2016). Safety concerns can arise at work. Questions about whether a person doing their job might present a risk to the health of colleagues or clients might represent reasoned concerns but might also represent discriminatory discourses (Charmaz, 2010).

Preparing for Disclosure With Contingent Evidence of Illness

A few respondents talked about the importance of documenting their skin disorder with photographs. These pictures would provide evidence about the impact of their illness that could be used in discussions about accommodation needs with employers and institutional administration, such as occupational health departments at work. Sandra says, ‘I did manage to get some photographs so where I was in a lot of pain I could say well this is the reason why, because I can't show them it’. Charmaz (2010) notes that disclosure involves risks of being misinterpreted and People who disclose may not be believed. Taking photographs of the skin at home enables a level of control to be able to document any visual signs of illness discreetly in private to be used for accommodation in the public setting of Sandra’s work environment.

Moreover, documenting the visual appearance of a skin disorder may be helpful as a way of providing evidence about the experience of illness which due to the often-changeable presentation of disordered skin may not always be visually apparent. The experience of pain and discomfort of a skin disorder, for example, might not relate directly to the appearance of exacerbation, yet may produce illness management needs that require accommodation for a person to be able to do their job. A visual representation of illness, documented with photographs, may be useful for helping another person to understand the extent and meaning of illness in a way that a clinical diagnosis or verbal description might not be able to evoke.

Conclusion

This chapter has sought to respond to calls to acknowledge the importance of embodied and socio-spatial experiences of chronic illness and disability (R. Butler & Bowlby, 1997; C. Thomas, 2004). Adapting the concept of “aesthetic capital” (T. L. Anderson et al., 2010) for application in medical sociology and chronic skin conditions, it was shown that concerns about the presentation of the skin were common among respondents. These concerns were often driven by the ways that a skin disorder can affect aesthetic appearance, producing stigmatisable markers of an undesired illness identity. Respondents recalled incidents of stigmatisation being enacted and reifying concerns about their aesthetic presentation. However, it emerged that incidents of enacted stigma were often rare in adult experience. Rather, the majority of experiences of stigmatisation were “felt” in the absence of being enacted, emerging instead from ingrained concerns about body image and identity based on a range of past experiences, norms and discourses about appearance ideals.

Respondents’ experiences of felt stigma relating to their bodily presentation often reflected a sense of ambivalence about appearance norms, but also highlighted the intractability of these feelings. While aesthetic concerns were often derived from stigma concerns relating to such appearances of illness, they were also about the ways that disordered skin reduced the possibilities for aesthetic distinction, challenging desires for freedom and choice about personal aesthetic style and the embodiment of valued identities through appearance.

Concerns about presentation also related to how disordered skin affected a sense of embodied capabilities. The work of Hawkesworth (2001, p. 316) emphasises the importance of considering the spatiality of the body in public policy and practice, and to acknowledge the impact of the ‘(re)construction of disabling spatialities’ on the embodied experiences of people living with disordered skin. Respondents were shown to have concerns about how their skin conditions affected their abilities to embody roles and identities, particularly in employment. These concerns often revolved around how illness needs could be managed around the demands of work schedules and practices, and how the bodily presentation difficulties associated with disordered skin could be negotiated around expectations about aesthetic norms and conventions.

Social networks and the relationships which comprise them were found to be a source of support for people living with disordered skin. For many respondents, social networks offered welcome emotional support. It was also common for respondents to seek access to networks that offered sources of relevant knowledge about their skin condition. Access to these and other resources, such as social and economic capital, enabled some respondents in the management of their illness needs and in fostering valued identities, but social circumstances that made such access possible varied substantially.

The issue of social support was found to be complex. The support that any network offers is limited in its scope, and while the support offered in particular networks was often understood to be well-intentioned it was not always welcomed. Support in the form of advice based on limited knowledge about living with disordered skin, for example, was not found to be helpful, particularly for people who had long-term experience of managing chronically disordered skin. Issues of timing and the state of disorder influenced perspectives on the value of support, where the support that was considered welcome, and the forms of support which were sought out, sometimes varied based on the particular stages of illness trajectory or phases of skin condition exacerbation.

While intimate networks of family and friends were often key sources of support, it emerged that the illness management needs of disordered skin sometimes added strain to relationships amid the complicated demands of everyday life. Family and friendship networks did not always offer appropriate support, and in some cases interactions within these networks undermined valued identities or imposed identities that were unwelcome.

Engaging with networks of people who have shared experiences of the same skin disorder were often found to be particularly helpful. While a number of respondents had experience of attending support groups in person, most of those who engaged with such networks did so online. These networks were found to be useful in a variety of ways. They provided access to collective knowledge about treatment options and management strategies. Networks also offered opportunities to interact with others who could relate to the difficulties and concerns presented by their shared illness and whose empathy and advice was based on personal experience not available from other networks in respondents' social worlds. Moreover, those who engaged with networks of shared illness valued the sense of camaraderie they experienced with other members and the opportunities to contribute their own experiences within a community of support, helping others and themselves in negotiating experiences which often brought feelings of isolation.

Findings: Experiences of Living

The focus of this findings chapter is exploring bodily and material aspects of living with a chronic skin condition, addressing the ways in which the sensory and material aspects of disordered skin affected experiences of embodiment and how respondents managed these experiences. A primary aim is to explore the bodily and material implications of living with disordered skin for everyday life. This will involve an examination of sensory experiences of the body related to illness, as well as how disordered skin impacts mundane aspects of daily life that often go overlooked. Within the literature on chronic illness, work on a variety of long-term illness experiences, including chronic pain (Richardson, 2005) and Ménière's disease (Bell et al., 2017), has recognised the salience for experiences of negotiating the "mundane" as well as the meaningful aspects of embodiment in everyday life. Applying ideas related to embodiment, this chapter will address how skin disorders affect bodily and material realities for those who are affected. Given this primary aim, this chapter aims to answer the question, how does a chronic skin condition affect everyday experiences of embodiment?

Much work in sociology has demonstrated that the body is central to identity (Featherstone, 1982, 2010; Goffman, 1959, 1963; B. S. Turner, 2008). Human beings are "embodied" social agents (Nettleton & Watson, 1998). On this basis, changes in the body that emerge with illness can have a substantial impact on identity and experiences of daily life. There have long been calls to acknowledge the importance of embodied and socio-spatial experiences of chronic illness and disability (R. Butler & Bowlby, 1997; C. Thomas, 2004). It has been suggested that managing the physical problems that are generated in chronic illness is 'at the very epicentre of the coping experience and from which other social coping processes flow' (Kelly & Field, 1996). Given the central role of aversive bodily experiences related to their disordered skin in respondents' accounts of illness, findings in this chapter will draw on Leder's (1990) work on "dys-appearance" and the "absent" body, using the notion of "corporeal dys-appearance" as a framing concept. Leder's conceptualisation highlights the tendency of the body to be "absent" from awareness for much of the time, before particular physiological and social experiences of suffering, as often occur in contexts of illness, bring the body into explicit and uncomfortable awareness, or using Leder's term, "dys-appearance".

Leading on from the primary aim of examining how disordered skin affects everyday experiences of embodiment, a second aim of this findings chapter is to explore responses to the impact of corporeal dys-appearance on everyday life practices. Given this additional aim, this chapter seeks to answer the question, how do people respond to the bodily and material implications of their disordered skin? Practices and dispositions produced in response to corporeal dys-appearance will be examined, and consideration will be given to the impact of these responses for managing the body aspects of illness on lived experience.

Leder's (1990) notion of "corporeal", or "organic", "dys-appearance", which forcibly orients a person's focus towards a body that is perceived as an obstacle to goals and activities, has been illustrated by a number of studies within medical sociology. Contractions of bodily experience in which the disordered body becomes the focus of conscious attention during illness have been demonstrated. Corporeal dys-appearance is a sensation that emerges when bodily know-how, which normally operates pre-reflectively, becomes disrupted and disordered. Dys-appearance cuts through the predictability of bodily experience, problematically foregrounding the body in consciousness (Becker, 1997; Bell et al., 2017; Zeiler, 2010). The bodily presence that emerges through illness is typically characterised by experiences of objectification and alienation, as well as uncanniness (Svenaeus, 2000a, 2000b; Toombs, 1987). Dys-appearance is a process in which 'some body-part emerges as a foreign thing' and so becomes 'other' to the self (Leder, 1990, p. 77). Schmitz et al. (2011) refer to situations in which the body draws full attention and takes control as "corporeal contraction”. Applying this concept to experiences of chronic illness, van der Meide and colleagues (2018, p. 2246) noted corporeal contraction when people with MS endured ‘erratic and intense body situations’ and felt a ‘marked narrowing of the body’.

Dys-appearance can be disruptive to the intentions of the individual (Leder, 1990). Experiences of alienation from the body in illness have often been noted, aiding an understanding of how bodies can become unreliable and disruptive to personal intentions for people living with chronic illness. Drawing on Leder’s (1990) conceptualisation, G. Gibson and Kierans’ (2017) study explored how Parkinson’s disease disrupts a taken-for-granted or “absent” embodiment for men affected by this condition. For people whose bodies frequently dys-appear into consciousness, hopes can focus on ideas of bodily “normalcy” based on a more ‘volitional experience of embodiment’ (Gimlin, 2006, p. 711). In Gimlin’s (2006, p. 706) study of why women elected to have cosmetic surgery, it was found that physical “flaws” regularly ‘encroached’ upon individuals’ thoughts in ways that blocked out other interests, involvements and concerns. It was shown that pre-surgical bodies had emerged problematically into awareness. This thematisation of the body, which it was argued was caused by an alienating and objectifying social gaze, produced what Gimlin identified as a distancing between self and body.

A small number of studies have addressed aspects relevant to the concept of corporeal dys-appearance in the experiences of people with skin disorders. These studies have drawn attention to the overwhelming nature of bodily sensations experienced with chronic skin conditions and the fluctuations of experience over time. Experiences of eczema and psoriasis are often characterised by sensations of itchiness (Globe et al., 2009) which can be overwhelming and call upon affected individuals to resolve these aggravating sensations of the skin by any possible means (Nørreslet et al., 2010). In addition to “spatio-functional” aspects of these bodily experiences in which there is an uncomfortable thematisation of a bodily structure, (Leder, 1990) identifies "temporal" aspects of corporeal dys-appearance, which are losses of continuity over time in the structural stability of the body. A fluctuation of bodily experiences over time have been demonstrated in studies of eczema (Mollerup et al, 2013) and psoriasis (Watson & de Bruin, 2006). Such is the shift in bodily sensations from periods of exacerbation to periods of time when a person feels free from the symptoms of psoriasis, the experience has been likened to being released from prison (Wahl et al., 2002). While these studies have drawn attention to the bodily experiences of living with disordered skin, it is hoped that the conceptual focus around dys-appearance across mundane aspects of daily life that is developed in this chapter can add depth to understandings of these experiences.

A range of literature within medical sociology has addressed how people respond to and manage experiences of corporeal dys-appearance related to different types of chronic illness. A number of studies have focused on the sense of a need for perennial self-monitoring that people develop through their understanding of how their illness impacts everyday life. Van der Meide et al. (2018) found that people living with multiple sclerosis were nearly always in a mode of permanent bodily alertness. They termed this mode of unremitting focus on one's material body as "the mindful body". The mindful body signals a recognition of bodily limitations which may, it is suggested by van der Meide et al (2018), enable a person to live as well as possible with their chronic illness. Illustrating the anticipatory dispositions developed by those living with long-term illness, Boyle (2019) found that people who have chronic anxiety developed a "managed involvement" to practices in everyday life. Such an approach has been shown to offer a sense of control over spatial and temporal aspects of illness. The realities of timing, space and speed to undertake tasks with bodies in disability or illness which do not conform to social norms often require strategic planning for the negotiation of everyday life. "Bodily uncertainty" emerges through illness as the body may no longer function as is has in the past, which affects the sense of trust a person can place in their body. Living with an unpredictable body encourages planning in daily life as actions are determined and often limited by the body. This mediation of action by the body can result in the loss of spontaneity as the ‘immediacy between body and self is shattered by constraint’ (van der Meide et al., 2018, p. 2243). The exhaustion caused by a need for constant attendance to the body (Frank, 1995) through self-monitoring adds to the “invisible work” (Smith, 2003) of managing chronic illness, which combines practical, emotional and social elements (Bell et al., 2017). Moreover, anticipatory approaches reflect widespread discourses of risk related to health which, Lupton (1995) argues, continually inspire anxiety about the potential for illness.

The planning and establishment of practices for managing bodily needs as well as material and social environments with illness in mind have been identified in studies across different illness conditions. As part of managing chronic illness, objects and materials associated with healthcare environments are often brought into and combined with the home, which can alter its ambience and render the home a contested space (Angus et al., 2005). Practices are inherently interwoven with “things” (Shove et al., 2012), whether they are objects, fleshy bodies or atmospheric environments. Materials can be recruited to aid the performance of practices for managing illness (Bell et al., 2017). However, the material organisation of everyday life can also create barriers to the performance of social practices, particularly as public settings designed for supporting ‘healthy’ bodies may not be supportive of the socio-material needs of those whose are ill (P. Freund, 2001). Drawing on both “body as project” and “absent body” perspectives, Gimlin’s (2006, p. 712) work shows that ‘it is possible to recognise that the body is central to identity in high modernity while simultaneously accepting both that individuals sometimes experience the body as intrusive and limiting and that they take various steps to alleviate such experiences. Indeed, experiences of the body springing into focus through “dys-appearance” can provide motivation to take actions required to shift the body out of our immediate consciousness (Gimlin, 2006).

People living with chronic illness have been shown to find benefit in nurturing “personal havens” through activities and places that bring a sense of wellbeing and being at peace with oneself (Lundman & Jansson, 2007; Ziegert et al., 2009). Practices such as sewing, painting and gardening (Bell et al., 2017) that create such havens have been shown to offer a sense of relief from bodily difficulties. While any therapeutic value derived from such practices should not be assumed, these social practices have been found to allow the bodies people living with chronic illness to momentary “dis-appear” through being returned to the background of consciousness, removed from the foreground “dys-appearance” of aversive illness experiences (Groven et al., 2013). By contrast with experiential “contraction” noted with corporeal dys-appearance, Schmitz et al. (2011, p. 245) use the term “corporeal expansion” to refer to ‘a marked widening of the felt space in the region of one’s body, most notably occurring in a state of relaxation’. In certain situations, as (van der Meide et al., 2018) found in their study of multiple sclerosis experiences, people with illness may feel a sense of wellbeing through their body, which it is argued represents a reintegration of body image and body schema often separated through illness.

The body of literature that has addressed how people manage experiences resonant with the concept of corporeal dys-appearance in chronic skin conditions is limited, however, there are a number of insights that offer scope for development as part of this study. The physical and mental labour dedicated to managing disordered skin and avoiding further exacerbation emerges in the literature as being prominent to everyday illness experiences. Practices of picking, scratching or squeezing, as well as mental acts of analysing corporeal manifestations of disordered skin, have been identified as components of “grooming” the skin, a type of “skin work” which Lafrance and Carey (2018) identified among people living with acne. People whose disordered skin become exacerbated through contact with particular irritants may take protective measures, such as wearing gloves, to be able to undertake tasks that might otherwise cause irritation (Mollerup et al, 2013). The use of strategies for altering practices to minimise the “damage” caused to the skin through scratching, including “habit reversal”, has been shown to be valuable as a management tool for people with conditions such as eczema (Daunton et al., 2015; Norén, 1995; Norén et al., 2018; Norén & Melin, 1989).

Moral components of the illness experience, driven by feelings of shame or guilt about bodily practices and bodily emanations of disordered skin emerged as another important element in the management of a skin disorder touched on by previous studies but which could certainly be further developed. The aftermath of acts of grooming the skin has been associated with feelings of guilt and shame at the potential for “damaging” or further exacerbating acne (Murray & Rhodes, 2005). For those living with psoriasis, it has been found that the sloughing of skin flakes into living areas often produces the need for a daily cleaning regimen to clear up scales from carpets and furniture . Bodily emanations and substances produced by disordered skin that emerge or are sloughed from the body, such as the characteristic flaking of scales in psoriasis, have been framed by sufferers as a type of “dirtiness” that (Jobling, 2000) suggests can be related to the loss of “good order” framed in moral terms.

Experiences of corporeal dys-appearance and other issues of embodiment that emerged in respondents’ accounts will be outlined in this chapter. It is hoped that a framing that focuses on bodily and material elements will enable a detailed overview of embodied experiences of life commonly faced by those with chronic skin conditions, as well as the practices and dispositions respondents used as part of managing their embodiment. Given the relative paucity of studies pursuing understandings of embodied experiences of these forms of illness, there is clear scope for work in this area. The chapter will begin with a section defining and detailing findings that illustrate “corporeal dys-appearance”. This will be followed by findings centred on the notion of “grooming” the skin through self-contact, often in response to corporeal dys-appearance, and its implications for embodiment. Sleep was found to be a process of particular concern for respondents. As illustrated in the third section, corporeal dys-appearance often emerged as being important in understanding how disordered skin affected experiences of sleep as well as wakeful life. The material implications of corporeal dys-appearance, such as the bodily emanations of flakes of skin, blood or tissue fluids, often demanded attention and labour. The next section focuses on findings illustrating the need for practices of “containing” the messy material byproducts of corporeal dys-appearance. The final section addresses how respondents demonstrated dispositions and used practices that were often “anticipatory” in order to manage or, where possible, avoid experiences of corporeal dys-appearance.

Corporeal Dys-Appearance

The sensations and processes of bodily disorder play a central role in how people experience and respond to illness. However, the impact of these corporeal experiences and the material considerations and actions which they engender are often overlooked. In order to better understand the embodied experiences of those living with chronic skin conditions there is a need to address how those affected interpret the bodily sensations of disordered skin and the ways that they respond in managing illness. Drawing on phenomenological concepts inspired by the work of (Leder, 1990), this section seeks to explore the embodied reality of living with disordered skin as a form of corporeal “dys-appearance” which produces experiences that can be overwhelming, aversive and disruptive to everyday life. These bodily experiences of disordered skin will also be considered in temporal terms, where the implications of the fluctuating and patterned chronicity of illness common to the lives of many respondents is explored.

Corporeal Dys-Appearance as Alien Presence

A central part of the lived experience of disordered skin was often the bodily sensations and emanations that emerged in the course of their illness. The relationships that respondents had to these bodily symbols of illness demonstrated what Drew Leder (1990) calls “corporeal dys-appearance”. Leder shows how the perceptual organs, including the skin, open the body out on to the world and away from itself. Leder uses the term “ecstasis”, meaning “to stand out”, to explain the default state of the body. As Leder (1990, pp. 21-22) puts it, ‘the very nature of the body is to project outward from its place of standing’. This nature is paradoxical, in that while the body opens out on to the world for sensation, under most circumstances we do not perceive the body itself. Rather, the body is “absent” in its presence. Leder (1990, p. 14) explains that in perceiving through a sensory organ, this organ ‘necessarily recedes from the perceptual field it discloses’.

However, when a person is ill, the parts and processes of the body emerge from this absence. As Leder (1990, p. 84) elucidates, ‘in contrast to the “disappearances” that characterise ordinary functioning, I will term this the principle of dys-appearance. That is, the body appears as a thematic focus, but precisely as in a dys state’. In this usage, “dys” signifies that which is bad, ill or moving away from what is considered normal. As sensations and appearances deviate from those expected from a body that fits with norms of health, the source of this discomfort becomes the focus of attention. For many of the respondents in this study, the “thematisation” of the skin in the development of a disorder represented a shift of experience of this organ from absence to overwhelming and unavoidable presence. Before the development of illness, while always objectively *there*, for the majority of previous lived experience the skin had seemed to exist without ever explicitly making itself known. Healthy skin was neutral – *inert* – or at least did nothing to draw the attention. In the development of disorder, skin was now characterised by a feeling that was quite different to the inert and recessive qualities previously exhibited and thus at odds with personal expectation. In making itself apparent through its dysfunction, the skin "dys-appears". This dys-appearance of the body is experienced in ways that are 'aversive, involuntary, and disruptive' (Leder, 1990, p. 75). Spatio-functional aspects of corporeal dys-appearance occur when "prethematic linkages" in the body come apart. Parts of the body separate themselves from other parts through an awareness of their function. The skin 'manifests an independent pattern', signalling an opposition within the body. The spatio-functional elements of dys-appearance were particularly evident when the emanation of itch, pain and discomfort drew intense focus to the skin.

On the onset of dys-appearance, the sensory demands of the skin were often found to become overwhelming. Many respondents, especially those with eczema, and some who had psoriasis, commonly focused on a heightening or prolonging of sensations of itch far beyond anything they had experienced before the development of illness. Bodily experiences of the itch were framed as being far outside the everyday scope of the sensory field. As Helen puts it, 'I say to people, take a mosquito bite and times it by a million and you might be close to an eczema itch'. Reflective of the inordinate intensity of the experience of what she terms the 'eczema itch', Helen describes the magnifying frame of reference that she resorts to when speaking about eczema to others who have not experienced it. Through this hyperbolic metaphorical framing, the sensation of itch that accompanies eczema is presented as being inconceivable to those who do not have disordered skin.

The bodily experience of disordered skin was commonly framed as an "alien presence" by respondents. This framing emerged through descriptions of how skin disorders felt like they emerged as entities separate from self. Where the skin had for many demonstrated periods of largely silent accordance with the holistic experience of an embodied reality, in the development or exacerbation of a skin disorder there was now a sense of alienation between the bodily environment and the self. Erica says:

> you're not overly conscious of your skin when you're well. You know, it's just part of you. It's just- You know. But when it's flaring up and attacking you, you do start to disassociate it from who you are, in a weird sort of way. Because it feels like it is attacking you.

Erica differentiates a state of being “well” from a state in which her eczema is exacerbated using terms of a change in the relationship she has with her skin. This illustration of a “dissociation” from the body produced by exacerbation reflects S. J. Williams' (1996, p. 27) perspective on experiences of the painful body, which ‘emerges as “thing-like”; it betrays us and we may feel alienated and estranged from it as a consequence’. The sensory emergence of Erica’s skin in exacerbation results in an estrangement between her subjective self and the object of flaring eczema.

Leder (1990) argues that dys-appearance is accompanied by a twofold ‘telic demand’ that the person must both interpret and repair what is wrong with their body. Through ongoing attempts at “interpretation” and “repair”, the body ‘emerges as a foreign thing’, becoming further objectified and alienated from the self (Leder, 1990, pp. 75–76). Drawing on this aspect of Leder’s work, the dissociation between self and the sensations of disordered skin may be viewed as one response to the “telic demand” faced by those who are ill. On this basis, the interpretation of bodily discomfort as a distinct entity attacking the self enables the identification of this discomfort as a tangible focus for relief and repair. However, it became clear that for the majority of respondents, the phenomenological emergence of the skin through disorder often became a central source of concern and focus that damaged everyday engagement in activities.

Corporeal Dys-Appearance as Intentional Disruption

While Patricia further illustrates a sense of separation between her perception of self and the “alien” presence of illness sensations caused by eczema, she also emphasises how this alien presence inhabits and harms her broader lived experience. Patricia frames her skin disorder as being ‘like some alien living alongside you and eroding everything you do, and you can't get rid of them’. Patricia experiences the presence of illness as a force that is disruptive to her everyday intentions and actions. There was a disruptive quality to experiences of physical pain and soreness of the skin in the accounts of many respondents across each of the skin disorders that were represented. Heather, who has acne, speaks about how during her time at school the painful, burning sensation of her disordered skin affected her desire to attend classes. As Heather explains:

> I didn't want to go because my face was so sore. Um, I did learn well. I just got on with it. But the whole time I was there I wasn't there …. it felt really sore, and some bits would feel burny and some was itchy. It was just very irritating.

Despite her abilities and desire to learn, the pain of her skin condition marred Heather’s school experiences. Heather’s description of this period illustrates how the bodily sensations of exacerbation associated with disordered skin often become a thematic focus for attention that affected engagement with the external world. The thematisation of the body related to sensations of pain and discomfort commonly yielded experiences where respondents felt disembodied from their social environments and inhibited in acting on their intentions. The consequences of pain and discomfort noted in these extracts reflect what Leder (1990) terms an “intentional disruption”, in which projects that may otherwise be valued can be rendered unimportant by the aversive sensations of illness.

While the experiences of corporeal dys-appearance presented demands on the individual that were attentional, they could also be existential (Andersen et al., 2021; Leder, 1990). In adjusting to the development or progression of illness, for example, some respondents questioned whether there was meaning behind their suffering. Christopher alludes to complex feelings of both attentional and existential concerns of living first with acne and then eczema, which led to his questioning “why me?”. Christopher says:

> when it became bad on my shoulders, and it had been like that for a while, you know, and I would see myself in the mirror, you know, these huge spots. And the pain, and stuff like that, that it was causing me. I do remember sort of screaming to myself, like 'why me?', 'why is this?', you know. It was pretty horrible. Yeah, I could never understand it. And with the eczema, yeah, I couldn't quite understand that as well. Like why, I'd not really been affected at all. And I'd been in some stressful situations as well at university, sort of studying for exams. That was quite difficult. But yet, like, the eczema hadn't sort of, uh, you know, I wasn't affected by it then, so why now, in my working life?

Christopher’s experience of confusion and despair in the search for meaning as part of his ongoing trajectory with disordered skin illustrates the existential challenges facing people living with chronic illness (Andersen et al., 2021). These existential challenges accompanied a “betrayal” of fidelity by the disordered body. As Kleinman (1988, p. 45) puts it, during illness the body ‘menaces. It is out of control. One damned thing follows another…. The fidelity of our bodies… is the grounds of our daily experience. Chronic illness is a betrayal of that fundamental trust’. Searching for meaning in the sequential development of different skin disorders left Christopher feeling exasperated with the existential uncertainties presented by this ongoing bodily betrayal.

Fluctuating Trajectories of Corporeal Dys-Appearance

Corporeal dys-appearance is produced by what Leder (1990, p. 88) terms “spatio-functional” and “temporal” ‘sunderings’ within the body. Temporal aspects of corporeal dys-appearance are losses of continuity asserted across time in the structural stability of the body. Shifting focus to an aspect of the temporal discontinuities of corporeal dys-appearance in respondents' accounts, it was notable that respondents often experienced the ongoing bodily difficulties of living with disordered skin as the endurance of a perpetual succession of ordeals. Fluctuations in the bodily manifestations of disordered skin have been noted previously in a number of studies, particularly in the context of psoriasis (Watson & de Bruin, 2006), and for people living with eczema (Mollerup et al., 2013). Illustrative of these previous studies, a common experience for the majority of respondents with eczema and psoriasis was fluctuations in the trajectory of illness as periods of flare-up were followed by periods of relative quiescence before symptoms flared again. Addressing some of the consequences of fluctuating symptoms, it emerged that for many respondents, fluctuations in the state of illness had notable impact on the time and effort required to manage the skin as part of everyday routines.

Melanie speaks about a dichotomy of embodied experience and illness management needs in the fluctuation between the periods when there is an exacerbation of her psoriasis and periods when her condition is less apparent in its bodily manifestation. Melanie says:

> So I have two completely different, I have psoriasis all of the time, it's just when it's not flared It's really calm and you can't see it very easily and when it's flared it's just horrifically red and burny, so like in my normal life I'll get up, shower, I have to moisturise everywhere immediately, And then obviously like choosing what I'm going to wear and how I'm going to do my hair depends on what my skins like that day but normally involves covering myself from head to toe pretty much, and then if it's on my face and my put some topical steroid on there but when I'm in a flare hhhhhhhh [exhales] I try to wear a little clothes as possible because the cold helps the

> itching and the burning, but when I go out I'll put layers on because otherwise people stop me in the street and I'd rather, it's just easier to distract yourself.

The fluctuations between these different states of the skin alter the practices of illness labour and the time required to manage the body. When her skin is exacerbated, there is a need for Melanie to add additional steps to the everyday practices of treating her skin. These steps exemplify some of the additional demands, which in this case present conflict, of managing both social presentation and the somatosensory experiences of pain and discomfort that a state of exacerbation entails.

As this extract illustrates, the difference in labour considerations as part of a daily routine between periods of exacerbation and those when a skin disorder appears quiescent can be substantial. The marked difference in everyday practices and routines produced by the temporal fluctuation of symptoms seems to highlight the "biographical disruption" caused by illness (Bury, 1982). Conversely, or as a complement, as indicated in Melanie's extract, the ongoing and intermittent disruptions to daily life and the routine daily evaluation of bodily symptoms may also reflexively reinforce for the individual an awareness of their chronic illness (S. Williams, 2000).

There was a sense for those with many years of illness experience that disorder had become a normal state for their skin. Even for those with longstanding experience of disordered skin, experiences did not appear to illustrate strongly what has been termed "normal illness" (S. Williams, 2000) or "normal crises" (Pound et al., 1998). The concept of "normal illness" describes how for people who have experienced a chronic condition from birth or childhood, experiences of illness may be regarded as a normal part of everyday life and may not necessarily be considered disruptive. Rather, in agreement Larsson and Grassman (2012), exacerbations remained disruptive for all respondents, if not unexpected. Illustrating the impact of fluctuating experiences of illness, it was of interest that a number of respondents focused on how the experiences of quiescence in their illness took on a special quality when contrasted with the pain and discomfort which, over many years, had become a familiar experience, with sensory and material implications for daily life.

A number of respondents, particularly those with eczema, spoke about the perennial background "buzz" of aversive sensations from their skin. Helen describes her underlying bodily experience of eczema as 'like tinnitus of the skin'. Similarly, for Patricia, much of everyday life is suffused with a sensation of discomfort like 'having a buzzing in your ears constantly'. Contrasted with the heightened sensory experience of exacerbation, suffused with pain, discomfort, burning or itchiness, it emerged that fluctuations in the trajectory of illness that brought time free of these aversive sensations came to feel "special". Respondents illustrated a remarkable contrast in embodied and practical experience that result from a shift towards periods of relative quiescence with their skin. Patricia elaborates on what it feels like when the background "buzz" of her eczema subsides, making reference to a distinct and sudden 'hiatus' of discomfort that seems to happen as if 'someone turns that buzzing off and it's peace… you just have peace, because you're not itchy'. Patricia describes this peaceful phase absent of underlying discomfort as 'clear time'. One of the meanings of this "clear time", for Patricia, lies in how the absence of unwanted bodily sensation adds agency to everyday life. For example, speaking about the differences that she experiences during a hiatus from daily discomfort caused by eczema, Patricia focuses on how this bodily shift impacts the necessity for everyday labour in managing her body, saying:

> You haven't got to think about what you're wearing, how quickly you've got to get your 'jama bottoms on when you've taken off your trousers or you know or having a shower.

Patricia's extract elaborates on how being in 'clear time' impacts the effort necessary through decisions about clothing choices and practices, as well as bathing routines. Her experience illustrates how for those living with a chronic skin condition, some aspects of the illness labour that becomes a normal part of everyday living are no longer necessary during periods when symptoms of the condition are alleviated. Indeed, a period free of the symptoms of disordered skin has been described as like being released from prison (Wahl et al., 2002). As these extracts illustrate, as part of the ongoing fluctuating cycles of exacerbation, periods of "clear time" from the experiences and demands of corporeal dys-appearance had a distinct impact of diminishing respondents' sense of agency over their everyday practices. The next section concerns experiences of "grooming" the skin - practices involving self-contact that often followed and added to experiences of corporeal dys-appearance.

Grooming the Skin

The disembodying experiences of chronic illness characteristic of corporeal dys-appearance place demands on individuals to respond to these ongoing periods of both experiential and existential unease through acts of what Leder (1990) terms "interpretation" and "repair". Exploring these acts, this section will examine how individuals responded to the exacerbations and aversive sensations characteristic of corporeal dys-appearance, focusing on practices of "grooming", a concept used by Lafrance and Carey (2018) to describe a subset of the "skin work" that is involved in managing disordered skin. Grooming the skin (Lafrance & Carey, 2018) involves acts where individuals analysed visual signs and other sensory appearances of disorder in their skin, as well as acts of making physical contact with the skin to address these signs of dys-appearance. As well as these acts being responses to bodily demand that can offer sensory relief and an element of agency over the dys-appearing body, it will be demonstrated that grooming acts were often found to be subject to moral consideration of the impact that grooming could have in damaging the physical integrity of the skin. Moreover, it will be shown these moral considerations about grooming could often be viewed in correspondence with normative discourses related to gender.

"Grooming" is a type of skin work that Lafrance and Carey (2018) identified among people with acne as the regular and repeated practices of picking, scratching or squeezing spots. Grooming 'consists of the physical acts of prodding and popping as well as the mental acts of analysis and assessment' (Lafrance & Carey, 2018, p. 73). This means that grooming the skin is both a physical and mental labour. As the characteristics of "grooming" were often prevalent in respondents' accounts, the concept will be extended for application beyond those solely living with acne to respondents who have eczema and psoriasis.

Grooming to Reclaim Agency Over the Skin

It was clear that the actions of grooming the skin were attached to a distinct sense of ambivalence for respondents across each of the skin conditions. This ambivalence often related to a conflict between an embodied need to act on the skin and understandings about the consequences of these actions. For respondents with acne, in particular, grooming the skin offered a sense of control over the disorder. However, respondents undertook these acts with the knowledge that squeezing spots entailed the possibility of exacerbating bacterial infection and causing long-term changes to the structure and appearance of the skin through scarring. The physical consequences for injuring the skin through squeezing acne spots could be severe. Christopher says:

> when sort of they burst or, I would squeeze them as well, er, and you know, that would hurt, you know. And like it wouldn't sort of make things better. I don't know why I did it. It caused scarring as well, and I've got one particularly big scar as well where some of the spots sort of, they grouped together to make kind of one big one, and that, you know, I had to have like a plaster on that for a while, 'cause you know it was quite a deep sort of injury, well not an injury, like a wound I guess, from where it took ages to heal.

Christopher speaks with some regret about his acts of grooming acne, which caused “wounds” to the skin that led to scarring. Indeed, it has been shown people with disordered skin often express feelings of guilt and regret for this grooming after it has taken place as sufferers grapple with the aftermath of a compulsive act that can cause further exacerbation of their skin condition (Lafrance & Carey, 2018; Murray & Rhodes, 2005). Advice or admonishment from parents and others to avoid squeezing spots because of the consequences of scarring the skin often featured prominently in these respondents’ accounts. As Christopher says:

> sometimes I get from my parents, you know, you shouldn't squeeze stuff, it'll cause scars or dimples or whatever. And you know, it's true, you know. It wasn't like I disbelieved them or anything. Maybe it was a bit of compulsion or um, yeah, just wanting to [exhales] having some ability to like affect it in some way, even if it was kind of futile, at least I was doing something to maybe sort 'em out.

There is clear ambivalence in Christopher’s account of his experience of grooming his acne. Grooming as a form of skin work has been shown to be valuable to those with acne for reasons related to appearance, hygiene and control (Lafrance & Carey, 2018; Murray & Rhodes, 2005). As spots may emerge at any time, acne can appear to have its own agency. Therefore, as Lafrance and Carey (2018, p. 74) explain, grooming may be viewed as ‘an attempt on the part of sufferers to reclaim their agency and, in doing so, to exercise control – even if only fleeting – over the skin’. Squeezing his spots felt like a means for Christopher of gaining some control over his skin, despite both his own experience and advice from others not to groom the skin because of the scarring that can result. However, as Christopher’s experience illustrates, given that the skin is a dynamic phenomenon, the grooming of the skin entails never-ending work.

Grooming for Sensory Relief

For respondents with eczema, as well as those with psoriasis, whose conditions are frequently characterised by sensations of overwhelming itchiness (Globe et al., 2009), grooming the skin was often a response to feelings of urgent need for sensory relief. As Segal (2018, p. 100) suggests, ‘itching is an insistent and infuriating demand made by the body: just as a person cannot tickle themselves, so it is almost impossible to ignore the claims of an itch, which comes from the skin but seems to speak from the soul’. Given the intense itch that she experienced with her psoriatic plaques, Sandra felt compelled to act on her skin for relief. As Sandra puts it:

> It was just one of those things that was hard not to pick at it when it was itchy and sore. It was almost, the plaques would become quite dry and itchy, and sometimes the only relief was to kind of scratch or scrape them off.

The overwhelming sensation of itch calls upon the individual for resolution by any possible means. Respondents spoke about the involuntary urge they experienced to resolve the sensation of itch within the skin, which would far exceed any reasoned struggle against this urge that they might put up not to scratch their skin (Nørreslet et al., 2010). Illustrating the involuntary quality of experiences of bodily dys-appearance, Patricia highlights the overwhelming sensory demands presented by itchiness and the need for relief. She says:

> it's not something that you can stop for. You can't go oh well I'm not going to scratch 'cause I know I'm going to feel really sore and it's going to hurt me afterwards. You have no choice about it. You don't have a choice… I keep thinking I need to, even now, I sometimes think I need to conquer it myself. I mean I can't conquer it myself as in oh I'm just not gonna scratch. It's nothing as simplistic as that but sometimes I think maybe it needs to happen and it needs to come out through the skin and then... I don't know really.

Patricia emphasises the absence of agency over her response in the struggle against the overwhelming demand presented by itchiness, which she frames here as an entity that must inevitably ‘come out through the skin’. Yet in this extract it may also be inferred that attached to the action of relieving an itch through scratching is a sense of moral opprobrium around the failure to control responses to bodily urges despite intentions not to do so, based on past experiences of painful bodily consequences.

A Sensory Dilemma Between Itch and Pain

Addressing the phenomenology of skin sensations, Steven Connor (2003) discusses how the demands of itch differ from those of pain. Connor (2003) notes that:

> The body which is subject to itch is inhabited by a need that, though it is on our periphery, is also as close as it can be. Itching and scratching involve a rising to the surface of ourselves, a centring of ourselves at our edges. Unlike pain the intensity and tolerability of which are dependent on its closeness to the centres of consciousness – making a pain in the arse much more tolerable than a toothache or sinusitis – itch is always exquisitely proximal, always, veritably, upon us. (p. 230)

Even among those sensory experiences that brought discomfort, some were perceived as being more tolerable than others. Most commonly, the pain that emerged after skin had been scratched was found to be preferable to the persistence of an un-scratched itch. As Erica explains:

> I used to, as many children do, er, sort of scratch until they bled, 'cause that, at least the pain was more bearable, the sore skin was more bearable than itch. And I do recall doing that with the back of scissors and just things to release that sort of intense itch.

A number of participants spoke about this preference and their experiences of how the sensation of pain acted to relieve the itch. Indeed, these respondents presented acts which induced bodily pain for reducing the sensation of itch as an instrumental, strategic practice. Speaking about her use of ‘scalding’ hot baths, Helen says:

> when I was younger I used to get into a scalding hot bath because that would be less painful than the eczema but I now understand how much damage that was doing but at the time I really loved doing that. I used to have these amazingly hot baths and I used to keep topping it up so it's hot, hot, hot, hot, hot. And I was thinking, you can't itch 'cause it's like your nerve endings can't do hot and itchy, they can only do one thing or the other so um, so I always used to do that.

Helen’s use of scaldingly hot water and Erica’s use of scissors to scratch the skin and make it bleed are acknowledged as being “damaging” to the body or creating pain. However, these practices are presented in terms which characterise them as means of regaining some agency over unbearable bodily sensations, albeit through acts which substitute one form of corporeal dys-appearance for another (Leder, 1990).

Methods of relieving itch were often framed as being damaging to the body through the infliction of wounds to the skin. Yet such is the intensity of the itching sensation, this self-administered bodily damage was often viewed as an unavoidable corollary of relief, as was the experience of bodily pain following this relief. Connor’s (2003) framing of itchiness as unavoidably inhabiting awareness and making demands for action from a position persistently central to embodied experience is helpful for understanding how respondents related to and acted upon sensations of itch, despite the aversive experiences of pain and discomfort that often followed its relief.

Grooming as an Assault on the Skin

Scratching the skin, an act of bodily self-contact common to everyone both with and without disordered skin, took on an assaultive framing by respondents, whose conditions often provoked an overpowering need for the resolution of itch. Many respondents with eczema, and some of those with psoriasis, identified the force used in their acts of relieving itching as far exceeding what they considered to be common for people with healthy skin. Illustrating what she perceived as a difference in the practice of scratching between those who have eczema and those who do not, Patricia says:

> you're not just scratching look, you're not just doing this [demonstrates slow, gentle scratching] slow scratch, you are frenzied. You are sticking your nails in and you're trying to do damage.

Prolonged, forceful scratching at eczematous skin was recognised as being different to the quick and effective relief of an itch for someone who has “normal” skin in its duration and intensity, and as a consequence, its bodily impact. In addition to marking the skin with the “damage” of wounds, acts of self-contact involved in grooming the skin through vigorous scratching or abrasion to relieve itchiness could also be physically exhausting. Patricia recalls rubbing her feet together to as a way of building the friction required to bring relief through the abrasion of the skin. She says:

> When I was younger and I used to rub my feet together [rubs hands together as demonstration] it would be like afterwards I would be absolutely shattered 'cause it’s like doing running, you know [laughter].

Patricia’s recollection of exhaustion after the vigorous rubbing of her skin for relief is further illustrative of the labour involved in acts of grooming as part of skin work (Lafrance, 2018; Lafrance & Carey, 2018) that differed from routines of bodily self-care in those who do not have disordered skin.

Moreover, while many respondents with eczema and psoriasis reflected on the physical damage they had caused to their skin by scratching it with their fingernails or rubbing the skin to cause abrasions, some of these respondents also spoke about their use of a range of other implements to scratch or abrade the skin in order to relieve itchiness. Tools adapted for grooming itchy skin were often implements found in the bedroom, such as hairbrushes. Helen speaks about the use of her hairbrush as a grooming tool to relieve itch when she was younger, which often caused her skin to bleed. Helen says:

> But um when it's really, really bad then you just wake up the whole time scratching it. Um, but I think eczema sufferers really get used to it. I know that when I was younger I would do things like I would get up, get a hairbrush, scratch my-... scratch myself with the hairbrush 'cause my nails were too short, and I wouldn't even know I'd done it, and I'd wake up with the hairbrush in the bed, and I'm thinking how could- [laughter]. So you've actually got.. and I don't sleep walk but I guess that counts as sleepwalking, so the impulse to get rid of the scratch, the itch, was so intense. Erm, it must have impacted upon me as a child. Otherwise they wouldn't have drugged me with these drugs quite frankly [laughter].

Helen’s use of a hairbrush for scratching demonstrates a repurposing of household items for the work of managing the skin. This repurposing is reminiscent of the “hybridisation” (Latour, 1993) that has been noted in the adaptation of the home as a centre for medication and treatment practices (Dew et al., 2014). In an illustration of the extent to which respondents employed such hybridisation in their pragmatic use of household items, Pavana reflects on repurposing kitchen cutlery for relief from itching. As Pavana says:

> And you know, trying to find any, and you get there, you feel that itch and you just want to try to find any implement around you to scratch with. And I've used brushes in the past and things like that, which have actually caused more damage. Or you find a spoon, and you just wanna find anything at the moment to release that sort of itchy feeling.

The use of a spoon to relieve itching extends the use of tools beyond implements of personal care, demonstrating a pragmatic approach illustrative of how illness needs are often managed in everyday practice (Dew et al., 2014), but also illustrates a deeply embodied understanding of how sensations impact experience. Moreover, the use of tools to enhance the force of scraping at the skin for relief highlights one of the ways that grooming is viewed as "non-conformist". This is particularly the case for women, Lafrance and Carey (2018) argue, as it enacts a stereotypically masculine "assault" of the skin. Furthermore, as engaging in this type of skin work 'suggests impulsivity, delivers instant gratification and privileges short-term satisfaction' (Lafrance & Carey, 2018, p. 76), it can be argued that grooming the skin represents multiple facets of non-conformity to dominant feminine norms.

While respondents recognised that the consequences of these practices for the wellbeing of the skin might be to not only damage the skin in the moment, but could also stimulate ongoing exacerbation because of this further assault on the skin and a consequent need for the work of further treatment, the call to attend to the itch was often irresistible. A complex mix of bodily sensations, when combined with embodied knowledge of past exacerbations and ingrained moral discourses about the appropriate management of illness, often produced feelings of substantial ambivalence about this forceful act of grooming.

Grooming the Skin as a Moral Transgression

Anzieu (2016) suggests that the compulsive act of scratching often results in feelings of shame at this breaking of the skin, despite the momentary relief that this brings. As Anzieu (2016) puts it:

> the resulting shame derives from the feeling that once one begins to scratch one will not be able to stop, that one is led by a hidden and uncontrollable force, that one is opening up a breach in the surface of the skin. (p. 22)

There was a prevailing sentiment that scratching and "breaching" the skin was damaging the body, and on this basis was framed in terms which were imbued with moral sentiments. However, a more prevalent moral component focused on the implications of scratching in the aftermath of the act. Moments of temporary relief were often followed, for many respondents, by feelings of regret and guilt for having scratched, rubbed, burned or picked at the skin. Speaking about how when she was a child she used to rub her feet together ‘until they were raw’, Patricia reveals that following this act, ‘then you have a bit of self loathing’. Similarly, as Helen, whose has also lived with eczema since childhood, puts it, ‘You feel regret. Certainly there’s a guilt I’d say’. This sense of regret following acts of grooming the skin adds ambivalence to the experience of a chronic skin condition. Helen speaks about how she questions her own actions after she sees and feels the consequences of having scratched her skin, saying:

> Then when the itch has gone away and then you see what you’ve done and you think, oh bugger, why did I do that? [said in whispering tone] Why did I do that? [said in whispering tone]. It felt so good while I was doing it but why did I do that?

Helen’s feelings of ambivalence appear to emerge from a nuanced aggregate of embodied experiences combining the somatic pull of itch, her attempts not to give in to this bodily demand, and emotions centring around regret and guilt in the aftermath about the injury caused to the skin.

As illustrated in Helen’s extract, however, another component of the ambivalence surrounding the grooming of the skin was the sense of ecstasy that that could be produced through how good it felt to relieve a sensory demand. A number of respondents’ accounts of eczema and psoriasis illustrated what Anzieu (2016) refers to as an “erotic” tinge to the sensation of scratching to relieve itchy skin. Anzieu (2016, p. 22) argues that there is an ‘increasingly pathological circular reaction’ in which ‘shame, in its turn, tends to be erased by the return of erotic excitation through the act of scratching’. A respondent with eczema described how the intense demand of an itch may be met with the “orgasmic” feeling of its relief through scratching the skin. Patricia says:

> Well they talk about it being orgasmic, don't they… People say that the relief is equivalent to something like an orgasm…. and you can see with a child who scratches, the absolute sheer bliss on their face... when they're scratching, because the relief is so great from the draw, the itch, um, and it is quite amazing, it is the most cruel thing in a way, because it is the intensity of the itch is so strong that when you actually are scratching is, it is really um... sensory.

Through this acknowledgement of the feelings of ecstasy that can be achieved through the relief of an itch Patricia takes up a transgressive moral stance, embracing impulsivity and the instant gratification (Lafrance & Carey, 2018) offered by this act. However, the "cruelty" that Patricia identifies in the erotic 'bliss' of relieving itch further illustrates the complexity of bodily sensations in the fluctuation experience of disordered skin, as momentary delight will almost inevitably give way to pain, discomfort and the labour of treatment. This extract highlights once again the ambivalence that respondents felt towards acts of grooming and a sense that autonomy over responses to disordered skin are often decidedly limited by the sensory pulls of a demanding body.

Circumventing the "Bad" Behaviour of Grooming the Skin

In an account contrary to that of many of the respondents, Helen illustrates a greater sense of agency through the development of capacities to control her response to demanding bodily sensations. She describes a strategy of demarcating areas of her body that she allows herself to scratch while designating her face as an area that she expressly avoids scratching. Helen says:

> that's the thing where I now have learnt, after all these years that if I've got an itch here I will scratch this one instead…. The only time when I don't get away with that is at night. And then I'll wake up and I'll scratch my face. But if it's during the day I would not, I just would not scratch my face…. I wouldn't use a nail…. it bothers me

> unbelievably much if I'm kind of... just looking so weird for so long when I was a kid…. I choose not to scratch that and I think I can do that…. Maybe I just don't get eczema as badly on my face anymore…. Maybe it has moved around and I just think I'm being clever. But I DO think, you know, now I'm thinking there are a couple of itchy places on my neck where I'm thinking well I'm not going to scratch them.

Helen feels that over the course of her long illness trajectory with eczema she had developed a strategy to control her response to an itch in one part of the body by displacing it to another. In accordance with the accounts of all respondents, Helen's extract illustrates the importance attached to a sense of agency over responses to the demands of the skin as part of managing their chronic condition and reflects the value of self-mastery (Heaton et al., 2016; Kelleher, 1988) often held as important by people living with long-term illness. While Helen hedges her belief that she is consciously able to shift an itch from her face to other areas of her body by choice, both through examples of the lessened control available to her while sleeping and through her uncertainty about disease trajectory, the avoidance of causing damage to her face is clearly important. Helen's reluctance to scratch her face, and the tactic she uses to try to avoid doing so, illustrates an integration of the social importance attributed to the appearance of the face and the notion that the face is a reflection of the self (Featherstone, 2010). Working on the skin in a way that might compromise claims to beauty through the potential for further infection or scarring is, Lafrance and Carey (2018) argue, a form of "bad" behaviour often levelled against women in particular as it represents a rejection of dominant norms of femininity (N. Wolf, 1990). Drawing on a lifetime of appearance concerns, Helen's attempt to circumvent the "bad" behaviour of facial scratching, if not avoiding grooming entirely, exemplifies the power of these feminine beauty norms. It has been shown that relieving itch by scratching reinforces this grooming behaviour, which can develop into a compulsive and habitual practice, but that strategies for "habit reversal" can be effective

(Norén, 1995). In a reversal of her previous response of scratching her face, the habitual act of directing this bodily response away from the source of a sensory demand to another area of her skin, Helen's extract illustrates how these social norms about beauty can be reflexively embodied (Crossley, 2006) to limit the impact that grooming can have for external aesthetic appearance. Moreover, Helen's continual monitoring and redirection of bodily responses demonstrates how the embodiment of social beauty norms reinforces the requirement for aesthetic labour (Bordo, 2003), especially for women.

There was often a pronounced sense of ambivalence related to many aspects of grooming disordered skin. A major source of ambivalence stemmed from the conflicting needs of relief from the demands presented by the skin and an embodied awareness of the consequences of attending to these demands. While grooming often provided momentary relief and engendered a sense of control, understandings about the consequences of wounding the skin through the potential for infection and scarring meant that grooming practices were frequently viewed in moral terms. That is, an emergent moral sense of regret often centred on the notion of grooming as an assault on the skin that is socially and medically proscribed. Moreover, while gendered discourses of the body appeared to be evident in differences of how respondents related to grooming, resistance to these discourses was also evident as women framed experiences and actions which transgressed normative expectations of this type of skin work. The next section addresses experiences of concern that emerged about the essential daily process of sleep, which through its particular relationship with consciousness and its social significance, often raised unique issues concerning corporeal dys-appearance and grooming the skin.

Sleep Concerns

As S. J. Williams (2007, p. 142) points out, 'we are sleeping as well as waking beings'. While daily, waking life commonly presented a range of challenging issues for those living with disordered skin, the periods in which respondents were sleeping or trying to get to sleep offered up a host of their own concerns. Issues around sleep in relation to the management of disordered skin were prevalent across respondents' accounts. In this section, insight will be offered into how the experiences of corporeal dys-appearance associated with disordered skin interacted with the distinct process of sleep as part of each day. Societal and moral aspects of sleep will be discussed in relation to components of the social etiquette of sleep and issues around productivity.

Vulnerabilities of the Absent Sleeping Body

The night hours, when most were aiming to sleep, caused particular problems for respondents with chronic conditions that caused skin to itch or to flake. Many of those with eczema, and some with psoriasis, found that they scratched more at night, “damaging” their skin unintentionally while they were asleep and powerless to resist the itch sensation. Brooke, who has dyshidrotic eczema which particularly affects her hands, spoke about unintentionally scratching while asleep during the night. She says:

> The more you scratch it the worse it gets, and I've found something that helps with my itch, but I'll wake up in the middle of the night itching and not even realise it, and have itched my fingers raw [laughs].

Brooke suggests that this unintentional response to night-time itchiness might be a consequence of an absence of an attentional focus or the dispersal of social inhibitions while sleeping. In bodily terms, Leder (1990) argues, sleep represents a phenomenological transition from an ecstatic mode where the body projects towards outward experience to a recessive mode in which the body withdraws from conscious experience into a state of ‘depth disappearance’ (Leder, 1990). As sleep represents a loss of consciousness, we can only access the sleeping body indirectly. In this way, sleep involves a form of absence from self and others. A sense of this bodily absence produced through sleep is illustrated in Brooke's extract as a source of frustration. Despite both an understanding that the bodily practice of scratching exacerbates her condition and having ‘found something that helps’ in the form of treatment that is effective for managing the sensory experience of her condition when she is awake, Brooke does not have control over her actions at all times. Rather, during sleep, Brooke’s body may act in ways that undermine her well-intentioned plan for managing illness. Given the loss of conscious bodily control, sleep makes us ‘vulnerable to ourselves’, as demonstrated in experiences of sleep disorders, such as sleepwalking (somnambulism) and sleep apnoea (S. J. Williams, 2007, p. 146). As Williams points out, these conditions present ways in which bodies may behave “badly” when we sleep, creating risk for self and others and the potential for acts that are stigmatising. For Brooke and other respondents for whose experiences of illness centre around periods of itchiness, the “bad behaviour” that her body engages in involves unknowingly responding to the sensation of itch by scratching at her skin.

Moreover, Williams (2007, p. 144) notes that it is upon waking from sleep that a person may ‘fallibly piece together the nature, quality and quantity of my sleep. How do I feel, am I (still) tired, did I get enough sleep?’. Elaborating on this waking realisation of the traumatic impact of scratching itchy skin, Erica says: it's the symptom of the itch and how it disturbs your sleep…. you get hot and you get sweaty, you start to scratch in your sleep and it turns into a vicious cycle then, and that's when you can sometimes wake up with sort of bleeding and scratching marks on you. And you've done the damage, the physical trauma to your skin without even being aware of it. Only on waking does someone who scratches in their sleep become aware how “badly” their sleeping body has behaved when the signs of their bodily vulnerabilities become apparent through the trauma caused to their skin.

The Difficulties of Sleep Amid Corporeal Dys-Appearance

While we may try to influence its occurrence, sleep cannot be directly willed or controlled and ultimately comes of its own accord (Merleau-Ponty, 1962). Illustrating the capricious nature of sleep for many of the respondents, Pavana often found herself unable to relax at night-time, as short bouts of sleep were interrupted by sensations of itchiness, periods of scratching for relief, and practices of moisturising to try to soothe her skin and help her return to sleep. Sleep problems caused by her eczema lead Pavana to experiences of frustration and uncertainty most nights about her undesired wakefulness. Her account was filled a sense of foreboding about how these night hours would unfold. As Pavana explains:

> at night-time you just, and even it's just you don't mind not sleeping, but you can't even lie down, because if you lie down you just, it's not relaxing. It's not like you're an insomniac who can just lie there and watch something. You have to keep moving around, you know, and then try again after half an hour, lie down, try to sleep. And sometimes I, I actually stop for a good two hours, 'cause I think, I'm just getting really frustrated, so I stop for two hours, trying to sleep, do something, really switch off, try to relax, try to moisturise and sit there, and sit-, and so you're vertical and so there's no way you're going to sleep. And then try again. Lie down, try for another forty minutes otherwise I'll do too much damage, then get up again. And sometimes you wi-, sometimes you'll go off, sometimes you won't, but, it's all guesswork as to what it'll be like that evening sort of thing, so um, yeah, just swings and roundabouts.

Williams (2007) demonstrates that if efforts made to bring sleep prove unsuccessful, concerns about the need for sleep may lead to anxiety brought on by this unwanted wakefulness. Drawing on (Leder, 1990) work on the “absent body”, Williams (2007) points out that when sleep is called for, remaining awake becomes a problem, transforming the experience of a wakeful state from normal corporeal “dis-appearance” to a problematic mode of corporeal “dys-appearance”. Despite her efforts to encourage sleep, Pavana experiences continual uncertainty about whether or not she will be able to sleep at all, which adds to a sense of frustration as her body “dys-appeared” through its unwelcome state of wakefulness in the night hours.

Though it may not be possible to will oneself to sleep, people commonly engage in daily routines which they undertake actively as part of managing their sleep (B. Taylor, 1993). The routines and rituals involved in going to bed are part of a process that facilitate the passage into sleep. It is through these mediating practices that sleep may be brought under partial control. Giving emphasis to the “embodied vulnerability” inherent to slumber, Williams (2007) notes that the preparatory rituals undertaken in the transition to somnolence, such as bathing, dimming light and changing into night clothes, are a means to establish the “ontological security” that is necessary to be able to rest, and in turn, to sleep. For those respondents whose disordered skin is characterised by symptoms including itchiness, this management sometimes included the use of medications such as antihistamines and sedatives (Globe et al., 2009; Nørreslet et al., 2010) to help to bring sleep under partial control. Monica, who has psoriasis, outlined the impact of her itchiness at night-time, which through the difficulties itchiness presents for sleeping proved a particularly difficult aspect of her illness experience. She says:

> When I had the swelling and rashes on my face- So something about it being next to your eyes- That it's itching that's just maddening. Like so much worse than pain. Like pain you can deal with, you can sleep through. But when you try to sleep and you're itching it's like, oh man, it's so bad. So I would have to take like- I would take antihistamines and, like, sedatives, and all that type of stuff just to get through the night. And with the itching, you know, I didn't have a flare-up one hundred percent of

> the time, but the periods that I did have it, I mean, it was almost impossible to sleep. Because once you get it in your head that it's burning, that's all you can think about.

Echoing the views of many other respondents with psoriasis and eczema, Monica finds the sensory experience of itch to be particularly difficult when trying to sleep, relative even to sensations of bodily pain. This experience supports findings on the prevalence of night-time itchiness affecting sleep with psoriasis (Globe et al., 2009; Nørreslet et al., 2010) and the phenomenological nature of itch relative to pain (Connor, 2003). This is especially so in Monica’s experience of itching in the skin near her eyes, which was further amplified while trying to sleep at night-time. The impact of night-time itching was lessened through Monica’s use of a range of medications taken both to aid her sleep and to provide some control over the itching that made sleep so difficult. While the corporeal dys-appearance of night-time exacerbations often caused a great deal of difficulty to respondents, the routine use of medications for sleep was found to be helpful to achieve a restful state, and as a consequence, enable the ontological security required for achieving sleep.

Negotiating the Social Etiquette of Sleep

Deviations from the social and cultural norms of “doing sleeping” violate what Williams (2008, p. 643) refers to as the ‘social etiquette’ of sleep. Owing to the wide-ranging scope and depth of her accounts of difficulties with sleep and the actions she took to negotiate her sleep issues, much of this section will focus on the experiences of Pavana, a woman with eczema. The issues Pavana experienced illustrated, in vivid terms, an embodiment of the rules of social etiquette around sleep, the consequences of breaching these societal rules, and her negotiation of sleep given these difficulties.

Sleep deprivation, particularly if it is prolonged, engenders embodied vulnerabilities through its wide-ranging detrimental impact on health (S. J. Williams, 2007). Illustrative of these concerns, sleep was attributed a great deal of therapeutic value by respondents. As well as acknowledging its importance for wellbeing generally, its loss seemed to compound the physical impact of the skin disease itself for many. As Roshan attests, ‘the second you fall asleep and your body obviously goes into healing mode, you then wake up itching everywhere’. Similarly, Erica, whose experience of eczema includes night-time exacerbations which cause her to scratch her skin, points out that, ‘at the time when we should be resting and repairing you have such sleep disturbance’. As is apparent in Erica and Roshan’s extracts, many respondents framed difficulties with being able to sleep as interrupting processes necessary for the “healing” or “repairing” of their skin, which meant that loss of sleep held serious implications for the management of their illness.

Reflecting rhetoric which espouses the importance of nightly sleep in particular for all forms of health, happiness and personal effectiveness in daily life, which a common focus of moralistic media discourse on the issue (Kroll-Smith & Gunter, 2005), nocturnal sleep lost as a result of skin conditions seemed particularly frustrating for many respondents. Despite the difficulties that some respondents often experienced in managing to achieve restful sleep at night, sleep that took place during the daytime in the form of naps was a notable source of concern. As Pavana says:

> I probably don't get enough sleep but the nap REALLY makes a difference. And I used to not wanna take it 'cause I thought, goodness that just sounds really bad to take a nap in the day when there's stuff to be done, and I was a bit embarrassed about taking a nap in the day, but now I've realised, you know, I don't care, I literally don't care. And so, um, it makes me feel so much better, so whenever it is, I will just, but it means that, you know, before I had eczema I was a person of routine.

Williams (2008) points out that sleep is a socially negotiated and regulated role that involves demands and expectations of both the sleeper and those who are awake. As Williams outlines, one of the societal demands of the “sleep role” is that sleep should take place at times that are socially sanctioned and in places that are socially approved, dependent on cultural norms that assign legitimacy and appropriateness to some practices while condemning others. Sleeping in one's bedroom at night is socially endorsed. Sleeping elsewhere or napping during the daytime may breach temporal and spatial norms (S. J. Williams, 2008). While there is evidence of developments in considerations about the value of napping (Kroll-Smith & Gunter, 2005) daytime sleep continues to incur social disapproval (S. J. Williams, 2008), particularly through its impact on work productivity.

Pavana makes a comparison between her experiences of sleep before eczema when she 'was a person of routine' and her sleep routines since developing this condition. Despite the need for supplementary sleep caused by her fractured night-time sleep experiences, such is the power of social disapproval about breaching temporal norms of sleep, Pavana was confronted with feelings of shame about taking daytime naps, due especially a perceived loss of productive time. However, given that sleep has been problematised as an issue that involves a heightened awareness to the "risks" associated with a lack of sleep (S. J. Williams, 2007) individuals are also tasked with ever greater vigilance about sleepiness. Pavana points out, for instance, that she 'probably doesn't get enough sleep'. Consistent with late capitalist imperatives, sleepiness that results from a lack of sleep is presented as potentially hazardous to self and society, in terms of health, happiness, productivity and performance in all aspects of life (Kroll-Smith & Gunter, 2005). Bound by societal requirements for sleeping practices that enable adequate sleep to ward off the risks of sleepiness for self and society, yet which demand that this sleep takes place in appropriate places at designated times, Pavana's experience illustrates the complex moral negotiation required of the sleeper.

Facing perennial difficulties in achieving restful sleep, Pavana took up a practice of shifting the place where she spent each night from her bedroom with her husband to a mattress downstairs in her living room. (Schwartz, 1970) notes the intimate relationship between sleep and residency. From a physical perspective, sleep tends to be associated with designated spaces which are often, though not always, in beds in the bedrooms of our own homes. By sleeping downstairs on a mattress in the living room of her house, rather than upstairs in her bedroom, Pavana is in breach of an important spatial aspect of the social etiquette of sleep.

Part of the reasoning Pavana uses for sleeping alone centres around the embarrassment caused by the stigmatised act of scratching, as well as concerns about flakes of scratched skin shedding in the bed, in the presence of her husband. She says:

> so in the night, and it's just all the bedding is covered in bits of skin and all this sort of stuff, and you're kind of changing it all round, and... yeah, no, no, and it is, you're downstairs, and you've got a mattress downstairs, and you're trying not to sleep on the sofa because that's so bad for your neck and everything and stuff…. And at night you lose the embarrassment… that you have in the day. Ooh, my daughter's there or my husband's there and, ooh, I can't flake or, you quite happily will flake away and remove, whereas you might be able to stop yourself a bit at night, you're like, oh, sod it, what do I care, and just scratch like a, you know, much more than you would do, without having the sort of social things to stop you if you like.

As Pavana's experience illustrates, the shame attached to stigmatised acts is often deeply ingrained, regardless of the perception others hold. However, being on her own at night eases Pavana's shame about her need to scratch her flaky skin. For many people, sleep involves being together with someone else, rather than alone. As Schwartz (1970) notes, sleeping with a partner demonstrates a level of trust and intimacy beyond the physical or sexual act. Indeed, it has been contended that sleeping together is a symbolic and embodied expression of a relationship upon which modern coupledom is predicated (S. J. Williams, 2007). In breaking with the norms of a process tied with the enactment of intimacy, sleeping separately from a partner can raise issues of both symbolic and practical significance.

It is also a societal expectation that someone who is asleep should be free from disturbance, which Williams (2008, pp. 642-643) notes is ‘simultaneously both an entitlement for the sleeper and an obligation for those still awake’. Another aspect of the reasoning Pavana offers for sleeping at a distance from the rest of her family illustrates a response to this entitlement of her family in their roles as sleepers to be free from the disturbance of her scratching and other night-time activities. Given that she expects to spend periods of the night in a waking state, Pavana’s actions comply with the obligations of the waking role. As Pavana explains:

> night time, I'm, I often sleep in the living room because I don't wanna wake people up, so I move into the living room and then I'll watch TV or I walk around or I, it's trying to find things to do at night, so I'll try cleaning or something or another, so it's trying to find things to do and just the frustration, and when you're falling asleep, and when you do get to sleep it's like seven, eight in the morning, the time that you need to wake up.

The aggravating bodily sensations that so often affect Pavana’s lived experience have created a sense of deep uncertainty about the possibilities of finding sleep on any given night, and subsequently an absence of agency over the sleep process. When considered alongside the extent to which the spatial, temporal and social qualities of Pavana’s sleep have been modified or compromised, and the laborious routine practices she engages in to fill the night hours, it is understandable that the ontological security necessary for sleep (S. J. Williams, 2007) may prove elusive. Pavana says:

> And I've got to the point where I don't care whether I sleep or not, because I will, I've found that I'm just going to nap in the day. If I don't get sleep in the night, well at

> some point I'm gonna... fall asleep, so if, because I'm not working I can deal with that issue, you know, ok, what the hell, I'll sleep in the day, I'll set the alarm [banging hand on table while speaking]… pick up um [daughter] from college and things. So, I've given up trying 'cause I've found the frustration of trying to get to sleep so annoying that I'm just... decided for me what works best is not to care. If I fall asleep I fall asleep, if I don't, I don't.

As a means of coping with a lack of control over the temporal pattern of her sleep, Pavana has taken steps to work around the practical issues this presented for performing her daily routine and social roles. In addition however, as Pavana makes clear, this adjustment has been accompanied by a critical reevaluation of the importance of conforming to the normative social etiquette of sleep (Schwartz, 1970).

Putting Sleep to Work

While the night was often a difficult period and sleep a problematic process for many of the respondents, particularly those whose skin produced irritation in the night hours, others had a more harmonious relationship with these aspects of each day. Meghan found nightly periods of sleep could be put to use as productive time for treating her acne. As Meghan says:

> sleep's like really important to me, 'cause that's when I do like all the big treatments for my skin. 'Cause it's like, I've got eight hours' time now, where I'm not doing anything, so let's put on like a facemask or put this on, or like, and like you can leave it on for that whole time then. So, yeah, sleep's a really good time for me to do a treatment or something like that. So I do, yeah, I do often use that time quite a lot…. I always put like a certain cream on at night, that's like a more intensive moisturiser or treatment that I wouldn't put on during the day. I'll put like an oil on at night, which would make you look like really shiny during the day, 'cause you've got extra oil on, so I wouldn't put that on if I was going outside. Or like, this other cream I used to put

> on, was just completely white [laughs]. It was like really, like just white, so I wouldn't put the [inaudible] go out with like a white face, um, or like, facemasks, like some are green. Um, yeah. so it's quite a good time.

With relevance to discussions about late capitalist obligations towards productivity and performance, Meghan's experiences illustrate how sleep may be put to work (Kroll-Smith & Gunter, 2005). Meghan uses the time that is available to her when she sleeps to optimise the effectiveness of her treatment regime. She makes the most of this window of time to apply 'big' or 'intensive' treatments to her skin, so that they can remain on her face for the whole night. The privacy she experiences through sleep provides an opportunity for messy skin treatments to be used on her skin, such as oils, opaque moisturising products and brightly coloured face masks. Meghan would not feel comfortable applying these messy treatments during waking hours or in public as they would have an undesirable effect on her aesthetic appearance in the presence of other people. However, given that nightly sleep is an important period for treating her skin, interruptions to her routine which compromise the duration of her sleep equate to time for treatment being 'wasted'. Meghan says:

> it's always annoying 'cause if I'm, like, if I'm in a rush and get to bed late, and don't have time to do my routine, then it does really annoy me 'cause I'm like, ugh, what a waste of time, I should have gone and put my cream on, but I'm only gonna get five hours' sleep so let's just go to bed, so um, yeah, that does annoy me when it's like wasted time, when I should've like put something on.

If Meghan is to be able to apply treatments at night-time in the manner that she feels is most effective, this presents difficulties for negotiating the many competing demands of everyday life, both in terms of her waking routine and in her sleep arrangements. Moreover, the process of treating her skin in this way demands a substantial investment in labour, both for mental planning and preparation and in the physical application of these treatments.

Sleep, Disordered Skin and Emotional Disruption

Many of the respondents referred to emotional elements surrounding sleep in relation to the experiences of disordered skin. Indeed, respondents' experiences often illustrated ways in which emotions can be intimately and reciprocally connected with sleep (P. E. S. Freund, 1990; S. J. Williams, 2007) and the state of their skin. In a discussion of the relationship between sleep and emotions, Williams (2007) writes:

> I will not… sleep soundly if I am feeling anxious, insecure or unsafe, or if I am feeling sad, angry, fearful or stressed about something. The nature and quality of my sleep, in reciprocal fashion, is likely to affect my mood and feelings in significant, though perhaps unacknowledged, ways. If I have not slept well, for whatever reason, I may be moody, irritable, bad tempered, prone to emotional outbursts or just plain unbearable to live with, particularly if my sleep problems continue unabated. (p. 150)

With reference to a period when his psoriasis was particularly severe, James' recollections drew together a mutual relationship between his psoriasis, his sleep and his emotions. James says:

> But it's the mood, it's the mood. Because you're very- you're not suicidal but you're low mood, you know? And it's interesting when I read back through the notes from [the hospital]. It's all about the mood. You know, low mood…. it's all linked…. everything was up the wall, like sleeping, so I'd sleep during the day, I was awake at night…. Very, very tired. I was depressed, you know? Very, very depressed. And it was just this horrible looking in the mirror and skin….

James' experience illustrates the difficulties he faced with sleep during this time when his psoriasis was proving to be incredibly difficult to manage. Making the point that 'it's all linked', this extract highlights in particular a reciprocal relationship that James experienced between the condition of skin, his mood and the patterns of his sleep. This linkage reflects developing knowledge of the emotional impact of skin disorders such as psoriasis (Rasmussen et al., 2012).

Disturbances to sleep caused through scratching at night-time often left respondents feeling that that they were “missing out” on sleep, for reasons that were both physical and emotional. A number of respondents spoke about their sleep being disturbed because of their awareness, on waking themselves from sleep through rubbing or scratching at skin, of the need to give care to their bodies and clear up their sleeping environments in the aftermath of these unconscious bodily actions. Rebecca says:

> it does affect sleep because you wake yourself up because you've itched yourself raw, and then you wake yourself up and then you think awww, and then you really then should be putting cream on and everything, and then you're actually awake and you're up, and you're putting cream on and then trying to go back to sleep, and so yeah, it definitely affects sleep. The worse it is, the more it affects sleep… when you're itching and you're waking yourself up through itching you've then got to deal with it, because you can't go back to sleep with your arms covered in like blood and weep and all that sort of thing. And also, when you wake up, when you've itched it that much you then wake up because it's hurting, it's sore, so then I'd normally go to the bathroom, put like cold flannels on my arms, because that would help as well…. It's not just a case of waking up, rolling over and going back to sleep. It's waking up and dealing with whatever you've done in your sleep, like, itching, and sometimes I've woken up before and there's been like, not a lot, but blood and weep on the sheets. And, like, yes, you wouldn't change it in the middle of the night, or I haven't, but then you sort of think, 'oh, god, I've got that to do tomorrow', and so it does affects your sleep and because you subconsciously think about it then, so when you go back to sleep, you might possibly not go back to as deep a sleep as you were in, because

> you're then subconsciously thinking, I don't want to itch my arms anymore because I've made a mess of them.

While there is a need for extra practical labour, the impact on Rebecca’s sleep also appears to be a product of the mental and emotional toll that this experience produces. Emerging together in the moments after waking from sleep, concerned thoughts arise about her vulnerability (S. J. Williams, 2007) to further bodily wounds caused by the dys-appearance of a sleeping body that is out of her control and the next day’s laborious tasks to address the mess. These concerned thoughts deter the possibilities for ontological security (S. J. Williams, 2007) and seed anxieties which, as Rebecca’s extract illustrates, can then reduce the quality or “depth” of sleep available for the remainder of the night. In the next section, the subject of these sleep concerns - the need to clear up after corporeal dys-appearance - will be addressed.

Clearing Up After Corporeal Dys-Appearance

This section will explore the sensations and experiences of bodily exudations from the skin that were associated with illness and the processes of managing these exudations. The shedding, oozing and flaking of the skin from the body and on to clothing and soft furnishings in the home or other indoor spaces often presented concerns for respondents. The bodily emanations of disordered skin that emerge or are sloughed off were often framed by a sense of untenable “dirtiness” produced by the loss of “good order” (Jobling, 2000), where the impact on domestic cleanliness may be viewed as detrimental to a sense of moral adequacy (Douglas, 1966). A range of strategies and dispositions were taken up by respondents to manage the bodily by-products and material signs of disordered skin. To restore a sense of orderliness to the disordered body, individuals were faced with the task of clearing up these flakes, scales or bodily fluids in perpetuity which, it will be shown, commonly mounted up to a substantial burden of additional labour. In an extension of

Lafrance and Carey's (2018) conceptualisation of the different forms of "skin work" performed by people living with acne, an additional concept of "containment" will be proposed to include the work of clearing up organic matter produced through the processes of disordered skin.

Disorder, Dirtiness and Disgust

Wetness and Viscosity. The period after grooming, following an episode of scratching or picking at the skin, was often accompanied by visible changes in its surface that reflect the impact caused to its physical structure. Vigorous grooming was often followed by the emergence of a range of fluids and other matter from inside the skin as blood or translucent plasma began to ooze from the wounded surface. Abrasions from scratching could leave the skin feeling sore and uncomfortably dry and vulnerable to splitting or cracking, opening the skin up to the external environment and weeping with fluid. As the following extracts will illustrate, many respondents, particularly those with eczema and psoriasis, found experiences of the skin bleeding, splitting, cracking or oozing, and the scabbing of tissue fluid or blood emerging from weepy skin, to be highly challenging - practically, emotionally and existentially.

The emergence of visceral fluids from the skin after its abrasion through scratching were aspects of eczema that drew feelings of disgust from many respondents. Describing the 'horrible' experience of weeping skin, Rebecca says:

> And when it was weeping and everything you feel disgusting as well. [Laughter]. It's bad enough when its dry and flaky, but when it's raw and like weepy, and obviously covering it makes it worse, and obviously creams don't soak in, because there's like a layer of like weepiness and, it's just awful, like really, really horrible.

As illustrated by Rebecca's experience of weepy skin, the horrible nature of these experiences of weeping, cracking and bleeding skin often focused around unwelcome sensations of wetness and viscosity. The body and its secretions are subject to taboo (Douglas, 1966). Indeed, all bodily substances may be considered culturally problematic (Mauss, 1979) and the perception by others of being unable to control bodily fluids can put human dignity at risk (Isaksen, 2002). Jean-Paul Sartre (1943/2003) discusses how viscous substances represent a loss of surface, and are associated with feelings of degradation and disgust. From this viewpoint, the emergence of bodily fluid leaking from the skin indicates a loss of the physical surface integrity of the body - and by way of embodiment, the self - as its structure is breached and its physical and existential boundary (Jobling, 2000) opens out on to the world. The loss of the ability to control bodily functions such as the weepiness of the skin creates a sense of bodily ambiguity. Isaksen (2002, p. 803) argues that ‘when the limit between nature and culture no longer is clear and unquestionable, the ambiguity of the body becomes visible and can easily evoke a feeling of disgust’. Indeed, as Rozin and Fallon (1987) explain, reminders of the organic nature of personhood are often associated with feelings of disgust.

Malodours From the Skin. Focusing on the aversive quality of bad smells related to his eczema, Roshan spoke about how the odours of exudations from his skin made him nauseous. Roshan says:

> the smell was of blood, sweat, pus, and blood plasma. It was the nastiest concoction you could ever smell, because you feel like puking when you smell it. And that's what you smell like. Which means that I used to take like two showers a day.

Classen et al. (1994) point out that malodours from the body are particularly stigmatising. Given his focus on how the way he smelled became associated with the malodorous qualities of this ‘concoction’ of organic fluids seeping from his body, the heightened need Roshan felt towards showering illustrates this stigma attached to bad smells. Moreover, even after a period of time has passed since these nauseating experiences, Roshan talks about how the smell of blood plasma oozing from his body still ‘haunts' him. He says:

> And that smell of blood plasma. Because it oozes out of areas where you're having allergic reactions. Oh man, that smell still haunts me. If I smell it now I'm like "aughhhh, go away from me". 'Cause it was so strong during the periods of real hardship. 'Cause without fail, that's what always comes out. No blood, no pus, ok, that's fine. But blood plasma, it seems like for a specific period it was just always there and you were like, "come on, please, just go".

For Roshan, the smell of blood plasma came to be associated with a time when the state of his illness with eczema was especially severe and this fluid would ooze from his skin, representing a loss of autonomy of his bodily boundary. As Shildrick (1997, p. 178) writes, the skin provides ‘not only protection of one’s own body from encroachments, but a denial of the leakiness between oneself and others’. Despite his existential pleas for relief from this oozing substance, this smell acted as a reminder of his illness through his inability to control the emanations of his “leaky” body.

Erica frames her own experiences both from the perspective of her work as a medical doctor and from longstanding personal experience of living with eczema. A biomedical framework is drawn upon in this extract to explain the processes happening after the skin has been wounded, with reference to the way that people with eczema found their skin took on a foul smell when oozing with fluid. As Erica puts it:

> talking to sort of patients or clients that have eczema, they often say that the discharge, the ooze, it stinks, I think that's when it's been a kind of chronic ooze. I'm not sure mine ever got, didn't ever really get particularly infected eczema. I think that's probably when it's got infected that it's probably oozing and stinky and a bit pusy, because there's just no barrier there and the bugs are just getting in and the

> body's just trying to protect itself as much as possible with the producing pus. But yeah I found it didn't smell. It was in the acute phase where I'd scratch so much that it would sort of abrade the skin, the top level of skin, so it's just clear, clean tissue fluid that's oozing out.

Drawing on a biomedical perspective, Erica frames odours emerging from oozing skin as being the result of bacterial infection. In line with this discourse, Erica’s depiction focuses on providing an explanation of processes at a cellular level rather than providing an emotive narrative of daily personal impact that was offered by some of the other respondents.

‘Smells are taken to mean dirt only when they signal either consciously or unconsciously the threat of contamination from a body’s interiors’, writes Lawrence Kubie (1937, p. 393) in a study of perceptions of dirtiness. As dirt and bad smells are related to danger and disease, things that smell bad, strange or unexpected are often viewed with aversion (Isaksen, 2002). The tendency to draw on a bacteriological aetiology of infectious disease, Isaksen (2002) suggests, may be a rationalisation of fears about dirt and contamination, as illustrated by Erica’s recollections of her patients’ concerns about infection and by Roshan’s concerns about the emergence of foul-smelling fluid from the inside of his body.

Containing the Skin

Extending Lafrance and Carey’s (2018) conceptualisation of “skin work”, which was based on the labours performed by people living with acne, an additional concept of “containing” is proposed for relevance to understanding the experiences of a broader range of skin conditions. Capturing a component of skin-related labour that is not included as part of either “concealing”, “grooming” or “medicating” in Lafrance and Carey’s (2018) model, the proposed concept of “containing” recognises the work of clearing up organic and other material matter that often represents a major aspect of the labour involved in everyday life with disordered skin. As will be illustrated, the work of containing the skin takes place across a range of social spaces, particularly the home and places of employment, it is shaped by conceptions of dirtiness, and it levies a burden of both physical and mental labour produced through a constant reflexive attention to the shedding and exudation, and then the eradication, of skin-related matter.

Dealing With the Shedding of Scaly Skin. The massively increased volume of skin produced in psoriasis that is then sloughed off as scales, and the shedding of skin flakes by those living with eczema, meant the respondents with these conditions often experienced a continual need for containing matter comprised of the skin. The build-up of deposits of skin commonly required frequent vacuum cleaning to avoid homes becoming dusty and feeling unclean. ‘I don't wanna be unpleasant but, you know, little bits of skin go-, you know, you scratch and then there's skin everywhere, so you're cleaning from that sort of thing’, says Pavana.

The need to clean up deposits of skin flakes was particularly common in areas of the home where more time is spent, and where more skin is shed, such as the bedroom, or around the desk area of an office work environment. Organic waste is an inevitable by-product of everyday habitation. As such, many of the tasks of homemaking are directed at containing and eradicating this organic matter (Angus et al., 2005). Douglas (1991) argues that within the domestic field the cleanliness of a home is considered a sign of personal and moral adequacy. Scaling necessitates a daily regime of cleaning to remove scales from floors, beds and other furniture (Uttjek et al., 2007; Wahl et al., 2002). As the aspect which principally characterises psoriasis as “dirty” is this ‘shedding of scaly skin’ (Segal, 2018, p. 97), the work of containing the bodily deposits of skin debris becomes a matter of importance both in material terms and in terms of moral virtue. Laitala and Grimstad Klepp (2019, p.133) point out, ‘the relationship between cleanliness and dignity is central for not only well-being, but also social inclusion’. Exemplifying the importance with which this facet of personal dignity is held, James illustrates the endless effort he gives to the labour of containing skin flakes shed from his body despite the continual difficulty of maintaining cleanliness in his shared work office. James says:

> I have a desk. It’s grey and the keyboard is black. Obviously I clean it but yeah, down on the floor is tiles and they’re grey, so you don’t see anything. But my keyboard, I’ve got the air duster. SSSSSSSSTTT. But sometimes I end up just like SSSTT like release [laughs while speaking] and a snow storm comes out [laughs while speaking]. It just depends. Every day is different. And I've got a habit, when I'm on the phone of scratching and pulling at a bit of psoriasis. You know, I've got a few clumps round here, so when I'm on the phone I'll be pulling and [inaudible] oh my god, and then you go like this, oh, and then you just think oh bloody hell, you know what I mean? And then you've got the black keyboard and it's all going under the keys. It's never-ending. It's always there. Just constantly cleaning. I mean I think it's impossible. But even the dermatologist says it's completely and utterly clear, you know? It's always going to be there. It's just, with me, now, it's obviously very, very mild, but yeah, I'm still doing this cleaning, and on my desk I have a little pod and I've got two of these dusters there, one with a long thing and it goes in between everything, you know. It's OCD.

This extract illustrates the mental and physical containing work that James undertakes for managing psoriatic scales in an office environment. As evident in James’ extract, those living with psoriasis, a condition in which sizeable pieces of skin may be shed from the body, were particularly sensitive to the colours of furniture and other materials in their physical environment. Noting how diseased skin relates to cultural ideas about dirt and lack of order, Jobling (2000, pp. 98-99) writes ‘The signs of skin disease threaten the fundamental system of categorisation we employ to order all things. They dirty the pattern'. Illustrative of the mental labour performed to contain the impact of his skin within his work environment, James is well aware of the colours of his work desk, keyboard and floor tiles in relation to the colour of flakes of skin shed from his body. James' experience has been that darker surfaces act to highlight his lightly coloured skin flakes, whereas these flakes tend to blend more easily visually with lighter coloured materials. The differential between surfaces affects the extent to which flakes of skin affect the important semblance of cleanliness by the way fallen scales affect the visual orderliness of materials.

As James' experience illustrates, the mental work of containing the material evidence of disordered skin is substantial. It includes both an awareness of scales shedding from his body on to the surfaces around him and a feeling of the necessity to clear up this "dirty" material. When combined with acts of frequent and ongoing physical labour, the 'never-ending' work of containment can add to the Sisyphean qualities of the illness experience. Given the many important roles of the skin for identity, such as its capacity as a boundary to contain and protect the self, as well as its role as an organ through which identity is displayed (Lafrance, 2018), experiences of a condition in which the skin is shed from the body can form an identity that is markedly affected. Jobling (2000, p. 97) argues that as a vital boundary, 'skin disorder spoils identity' because the 'sufferer is all too aware that [their] bodily boundary is constantly crumbling away'. In concert with the value of cleanliness for personal dignity (Laitala & Grimstad Klepp, 2019), it is understandable why respondents felt compelled to perform this work. Cleaning up the skin that falls in his office environment continues to be a focus of daily practices for James despite a clinically observed reduction in the severity of his psoriasis. Framing these acts using a discourse of mental illness - 'It's OCD'- it is clear that the performance of labour for containing the skin has become embodied through habitual dispositions and practices (Crossley, 2001a, 2001b, 2006). Despite a reduction in the severity of his psoriasis, therefore, it could be argued that the embodiment of habitual dispositions and ongoing performance of disruptive, time consuming and effortful work to contain disorder, serves to reinforce James' sense of chronic illness (S. Williams, 2000).

The phenomenon of shedding flakes of skin from the body was a common and disturbing experience predominantly for respondents with psoriasis. Participants with this condition often described the discomfort of experiences of leaving a deposit of skin in the places that they visited. However, feelings of unease about shedding skin were not limited to that of skin flaking on to the desks and chair of places of employment or the soft furnishings of the home. Rather, depositing particles of skin from the head into the hair, or from one part of the body into the open folds and creases elsewhere on the body, for instance, also produced a sense of aversion and a demand to contain the impact of the disorder by clearing this material up. Michelle speaks about how the buildup of psoriatic plaques in and around the ears, means there is a frequent need to clean her ears. 'I have got a little bit around my ears and I get it in my ears often' Michelle says, adding, 'so I have to clean my ears out all the time'.

The terms in which Michelle describes this aspect of her experience with psoriasis equate the sensation of these plaques of skin being in her ears to a feeling of "dirtiness", despite Michelle's iteration that the condition does not in fact represent what she would identify as dirty. As Michelle put it, 'it feels awful. It's horrible. Um... I've not got, you know, waxy, dirty ears. But your ears just feel dirty. It's, um, quite difficult to describe really'. Rather than holding any intrinsic quality, dirt has been defined as "matter out of place" (Douglas, 1966). Mary Douglas (1966) argues that dirt involves reflection on the relation of order to disorder, being to non-being, form to formlessness and life to death. Therefore, reactions to dirt are reactions to ambiguity. The particles of skin that had collected in

Michelle’s ears had just a short time earlier been part of a living, if disordered organ of the body, which had then become separated from the body. The unwanted presence of the now-detached organic matter disrupting order and producing ambiguity within a bodily space felt “dirty”, engendering a sense of disgust and a need to clear up this extra-bodily material.

Laundry Labour. Cleaning up the material by-products of the body with disordered skin, and maintaining the hygiene of the home environment, impose an increased burden of labour and time. As well as clearing up skin particles that had been deposited from the body, the work of containing disordered skin often involved substantial additional labour to deal with the impact of bodily emanations and treatment substances transferred on to clothing and bed linen through contact with the body. Speaking about the ‘hell’ of managing this additional labour, James says:

> all the washing, you know, I'm covered in cream [inaudible] steroid creams and... awful, staining every bed linen. I said to her, you know, blood on the T shirt and everything covered in blood, you know? And washing all the time. When you're totally covered, it's hell.

James’ experience illustrates the laborious demands of keeping up with laundry for people living with psoriasis (Dubertret et al., 2006). Clothes act as a boundary between the body and society (Entwistle, 2000). Moreover, the cleanliness of clothes is highly important to maintain the clarity of this boundary (Shove, 2003). As illustrated in James’ extract, the transfer of substances from the body into the fabric of clothing meant that the boundary between body and society often became blurred. For James, this ‘staining’ produced a sense of distress and added to the labour required to contain the impact of disordered skin on his clothing. Organic exudations from inside the body and skin flakes sloughed on to clothes, sheets and soft furnishings are physical signs of illness that mark the material structures in the environment that surround it. Additional to the bodily emanations of blood, clear tissue fluid and pus, and the flakes or scales of skin that have been scratched off or shed, remnants of treatments in the forms of creams and ointments are similarly transferred to the environment in contact with the skin.

The sense that efforts at hygiene were made in vain often added to feelings of frustration at the work required to manage skin disorders. In spite of his efforts, Christopher found that items often retained stains or signs of greasiness even after laundering them in the washing machine. Christopher says:

> with the eczema, it was, there was a lot of discomfort there, not just in terms of how irritating it was, but also, I'd use, say, quite a lot of the emulsifier, and I'd get my bedsheets quite greasy and clammy, and that would make it uncomfortable to sleep in those, and, you know, and say, I have thrown away at least one sort of set of duvet and bed sheets and literally when, because you'd put it in the wash, and it wouldn't come out the stuff, you could still feel it.

Fabrics often became greasy or saturated with congealed mixtures of organic bodily substances and the various pharmaceutical formulations used for treating the disordered skin, creating a sense of ambiguity and viscosity about their surface textures that is associated with dirtiness (Douglas, 1966) and degradation (Sartre, 1943/2003). Respondents found that clothes and bedsheets had be washed frequently and often repeatedly to try to get them clean, demanding labour which, as Christopher and James' experiences illustrate, often result in clothes and bedsheets that still did not feel clean. Given the existential importance of maintaining cleanliness in the clothes they wore, respondents often went to significant effort and expense to launder their items, but were often disappointed when clothes emerged still saturated with the substances and bodily emanations which they had worked to cleanse.

Respondents’ extracts illustrated a constant awareness about the shedding of skin and exudation of substances from their bodies. Moreover, respondents were compelled to undertake substantial physical labour in maintaining a sense of cleanliness in their clothing, and in their home and work environments, in order to contain the impact of their disordered skin. Corresponding with this need to manage and “contain” the material impact of disordered skin, it was often notable that respondents developed anticipatory dispositions and practices focused around material and bodily concerns, the subject of the next section.

Anticipatory Dispositions

Daily routines and practices were often shaped in large part around the avoidance of causing further exacerbation of illness. For many respondents, this contributed to a cautionary approach to practices that was highly attuned to the interface between the body and particular material and social settings that could contribute to flaring or a worsening of illness. Ben Anderson’s (2010, p. 777) concept of “anticipatory action” describes how orientations to the world are ‘made and lived in the name of pre-empting, preparing for, or preventing threats’. This concept is useful for understanding how anticipatory processes involve the projection of past experiences into the future, and how this shapes the practices, routines and itineraries of the present. As B. Anderson (2010, p. 785) puts it, anticipatory acts ‘strategically intervene on the future’. Drawing on this concept, this section will examine how strategies were deployed for managing the corporeal and material aspects of illness. A range of anticipatory strategies cautious of exacerbating the skin, and the implications of their enactment, will be explored. As will be demonstrated, in the habitual use of anticipatory practices, respondents often developed a “managed involvement” (Boyle, 2019) to everyday life.

Attention will also be brought to how respondents related to and produced the material environments of their homes with respect to their chronic skin conditions. It will be shown that anticipatory dispositions focused on minimising threats of exacerbation led respondents to adapt their living environments as “hybrid” treatment spaces for managing their illness (Dew et al., 2014). The construction of home environments as hybrid treatment spaces will be examined through the strategic selection of materials for furnishing the home and the adaptation of spaces within the home for storing treatment products.

Adapting Domestic Environments as Hybrid Treatment Spaces

Beyond being a place to dwell, the home is related to issues including identity, privacy, routine and care (Mallett, 2004). Home and self become interwoven, as dwellers decorate and personalise their homes with objects which reflect aspects such as their leisure interests and healthcare needs (Morgan and Pritchard, 2005). Pragmatic approaches were often taken by respondents which addressed choices about the materials of home furnishings and décor of living spaces, in order to resolve common concerns about cleanliness associated with the shedding of skin and other bodily exudations. A number of respondents had also taken action to shape their homes as spaces that would help to minimise the potential for exacerbating illness further.

Frustrated by continually vacuum cleaning carpeted floors and feeling concerned that hoovering did not fully clean carpets to a level that was sufficient, Pavana had wooden floors installed to replace the carpets throughout the house. ‘We've had all the floors put in because of the dust issue, so we've got wooden floors everywhere’, she says. While dust was more likely to be visible, from Pavana’s perspective this was seen as beneficial, as the smooth wooden surfaces were easier to clean than carpets. Similarly, Pavana’s fabric covered sofas were replaced with smooth alternatives, making the process of maintaining the cleanliness of the home more straightforward. Angus et al. (2005) demonstrate that the aesthetic qualities of healthcare spaces typically differ from those of the home. Healthcare spaces are often driven by logics of cleanliness, fiscal restraint, expedience and standardisation, rather than sensory enjoyment and comfort. Moreover, objects associated with healthcare are rarely considered decorative – priority in their design is given to the use of materials that are durable and easy to maintain and keep clean (Angus et al., 2005). Pavana’s extract illustrates how the prioritisation of managing her health needs shaped the actions taken about material aspects of the home in a way that incorporated the qualities of a healthcare space. By making practical changes to the flooring and furnishing of her home to facilitate the monitoring of fallen skin particles, vacuum cleaning and wiping down surfaces, the logic of the home space was shifted towards that of cleanliness and expedience in the management of illness.

As well as modifying the décor of the home, respondents sometimes designed or constructed private spaces to be amenable to the management of skin disorders in other ways. Changes were made so that the environment of the home would be less likely to contribute to exacerbation. Patricia speaks about the problems caused through the exacerbation her skin eczema by environments that are too warm. ‘I don’t like heat. When I get too hot I’m more likely to itch’, she says. Patricia’s use of an electric fan helped to provide more control over the temperature of her environment. ‘I have a fan by the bed and I just keep my temperature down with that really’. Electric fans were placed around the homes of a number of respondents with eczema to help keep rooms cool in order to avoid exacerbations caused by heat. Similarly, keeping the temperature of the house low by leaving the central heating off helped to reduce how itchy Pavana, who has eczema, feels while she is at home. Pavana says:

> I will sit down in front of a fan. That can be quite helpful. The coolness of that really is soothing sometimes. And also I literally sometimes won't put the heating on, and I'll walk around really cold and shaky and freezing, but the eczema goes down. So you've got this real level of discomfort, on the one hand, because you're cold, and you really want to put on a cardie and jumper and stuff but, because you're free of that itch, it's preferable.

By maintaining a low temperature throughout her home, Pavana was able to feel greater control over the management of her skin. However, while the cool environment was broadly ‘soothing’ for her itchiness, Pavana acknowledged the discomfort that results from living in a cold house.

Moreover, given that the house is a social space shared with others, it is not only Pavana who feels this discomfort. Rather, Pavana recognises that the cold environment she creates to manage her eczema also means that her home may be uncomfortable for family and guests:

> I’ve had guests that come and don't take their coats off at times, you know, you just kind of realise that you've put everyone in the same boat. You don't realise sometimes how cold you leave it sometimes, so yeah. You put yourself in discomfort to alleviate the other one.

When objects and materials associated with healthcare environments are brought into and combined with the home environment to meet illness needs, this can alter the “ambience” of the home. With their introduction and assimilation into the spaces of the home, as Angus and colleagues (2005, p. 172) put it, ‘the transposition of these aesthetic schemas rendered the home a contested space’. Moreover, the home is both private and public as it is constructed through social relations and forms of communications that stretch beyond its walls (Massey, 1994). The assimilation into the home of furnishings made of materials chosen for their expedient cleaning rather than their decorative or comfort-giving qualities, and strategies such as allowing rooms to become cold in the absence of central heating clearly altered the ambience of Pavana’s home. The decisions that Pavana has made illustrates a difficult compromise in choosing to suffer one form of discomfort, the sensation of cold, in order to experience the relief of another, the unbearable itch of eczema. Furthermore, the option that is preferable for managing the symptoms of illness induces discomfort that is both physical and social, as it creates a home that feels cold not only for Pavana, but for her family and friends too. The transposition of aesthetic schemas conceived for the management of disordered skin illustrates the rendering of Pavana's home as a contested space in which there is somewhat of compromise between its use as a space for convivial social relations and as an efficient healthcare environment.

For one respondent, however, the bedroom had become a space within the home that was quite starkly contested and caused disagreements between Roshan and his family about how the room should be characterised and treated. Having experienced debilitating exacerbations of his eczema, Roshan had become socially withdrawn and retreated into spending increasing amounts of time alone in his bedroom within the family home. As a means to better understand and bring his condition under control, Roshan reframed his bedroom as a laboratory, with prohibitory guidelines for how it should be treated by his family members. As Roshan explains:

> I used to argue with my family…. I said things had to be done THIS way. If they were not done this way, then I could go nuts. 'Cause if it messes up my- 'Cause I'm already losing years. If it means that I get another reaction, it means I can't sleep for three days. So I'd just be like "it's gotta be strict". I used to say, "treat my room like a lab". When you come into a lab, you don't contaminate the lab, yeah? That's it. Now I'm ok with it now. Like the other day the door was open while my mum or dad was throwing out some stuff from the house. Last summer, I would have been like "shut that door now".

Issuing strict rules to his family on the avoidance of potential "contamination", Roshan's bedroom became a highly contested space, both part of the home and conceptually separated from it. Moreover, Roshan's concerns about the further exacerbation of illness influenced the everyday routines and social relations of his family members within the space of the home. In accordance with work on "therapeutic landscapes" (Dyck et al., 2005; Gesler & Kearns, 2002; A. Williams, 2002), Roshan's designation of his bedroom as a laboratory is a vivid illustration of how interpersonal routines within domestic spaces can reconstruct the home as a setting for care.

The use of medications exemplifies the movement between public and private as they often enter into the home from outside, breaching this divide (Hodgetts et al., 2011). Adapting the home environment for the management of illness commonly included the use of space for the storage and consumption or application of medications. Indeed, the home has been shown to be a significant place for both using and storing medication (Sorensen et al., 2006). While creams, ointments or body wash products were commonly kept in bathrooms or bedrooms where they might be more convenient for application to unclothed bodies, some of the respondents spoke about how they used space in other locations within the home, such as the kitchen. A few spoke about their use of the kitchen refrigerator for keeping treatments that required cold storage or which made their use more comfortable when required. Speaking about her practice of keeping Vaseline in the fridge, Erica says:

> I would always carry Vaseline around with me as a-, because I recognised that as soon as my skin got dry or cracked it was just gonna get more itchy, so I would always be quite vigilant with having little pots of Vaseline with me or keeping them in the fridge, keeping them cold, because that was really nice and soothing.

Hodgetts et al. (2011) demonstrate that the carefully considered and strategic placement of medications within the home facilitates the forging of routines of consumption and care. Through her vigilance to keep treatment products within easy reach in the refrigerator and to monitor the condition of her skin, Erica developed a care routine of applying soothing treatment as a pre-emptive before her eczema became too itchy. While Erica's use of the fridge for storing treatment products made its routine application more convenient and pleasant, the product could be stored elsewhere and, as a product that is used commonly as part of skincare regimes, did not appear to produce concerns about stigmatisation from people who saw it in the fridge.

By contrast, Monica's repurposing of fridge space to store packs of injectable vials of biologic treatments for psoriasis, a condition that affected both her skin and her joints, was essential for the viability of a treatment which needed to be kept cold. This presented a range of social complexities. As Monica explains:

> then there's the arthritis part of it, where I tend to not want to let people too close to me, because I mean if they come over and open up my fridge, and you know what Humira is? And they see a pack of Humira. I have to tell them. Or if they open my drawer and they see all these needles, they might ask why. Or if I go to their house and I have to put it in their fridge because I'm staying there for a few days. You know, I have to think way harder about do I really want this person to know that I have this? Because I don't want them to treat me differently.

In this case, storing medication in a place more conventionally used for convenient access to fresh food items presented concerns about stigmatisation, disclosure and thus the development of social relationships. This concern for stigmatisation was compounded by the need to store needles required for injecting this medication in the home, given the negative social connotations that are attached to vials, syringes and the use of needles (Schabert et al., 2013), such as their links to illicit drug use.

Anticipatory Dispositions and Practices

Planned Orientations to Everyday Life. Moving between states of relative quiescence and skin that was itchy, inflamed, weeping, dry, cracked or sore, the habitus of respondents was often framed by a necessity for the near-constant use of practices for alleviating, managing or avoiding profound physical discomfort. As part of the ongoing practices to manage the sensory and material bodily aspects of illness, strategies of anticipating and avoiding exacerbation often became habitual aspects ingrained into everyday life. In this section it will be shown that anticipatory strategies were applied in the finest of details to bodily conduct across an array of social spaces and material environments. These strategies sometimes involved a great deal of mental labour through foresight and planning in addition to the physical burden of conducting everyday actions with meticulous precision. Moreover, the unpredictable nature of chronic illness and everyday interactions meant that this “managed involvement” in daily living could not always offset exacerbations, despite the heavy toll which these anticipatory strategies demanded. Respondents sometimes experienced a sense of ambivalence at how the use of these strategies for avoiding exacerbation shaped their daily routines in ways that felt out of step with their ideals and other aspects of their lives.

The priority she must give to managing her skin produces a planned orientation to daily living that contradicts with a sense of autonomy that Helen greatly values, and which she feels in other aspects of her life where she is able to act with greater spontaneity. Helen says:

> So I'll always kind of, you know, like an old person, have a bath at about nine o'clock. I would never kind of like have a quick bath just before I went to bed because of the procedure. If you rush it you can kind of trigger an attack. [Deep breath][Laughter] Poor me! [Laughter] Bet you know it sounds a bit like that, but you know, you can kind of trigger just like a mad itching attack, I don't know how you do it but…. I guess it's that planning idea. I don't like the idea of planning. It is that. I think it's that. It's not being able to be kind of like ooh I fancy a bath! It's kind of like, ooh, I'm going to have a BATH tonight so I'd better plan it because it's a big procedure.

The tight scheduling of her baths, always around 9 o'clock rather than at any time she chooses before bed has identity implications for Helen, as it makes her feel 'like an old person'. The lack of freedom that Helen experienced as part of this bathing schedule centred on the required 'planning' of an act that she would like to be more spontaneous:

> I guess it's that planning idea. I don't like the idea of planning. It is that. I think it's that. It's not being able to be kind of like ooh I fancy a bath! It's kind of like, ooh, I'm going to have a BATH tonight so I'd better plan it because it's a big procedure.

Through its exaggerated production, the evening bath become what Helen terms a 'big procedure', which involves a level of consideration at odds with the capacities and options that Helen values and perceives of herself as having in other aspects of her life. Drawing on findings from disability research (N. Hansen & Philo, 2007), it has been shown that the realities of timing, space and speed of undertaking tasks with non-conforming bodies require detailed planning and strategic negotiation to a point where practices are habitual only to the extent that they take place as part of everyday life. Helen's resignation towards her carefully planned 9 o'clock bath can be understood as a response to how her skin condition demands a lifestyle in which each day is imbued with routine labour merely to avoid exacerbation. Moreover, a need for the careful planning and enaction of even mundane daily activities contributes to an identity centred around illness (Kavanagh & Broom, 1998; Morden et al., 2012) that is at odds with her ideals and intentions.

Accounts of the material management of the skin illustrated a heightened sensitivity to the risks presented by the physical world and their own bodies (Kavanagh & Broom, 1998; Morden et al., 2012). Drawing on experiences of previous flare ups, this sensitivity to risk reflected feelings of vulnerability to environmental settings and substances, and well as bodily habits, that might lead to an exacerbation.

Negotiating Bodily Risks. Displaying a hyperawareness to environmental conditions and the risks of undertaking a range of everyday activities, respondents often demonstrated anticipatory or precautionary dispositions in the hope of negotiating control over aspects of their illness experience. Michelle describes how a dental surgery procedure caused an injury to her tongue that led to an exacerbation of her psoriasis. Michelle says:

> I went to the dentist a few weeks ago and I didn't have, it was an option of having a root filling or having the tooth removed… So I went for having the root filling because I didn't want an open wound, because I've understood that when you do have a trauma to your skin it can cause a flareup. And as it's all quite calm at the moment I didn't want to cause a flareup, so I opted for going for the root filling. And the dentist unfortunately, while I was having it done, burnt my lip and accidentally cut my tongue... so within um 24 hours I started developing a large patch on my other hand along the knuckle area, and I had a flareup underneath my arm as well, in my armpit, so, and that was the result I think of the trauma at the dentist… So I tend to be very careful about if I may injure myself or cut myself, um, because I worry that it'll cause a flareup, and then if it causes a flareup I know how I'm going to feel…. And even down to DIY. I, just, I, sometimes I say oh no I'd better not do that because I don't want to cut myself or, I don't want to risk giving myself any injury at all. So, I'm very careful.

A cautious approach was evident in Michelle’s strategy for negotiating the risks of exacerbating her psoriasis through bodily injury. This approach reflects prevalent health-related discourses of risk, which inspire ‘anxiety, vulnerability and concern about hidden illness or disease lying in wait’ (Lupton, 1995, p. 105). Michelle’s knowledge about the impact of injury to her body on her psoriasis in the past has led her to be wary of the potential for injuries to her skin, to anticipate the risks involved and enact plans to help reduce the risk of skin abrasions wherever possible. This is clear in her decision-making process about health-related procedures and in doing everyday practical tasks. This echoed findings from the quantitative psychological research of Mizara et al. (2012), who demonstrated that one of the "maladaptive schemas" leading to distress in people with psoriasis and eczema centred around "vulnerability to harm".

A precautionary disposition about the potential for bodily harm often appeared to limit aspects of respondents' agency over the scope of their involvement across a variety of common embodied activities, illustrating what Boyle (2019, p. 36), in a study of experiences of chronic anxiety, terms a 'managed involvement' in everyday life. Highlighting the temporal and spatial complexity of negotiating life with a chronic condition, Boyle (2019) notes:

> anticipatory notions are deeply intertwined with understandings of the habitual: on one hand they set in motion the transformative potential of habitual practices and routines that establish control and predictability; on the other, they embody the immanent and foreboding disruptive capacity of uncertainty. (p. 33)

Furthermore, the habitual labours of careful planning and action involved in anticipatory strategies were not always rewarded by an avoidance of exacerbation, demonstrating how experiences of unpredictability common to many forms of chronic illness can disturb the "illusion of consistency" proffered by habitual practice (D. Bissell, 2010). As Michelle's extract illustrates, the risks and uncertainties at play during invasive interpersonal procedures such as dental treatment, given the sensitivity of her skin to abrasion, make the work of strategic planning for the avoidance of exacerbation incredibly difficult. The often dynamic and unpredictable character of chronic illness means that the extent of habituation may remain persistently limited (Crooks, 2010). While practices such as DIY can be strategically avoided as a means to elude injury, the uncertainties presented by necessary dental care can disrupt even the most diligent of anticipatory planning and habitual routines for managing illness.

Workplace Anticipation. Respondents living with skin conditions that were particularly sensitive to exacerbation through exacerbatory substances touching their skin, such as people with contact dermatitis and other forms of eczema, were often highly attentive to the likelihood that their working conditions might impact upon the exacerbation of their condition. A number of respondents spoke about the anticipation and contingency practices required for managing their illness at work. Practices included carrying medications and other treatment materials to work, to be able to manage the skin condition while working, and maintaining supplies of treatment products in the workplace.

As part of managing the impact of contact dermatitis in his office workplace, Matt was keenly aware of the surfaces he touches that are also touched by other people. As the computer keyboard he used at work was shared with colleagues, Matt took steps to avoid making contact with any substances that might be left as residue on the keyboard surfaces. He kept cleaning products with him at work and wiped the keyboard as part of his daily routine. Matt says:

> At the moment, I'm working from home, so it's not so much of an issue. But I used to work in an office, and I'm doing software work, and we had shared workstations, you know? So at that time I used to be very conscious of every time I used to go to the office I used to have like an alcohol gel and some tissues, and I'd wipe down the keyboard. So that would be a daily routine thing that I would do.

When we spoke, Matt was in a period of working from home, which meant that the need he had for cleaning his workstation was no longer the daily requirement that it was when he was working in an office. Beyond the cleaning act in itself, working from home meant that Matt was freed from being ‘very conscious’ of the need to perform this precautionary labour. The appropriation of this environment as a place where treatments or precautionary practices, such as wearing gloves, might be used was sometimes negotiated with caution about the perceptions of others, such as the potential for stigmatisation (Scambler, 2009). Keeping medications and other illness management products in the workplace meant that the working environment also functioned to an extent as a treatment venue (Dew et al., 2014). The labour of managing the skin is materialised through the need to carry a range of treatment products around each day. The bags of respondents often grew heavy with the treatment products and other items needed to manage the skin. Pavana says:

> my handbag weighs an absolute tonne because there's any number of creams in there and the brush to help and the antihistamines and the antiseptic cream, and um, the cotton gloves to put on and off.

The contents of Pavana's handbag makes apparent the extent and variety of the daily practical needs for managing her skin, as well as the anticipatory approach required in preparation for managing a condition that fluctuates in its exacerbation and the subsequent illness management needs. The sheer weight and size of the bag and its contents that Pavana must carry to work adds to the labour to endure each day and acts as a constant material reminder of her illness. In terms of the amount of time, preparation and effort invested in its undertaking, the "hidden work" (J. Laws, 2013) of managing illness can be as constraining as it is liberating. As a physical metonym of her illness needs, Pavana's heavy handbag brings to light some of this hidden work.

Controlling Bodily Conduct

Rules for Self-Contact. Many of the respondents had developed clear rules for bodily practice, such as avoiding physical contact in particular environments and being careful to moderate self-touch. Such rules were commonly based on past experience of how contact with known exacerbators or forms of self-contact with the skin, such as scratching, could instigate exacerbation. Speaking about his moderation of self-touch for avoiding the exacerbation of eczema, Matt says:

> So there are small things like, for example, I never touch my face. If it itches and I need to touch my face, I always touch my face with the back of my hand. Or even, if my head is itching, I itch with the back of my hand. I find that's just one of those things, you know? Because at home, I can avoid any products that contain SLS, but once I'm, you know, out and about, that won't be possible. So I try to wash my hands often, but I come home and I'm trying not to touch…. And I find that it works. It works in two ways. First of all, it helps me, you know- If I have a flareup of my dermatitis then whenever I scratch I make it worse, you know? So it's like a cycle. So I try to avoid that, and by using the back of my hands, I instinctively- I implicitly avoid using my nails to scratch the wounds. So it's like a win-win for me.

Matt points out that the careful use of the back of his hand whenever he touches his face helps to avoid transferring exacerbatory substances he may have touched with his hands. For Matt, this practice has become reflexively embodied as a habit (Crossley, 2006) that is enacted even if his face is itchy and helps to avoid wounding his skin by scratching it with his fingernails. In addition to his rule about self-contact, Matt has also developed strategies for managing his concerns around exacerbation produced by interactive forms of contact his considerations for negotiating physical environments with his skin condition in mind, such as his strategic avoidance of handshakes (Hall & Hall, 1983), acts of social reciprocity involving skin-to-skin touching which could also be exacerbatory. As Matt puts it:

> And I try also for example, in general, I don't shake hands. [Laughs] I'm not a person who shakes hands. And I'm paranoid about, for example, sharing a hat or a cap. I don't do that….I try not to seem awkward, but when you meet someone, already, when you don't extend your hand, it is less likely. If someone really wants to shake hands, I will

> oblige. Or, for example, I do play tennis. After a tennis match, I do shake hands. And then I head to the showers, and that's it. But I try to avoid it when I- I keep like a ledger, you know, somehow in my head, saying oh, I have to wash my hands. Don't touch anything until you wash your hands. You know? Something like that. It's like something that I'm aware of, every day.

Matt's rules for contact appear to be helpful to him in the strategic pre-emptive management of his disordered skin in complex social environments. In addition, through the embodiment of these rules, Matt has been able to moderate the impact of his response to itchiness through an habitual shift away from scratching his face with his fingernails. Boyle (2019) argues that while the "micro-management" of daily routines and practices can extend control over spatial and temporal dimensions of experience, these acts also represent a process of 'creating, or maintaining, a cohesive, bounded and functional sense of self' (Boyle, 2019, p. 34). In this vein, Matt's micro-management of aspects of his daily routines and bodily practices help to manage his concerns about exacerbation that could arise in different social spaces, but his experiences of effectiveness in managing exacerbations using the habits he has developed also offer a broader sense of autonomy over his wellbeing. However, as Grosz (2013) suggests, the essence of habit exists:

> somewhere between the necessity of ease and the torment of need, one side directed to making the world readily habitable, and making the living being at home in the familiar; the other directed to a trajectory of infinite repetition, a tic, an addiction, a limitation and constraint on life. (p. 202)

Matt's skin-related habits, and his continual reflexive awareness in keeping a mental 'ledger' of his need to sanitise his hands if they have been in contact with something that is a cause for wariness, are clearly source of strain, but in relation to the agonising experiences of exacerbation they are habits that he is willing to perpetuate.

Distraction tactics. Strategies for avoiding acts of grooming the skin using techniques such as “habit reversal” have been shown to offer some effectiveness for people living with chronic skin conditions, albeit focusing largely on pruritic conditions such as eczema (Norén, 1995). The use of tactics for distraction and avoiding habitual scratching were discussed as a way to avoid the impact of acting upon the body’s sensory urge to scratch itchy skin. This was illustrated in stark detail by one respondent with eczema, Pavana, whose itchiness often made it incredibly difficult to focus on everyday activities. Pavana found that taking actions which required keeping the hands busy made it possible to reduce, to some extent, the accumulation of scratching and subsequent ‘damage’ to the skin over the course of each day. Her responses will be drawn on here extensively to illustrate the tactical planning that someone may put into everyday life in response to the demanding sensations of itch, and the implications this has for an embodied daily reality. Pavana says:

> I’m doing more sewing, 'cause I'm trying to do things that'll keep my hands occupied, 'cause it seems to be, whenever there's like a little gap or I'll park up to pick my daughter up, and there's a ten minute gap somewhere you just end up scratching, whereas, if you keep yourself constantly moving around, you get, you know, you're better off. So it's the distraction techniques that you're trying to do all day to avoid, sort of causing the damage.

Using sewing as a distraction technique that occupied her hands helped Pavana to minimise opportunities for scratching, which emerged during the “gaps” in time throughout the day. These gaps were often the periods of time between discrete embodied activities. Physical practices that required constant handiwork helped to fill these gaps by reducing the possibility for Pavana’s hands to be free to rest or to move in a less structured way. Any freedom from the continual physical occupation of the hands, Pavana had found, led automatically to the habitual practice of scratching that she aimed to avoid. As Pavana puts it, ‘if you keep yourself constantly moving around… you’re better off’. Pavana’s strategy of finding opportunities for external focus as a means of occupying her hands means that she often takes on further labour as part of daily living. One area of extra labour that Pavana takes on is in designating herself as driver for family journeys by car. Pavana has found that the embodied task of driving makes it less likely that she will scratch:

> And when we go to events and functions, I drive, because if I sit in a car with nothing to do, what I will do is do that [mimes scratching]. So I have to keep myself distracted with driving. And that's more comfortable to me than not.

Even while driving, Pavana faces the difficulty of negotiating the habitual demand to use her hands to scratch, should the flow of traffic come to a stop. ‘And if I stop at lights, red light, and it’s like, “keep on moving”, Pavana says. She wills the traffic to flow so she can keep on driving, or perhaps it is herself who she is urging to remain in motion. It is notable that the preferred distraction practices that Pavana speaks about share in common a distinct element of productivity. Indeed, Pavana addresses the importance of choosing activities that feel productive. She says:

> And uh I'm always trying to find activities. 'Cause I tried that colouring thing for a while thinking oh that would help, but it's just so bloody frustrating [whispered phrase] 'cause you don't achieve anything. You know, you've done four hours of colouring. What the heck am I going to do with that?! [laughter]…. At least the sewing produces something, you know. I need a product at least at the end of it.

A moral imperative to be productive is clear in these extracts. Pavana presents a contrast between sewing, the outcome of which she feels has a valuable material product, and filling in adult colouring books, which feels to her like a waste of time. In harnessing her physical capital and converting it through this handiwork for an outcome which ‘at least’ feels productive (Shilling, 2004), there is a sense for Pavana that the effort expended regulating her behaviours to deny the bodily urge to scratch can be morally justified.

The constant effort that Pavana puts into resisting scratching through performing distracting activities often took a toll on her mental wellbeing. This ongoing struggle, in which she impelled herself not to scratch and was perennially searching for strategies to distract herself, led Pavana to feel stressed whenever a "gap" between activities offered an opportunity for respite and mentally exhausted by the end of each day. Pavana says:

> you can't unwind. I feel like my head can never unwind because I'm always trying to keep busy, or my hands occupied…. So it's, I just find my head-, I find like I've got a heavy-, like I've got a migraine coming on at the end of the day, 'cause I've been trying to do-, trying to stop myself all day. "Don't scratch, don't scratch", in your head. Constantly think "don't scratch, don't scratch. What can I do not to scratch?" All the time…. I just feel it gives me such a layer of stress of when I should have those moments, those ten minutes or something just to unwind.

The loss of "unwinding" time added to the burden of work Pavana dedicated to managing her illness and compounded the impact on her daily life and her wellbeing. This constant mental and physical labour which she performed both alone and with her family to control her bodily actions illustrates that the management of chronic illness often entails 'invisible, embodied practical, emotional and social work' (Bell et al., 2016, p. 184). Moreover, despite her strategic efforts to establish routines to distract herself from her symptoms, many aspects of Pavana's day could not be controlled, or made attempts at control unfeasible, owing to the particular forms of embodiment involved in each activity. As Pavana says, 'when I wanna sleep, when I want to cook, when I want to read, when I want to- anything in my day, that's when I can't distract myself from it'. Activities where Pavana was not continually involved in focused labour presented opportunities for scratching to take hold. The incessant itchiness that Pavana experienced, and the insistent habitual practice of her scratching, meant that many of the activities that were important parts of her day remained difficult to negotiate.

Pavana's strategic efforts at control over her itchy body illustrates how the onset of chronic illness can necessitate new routines to help stabilise wellbeing (Boyle, 2019). However, Pavana's experience also demonstrates how bodies that do not conform can unsettle taken-for-granted spaces and activities (Smith, 2012). Irrespective of the mental and physical effort put into the planning and performance of manual routines to help occupy her hands and avoid scratching, everyday activities continued to be disrupted by an intransigent body.

Through the anticipatory dispositions and practices that respondents deployed, it was clear that there was often a profound sense of concern about the potential for illness to be exacerbated. Adaptations were made to help reduce the risks posed by environments, while habitual strategies were developed to try to minimise the potential for activities and bodily actions to cause exacerbation or injure the skin. However, the accounts in this section often revealed tensions within actions that may be considered habitual (Grosz, 2013), as the need for continual mental and physical labour that were required for planning, enacting and monitoring these anticipatory strategies frequently entailed a substantial burden.

Conclusion

Through an exploration of the everyday material experiences of living with chronically disordered skin, respondents' accounts highlighted several substantive areas of concern which stemmed from matters of corporeal dys-appearance, as well as the adoption of strategies for managing these concerns. Cutting across these themes however were issues of agency over the body, moral evaluation, and the performance of mental and physical labour. Moreover, owing to the erratic bodily manifestations of illness associated with chronic skin disorders, negotiating these issues often presented an ongoing and unrewarding challenge, yet this was a challenge that respondents were faced with the perennial need to undertake. In the course of this chapter, a number of thematic areas emerged as important for understanding issues presented for embodiment with a chronic skin condition, and the ways in which respondents attempted to manage these bodily concerns. Each of which areas will now be addressed in turn.

The first thematic area addressed the embodied experience of disordered skin as a type of “corporeal dys-appearance”. Drawing on Leder's (1990) work on the absent body, chronically disordered skin was found to emerge into awareness as an alien presence that affected a temporo-spatial sundering within the body, separating from and attacking the self. On exacerbation, distressing sensations emerging from the skin became the focus of attention, demanding resolution. The attentional focus of dys-appearing skin, which for many respondents included the overwhelming sensation of itchiness and other forms of discomfort, was found to cause disruption to intentions which respondents held towards projects that were valuable in their lives. Moreover, with experiences of bodily illness thrown into sharp focus, erratic progressions of symptoms and uncertainties about managing the disorder frequently produced concerns that were existential in nature. In this ongoing process of interpretation and repair respondents questioned the meaning behind their experiences. The disruptive qualities of corporeal dys-appearance were often found to take on distinct temporal qualities, as the symptoms of illness were frequently experienced along fluctuating trajectories in which periods of exacerbation were interspersed with periods of relative quiescence. Moreover, these fluctuating experiences appeared to highlight the differential between these periods, not only for the shift in sensory experiences between “flare ups” and “clear time” but for how this altered the necessity for routines of self-care.

The next area for thematic focus was “grooming” the skin. Respondents’ accounts revealed that practices of scratching at an itch, picking off psoriatic scales or squeezing spots were often an area of concern. These practices, and attempts at their avoidance, were notable for the amount of consideration they occupied as part of everyday life and could be categorised as a type of "skin work" (Lafrance & Carey, 2018) performed by those with disordered skin. Acts of grooming the skin took on a range of meanings for respondents. Grooming was sometimes framed as a means for gaining control over disordered skin, as part of illness management practices. Alternatively, grooming was presented as acts of sensory relief necessary for removing distressing sensations, particularly for resolving itch. However, across all accounts, respondents regarded grooming with a sense of ambivalence which, it was shown, stemmed from a consideration of the implications of performing these acts on the body.

Acts of grooming were presented as an assault on the skin, which brought momentary relief (and perhaps even pleasure) but had consequences for ongoing illness management, the long-term health of the skin and its outward appearance. Given this framing, grooming was frequently evaluated in moral terms as a transgression of norms about appropriate bodily behaviour, and was followed by feelings of regret. As obligations towards the management of external appearance are gendered (N. Wolf, 1990), grooming represented a particular transgression for women, since the consequences of engaging in these non-conformist acts could jeopardise claims around beauty.

Sleep emerged as a focus of bodily experiences for many of the respondents. While it is perhaps unsurprising that sleep should feature in respondents' accounts, given the amount of time dedicated to this restful act each day, the variety and depth of concerns around sleep was noteworthy. The relationship between sleep and corporeal dys-appearance was found to be complex and multidirectional. Through the agentic "absence" that sleep engenders, respondents experienced themselves as vulnerable (S. J. Williams, 2007) to bodily dys-appearance and the possibility of unwanted grooming. This vulnerability to the dys-appearing body, and the practical and emotional consequences of “damaging” the body while sleeping, created a range of concerns about going to sleep that often affected the processes required for achieving the “ontological security” necessary for sleep.

Moreover, corporeal dys-appearance that emerged as symptoms of itchiness while awake made achieving sleep each night incredibly difficult for many of the respondents, which led to experiences of tiredness during the daytime. Owing to the difficulties they often faced in achieving restful sleep, and their strategic responses to these challenges, respondents faced concerns about breaching a range of temporal and spatial expectations prescribed as part of the “social etiquette of sleep”. Drawing on elements of sleep etiquette which problematised daytime sleepiness and night-time wakefulness, respondents had concerns about the acceptability of napping, in particular for its impact on productivity. The contemporary drive for productivity amid a 24/7 society was also found to play a role in the way respondents “put sleep to work” (Kroll-Smith & Gunter, 2005) through the use of their sleeping time as an opportunity to apply treatments to their skin.

Following findings about the difficulties of achieving restful sleep, which often featured concerns about the “mess” caused to the body and bedclothes by scratching the skin while sleeping, the next theme addressed issues of clearing up after corporeal dys-appearance. In the aftermath of picking, squeezing or abrading the skin, the appearance of bodily exudations in the form of fluids and flakes of skin, or the emission of malodours from skin weeping after being scratched, were frequently found to be disturbing experiences that produced feelings of disgust (Mauss, 1979). As “matter out of place” (Douglas, 1966), the emergence and shedding of these substances off the body produced sensations of dirtiness and a need clear them up.

Developing the novel concept of “containing” as a type of skin work that can be added to those of “concealing”, “grooming” and “medicating” as part of Lafrance and

Carey's (2018) framework, it was shown that the work of managing disordered skin often required for organic exudations and other substances associated with disordered skin that have left the body to be contained to avoid soiling the environments in which they have been shed. While part of the work of containing disordered skin is physical, another part involves constant reflexive awareness of the body producing these "dirty" substances. The work of containing the skin was exemplified by the need to deal with the proliferation of scales of skin shed from the body and the laborious and often unsatisfactory work of expunging organic substances and the remnants of creams and ointments from clothing and bed linen through laundry.

The final theme addressed the emergence of "anticipatory" practices as a means of managing bodily experiences of illness. Applying the concept of "anticipatory action", which describes how orientations are 'made and lived in the name of pre-empting, preparing for, or preventing threats' (B. Anderson, 2010a, p. 777), it was found that respondents commonly took on anticipatory dispositions and actions in how they approached their everyday lives. By addressing the material environment of the home to aid the expedience of routines for using medication or for cleaning, and to minimise the likelihood of exacerbating illness, domestic environments often became hybrid treatment spaces (Dew et al., 2014). In addition to their application in adapting material environments, anticipatory dispositions were apparent in respondents' planned orientations to the routine aspects of daily life and the ways in which they assessed and negotiated risks. Based on a reflexive awareness of the vulnerability of the body to potential harm, there was often a sense of caution to how respondents approached everyday practices. Indeed, habitual practices sometimes appeared to constrain possibilities for action as much as they offered opportunities for control.

As well as material environments and orientations to everyday life, the behavioural conduct of the body itself was also a target for anticipatory actions. Respondents outlined rules for self-contact with the skin imposed as a means to avoid exacerbation through grooming or other forms of touch, which through their perennial enaction had become habitual. The strategic avoidance of exacerbation was also shown to contribute to the development of routines for distraction from the symptoms of illness. By putting the body to work through tasks that required a focus of physical action, rather than allowing the body to move freely, it was hoped that this may reduce the impact caused through habitual grooming. However, as so frequently illustrated throughout this chapter, the dys-appearing body often proved to be intransigent to intentions.

This chapter set out to explore how people living with chronic skin disorders experienced and responded to the corporeal and material aspects of their illness. What emerged was a sense of how central a concern the sensory and organic materialities of the body were for experiences of everyday life. What also became clear was the extent to which daily practices and dispositions were shaped in order to manage the corporeal demands and needs of disordered skin. The skin was often a source of substantial discomfort and problematised many aspects of embodied experience, but also engendered existential and moral concerns. Moreover, owing to ongoing yet erratic illness trajectories, responding to the wide-ranging difficulties presented by disordered skin required respondents to engage in burdensome labour, both physical and mental, which for some was experienced as a Sisyphean task. However, as has been illustrated throughout this findings chapter, respondents developed strategies for negotiating these corporeal difficulties that were creative and attuned to their bodily needs and social environments.

Findings: Experiences of Treating – i. Repertoires of Medical Treatment

The use of medical treatment practices are an important component of the management of many forms of chronic illness, albeit a component that is often associated with ambivalence on behalf of users (Gabe & Lipshitz-Phillips, 1984). Despite the prominence of medical treatment in the long-term management of illness undertaken by those with chronic skin conditions, there is room for greater understanding about the usage practices of medical treatments for the skin and how people relate to the treatments they use for managing their skin.

It is known that practices of accessing and using treatments in the management of chronic illnesses often require a great deal of work. Jobling (1988), for example, noted that the treatment of psoriasis often felt to patients like a Sisyphean effort using the treatments available in the era when that research was conducted, with a laborious burden that users did not feel was rewarded with effective relief of symptoms. It is an aim for this chapter to develop what is understood about the treatment practices used by people managing their disordered skin and what implications these treatments have for their broader lived experiences. Given the prominence of pharmaceuticals in the treatment of chronic skin conditions in the form of topical creams and ointments, tablets and other treatment modalities, a central concern for this chapter lies in better understanding the meanings that respondents associate with the use of drug treatments.

Using a framework developed by Dew and colleagues (2015) for the representation of different “repertoires” deployed by householders in discussions about their use of pharmaceuticals, it is hoped to gain understanding about how respondents relate to the medical treatments they have used for managing their illness. Dew et al. (2015) identified four repertoires around the use of pharmaceuticals - those of “disordering society”, “disordering substances”, “disordering self” and “reordering substances”. Put briefly, the "disordering substances" repertoire frames pharmaceuticals as a threat to physical or mental equilibrium. Meanwhile, the "disordering society" repertoire is based on a belief that a reliance on the use of pharmaceuticals represents a society in an unnatural state. Using the "disordering self" repertoire, pharmaceutical reliance signifies a moral failing of the user or a stigmatised failing of the body. Lastly, the use of the "reordering substances" repertoire demonstrates a view of pharmaceuticals as substances that sustain or restore order to wellbeing.

Evidence will be given to support the argument that respondents drew on each of these repertoires in discussing their use of pharmaceutical treatments, albeit to different extents and often in relation to particular circumstances in their illness experiences. It will be demonstrated that the use of the "disordering society" and "disordering substances" appeared to be most prevalent among discussions with respondents about treatments, while the "disordering self" and "reordering substances" repertoires were drawn on to a lesser extent.

Pharmaceuticals as Disordering Substances

In the "disordering substances" repertoire identified by Dew and colleagues (2015), pharmaceuticals signify a 'threat to one's physical or mental equilibrium', but crucially, 'still might be required' (p. 216). Under these circumstances, people must "weigh up" the risks and benefits of their use, facing responsibility for the use of substances and gambling on the consequences. In this way, pharmaceuticals can represent what Gabe and Lipshitz-Phillips (1984) described as a "necessary evil". Indeed, the Greek term "pharmakon" from which "pharmaceutical" developed means both remedy and poison (Riley, 2010).

Drawing on Parsons' (1958) "sick role", people who are ill have a responsibility to seek treatment. However, when pharmaceuticals are conceptualised as "disordering substances", this responsibility presents a moral dilemma for the individual in the treatment they pursue. Medications may offer a means of control over illness and it may be found that pharmaceuticalised governance is necessary, but when considered using a repertoire of disordered substances there remains a moral duty to maintain a stance of vigilant assessment over the precarious balance of risks and benefits. Indeed, managing the use of medication for chronic illness is often found to be a "balancing act". D. L. Hansen & Hansen (2006) describe this as an 'attempt to balance the positive and negative effects of the medication by considering past and present experiences along with concerns, expectations, and goals for the future' (p. 1280). Even where pharmaceuticals are found to be necessary for wellbeing, pharmaceuticalised governance may still be resisted for the promotion of individual autonomy over treatment.

Arduous Burdens of Treatment

Treatments for skin disorders are often experienced as being unpleasant, ineffective and draining of time and effort (Dubertret et al., 2006). The ongoing difficulties of treating psoriasis, for instance, can often result in feelings of despondency about the efforts given just in the attempt to stay "on an even keel" (Wahl et al., 2002). Treating a chronic skin disorder was often found to involve a series of arduous daily processes for respondents. Reflective of Jobling's (1988) work on psoriasis, the treatment of disordered skin across each of the represented conditions often required strict, ritualised and sometimes punitive practices to manage bodily symptoms and, to the extent that it was possible, restore "good order" to the state of the skin. Many respondents spoke about the labour required to manage the sensory discomfort presented by their condition through treatment. Treatments were often complex, and the processes involved in preparing or using treatments were sometimes very time-consuming. Moreover, the labour of managing illness often extended beyond the application of treatment itself. Respondents often spoke about the modifications they had made in their daily living practices to accommodate the time and space they needed for treatment.

Reflecting on the effort involved in carrying out ritualised processes necessary for treating her eczema, Rebecca says:

> after having a shower lagging yourself with cream, and then having to walk around with nothing on for ages, well no clothes on as such for ages until it's soaked in enough, so that was a pain…. then before you go to bed, same routine, cover yourself in cream, gloves, put your cotton gloves on before going to bed. And you feel like you're going to bed like a wax doll, because… when it was really dry, the best cream is a cream like Vaseline, like a grease, but that doesn't soak in, so however long you wait… you're still going to bed like a wax doll… that was like a daily thing then, like creaming and gloves and all that sort of thing. It was, yeah, it was quite a lot really, thinking back.

It was not uncommon for a great deal of time each day to be devoted to the management of the skin, spanning the waking hours, and for many, interrupting time portioned off for sleep. As Rebecca's account illustrates, the application of topical medications and moisturisers in the form of creams and ointments to the surface of the skin was often a lengthy process, particularly if much of the skin of the body was affected. This routine would often need to be repeated three or four times per day in the case of moisturising creams if medical advice was being followed, while the use of topical steroids to treat a flare-up might also need to be applied carefully to these same areas once or twice daily.

Allied to the time dedicated to the management of the skin, the physical effort involved was, for many, a daily source of frustration, while for others, the work required was experienced as exhausting. It was often less the effort required for any individual act of treatment that was notable, but rather an accumulation of fatigue at undertaking these elaborate processes. For many respondents, treatment required the fulfilling of a series of steps that each needed to be completed as part of an overall management regimen.

There is evidence in the literature that people living with chronic skin disorders sometimes perceive that any clear-cut rewards did not match the laborious efforts involved in treatment, as Mollerup et al. (2013) noted in their study of experiences with hand eczema. Mollerup and colleagues (2013) found that the sustainability of a regimen for treating the skin with topical products and the continual management of the skin through protection with gloves often became subject to a cost-benefit analysis. Furthermore, outcomes of efforts to manage chronic illness treatment have often been equated with the Sisyphus syndrome, as identified in the management of chronic conditions including psoriasis (Jobling, 1988).

It became clear from all of the respondents' accounts that managing the body with chronically disordered skin required substantial work to meet and relieve the sensory demands of a flare-up of the skin. The practices used for relieving sensations of itch, pain or discomfort were often time consuming and laborious, and had to be repeated daily or even multiple times each day. Given the unpredictable quality of the skin and its erratic, phasic cycles, allied with a continual search for effective treatment options, the efforts required for in treating the skin was often framed as a Sisyphean task. Drawing on her experiences of the burden of treatment for pompholyx eczema, which had emerged over the course of the previous year, Tanya says:

> Well I just have to deal with it but it's quite scary as it has added a new dimension to my life really. It's something I've not had to deal with before and now every day I have to think about, right, steroid cream, moisturise. And… it's added a whole new element to my day really, every day, that I could be stuck with for quite some time really. This thing could go on for years.

The labour required for treating her condition had demanded substantial changes in Tanya's daily routine. By contrast, Helen had long-standing experience of the need for maintaining a ritualistic daily practice of treating her eczema with topical creams. Helen says:

> you HAVE to, to manage it... It's not a... [laugh] military operation but you can't just go oh my skin's great I'm going to ignore it. If you do it gets worse. So you kinda have to go... [deep breath] get up, you're in a rush. I kind of moisturise every morning, 'cause it seems to keep my skin in better nick. So I moisturise all over. Don't have to have a shower or bath, I just slather it on the top But yeah I'll do that pretty much every day, even when it's good.

The labour required for treating her condition had meant substantial change in Tanya’s daily routine. By contrast, Helen had long-standing experience of treating her eczema. However, it was clear that the complex and laborious treatment processes continued to present a daily burden to Helen, regardless of her familiarity with undertaking the procedures required for her treatment regimen. More broadly, these experiences illustrate respondents’ awareness to the costs levied on their daily lives by laborious treatment processes, whether long-standing for Rebecca and Helen or more recently for Tanya. Moreover, these quotes demonstrate a sense of the Sisyphean task that respondents experienced in the ongoing work of carrying out skin treatment regimens, both in their past and current experiences, and looking into the future.

Maintaining Agency Despite Pharmaceutical Necessities

Several respondents noted how they would respond to treatment demands on their time and effort by planning how their skin treatment routine could fit in with other activities in their lives, rather than allowing the treatment of their skin to take precedence at the cost of other interests. These responses appeared to enable agency in navigating the varied desires and demands of everyday life. Speaking about the considerations she makes in negotiating the management of her psoriasis relate to her plans to go out with friends, Jennifer says:

> if something's planned for me, I don't know, socially, my psoriasis is quite thick, and I know it's time to put the steroid cream on, I'll be like, oh, shit, how am I gonna do that

> from going out tonight, I'm not gonna have enough time, um, to have it on before washing it off before work tomorrow. I don't think it would stop me, but I certainly try and plan for it.

Jennifer has long-standing experience about effective timing for the use of different treatment. She has found that it is important to apply a particular steroid cream in the evening so that this topical medication has sufficient time on her skin overnight to produce a beneficial effect. As this extract illustrates, Jennifer has been faced with a dilemma in deciding how to manage the conflicting needs of her skin condition and her social relationships. If she goes out with her friends and returns home late, then this may compromise her treatments, as even if she were to apply the medication to her skin there may not be enough time for the steroid cream to act on her skin in a way that relieves symptoms to the same extent as if she applied it earlier.

While applying treatment late at night after an evening out with friends may not be ideal from the perspective of treating her psoriasis, this approach allows Jennifer to manage her skin condition to some extent, but also enables her to maintain her intimate relationships. Maintaining control over her skin is made more difficult for Jennifer if plans are made for her by others, as opposed to plans she makes for herself, but she resolves not to allow her skin condition and its treatment deter her from enacting other important aspects of her life. ‘I don't think it would stop me’, she says, before adding ‘but I certainly try and plan for it’. Jennifer is keen to be able to live in a way that minimises the impact of the skin condition on her personal life. Applying a deeply embodied understanding of the costs and benefits associated with her treatment regimen, Jennifer’s contingency planning enables a level of control over her skin treatment that also takes into account the value she attributes to her leisure activities.

Demonstrating a detailed planning strategy for managing both her treatment needs and her leisure time, Monica says:

> I'm anyways twenty-five years old, so, take it on Wednesday, which means by the time I get to Saturday night, if I drink, I'm not going to destroy my liver. So that's been hard. Because if I- They say, what is it, forty-eight hours within the injection you shouldn't touch alcohol. So then I organised, not just to be able to drink, but to be able to have the option of living a normal life, I organised my work schedule and when I would take the drug so that it would be out of my system by the weekend. But I might not always have that freedom.

In this extract, Monica outlines how she organises her weekly plans for managing her treatment and her leisure activities in a way that takes into account a contraindication between her treatment with injected methotrexate and consuming alcoholic drinks. It is interesting to note that Monica is cognisant of how changes in her responsibilities in later stages of life may restrict the agency she has over her weekly schedule and in turn what is possible in terms of ‘living a normal life’ that includes having some alcoholic drinks with friends. Monica and a number of other respondents made it clear that despite the extra demands placed on their schedules because of the need to treat their skin, it was important not to allow their illness needs to overrun other aspects of their lives.

Evaluating the Tolerability of Side Effects

Viewing pharmaceuticals as a source of disorder is apparent in experiences of side-effects, ‘causing disorder in one’s very sense of being, turning the participant into a different sort of being, unrecognizable or unknown to herself’ (Dew et al., 2015, p. 277). In this way, the side-effects of medication can add to the existential demands of corporeal dys-appearance and the sense of a disordered life that are produced as part of the illness experience. A key aspect of the “disordering substances” repertoire revolves around the evaluation of side effects with respect to the effectiveness of a medication. Discussions about whether the use of a drug was “worth it”, in terms of a balance between its negative side effects and its remedial benefits, was highly prevalent for respondents across each of the skin conditions represented. Illustrating the “necessary evil” quality of pharmaceuticals in the “disordering substances” repertoire, Monica explains why she considered methotrexate to have ‘bitter sweet’ qualities. Monica says:

> with the methotrexate, it was such a bitter sweet drug…. it's the first time in my life when my skin is perfect. And that's like, awesome. That's just like so amazing for me, because it's the first time when I like, I almost feel it's the first time that I really realised what my face looks like, because I was so used to- I always, I mean as long as I can remember, had a rash, redness right here. This weird thing. Like all the time. Unless I put huge piles of cortisone cream on it and slept with globs, then maybe I would have one day of being ok. So that was- I mean it's great. And I also have to kind of remind myself that this drug, that kinda sucks to take, is really helping me. But the emotional part of it is the hardest because it IS a toxin. Methotrexate is a toxin. So now I'm way more used to it and I'm way better at handling it. But in the first couple of months it would wipe me out. I mean it would wipe me out where I was like I actually organised my work schedule so that the day after I took the drug I would go in at noon.

There is a clear sense of ambivalence from Monica in this extract, because while she found the toxicity of methotrexate led to unpleasant and impactful side-effects this medication was also extremely effective in treating symptoms of her psoriasis, which had greatly affected her visual appearance for much of her living memory. In a similar vein, Meghan viewed the experience of severe and wide-ranging side effects that resulted from her use of a drug for acne as being “worth it” for the beneficial change that it brought to her long-standing acne symptoms. Prescribed Roaccutane for her acne, Meghan experienced intense dryness in her skin with ‘eczema-like symptoms’ and painful dry eyes. She speaks about the pain and scarring that developed as a result of her dry lips splitting, saying ‘my lips actually split on both sides, and they stayed split for what must have been like two weeks and it was so painful, I've still got a scar here from where it split, oh, it was awful’. Meghan also experienced an aching in the bones of her back and incessant fatigue. However, for Meghan, the discomfort of managing daily life with these side-effects paled into insignificance against the ways in which the successful treatment of her acne could benefit her wellbeing. Meghan says:

> Well when I started taking it, I knew, I was prepared to get all these side effects and I knew I probably would, but I just didn't mind, um, because I think it's worth it, 'cause um, it is, it's amazing, like, it's really helped and it helped so quickly, um, yeah, so I'm just dealing with the side effects because it's worth it in the end…. I'm just hoping that it will keep it nice for longer, and it's probably worth it. Yeah, it is worth it, 'cause yeah, having acne is yeah, no fun, so I'd rather have dry skin and chapped lips and not have acne.

As Meghan put it, the change that Roaccutane could make for her wellbeing mean that continuing this treatment despite difficult side-effects was ‘worth it in the end’. Mirroring Meghan’s experience of using acne medication, both in terms of the pain and difficulty of the process and her evaluation that these side effects were worth tolerating, Heather says that Accutane was:

> a life saver…. I haven't had one spot since I finished. And the process was quite hard. Because you've got such dry skin and your lips are cracked and bleed. My nostrils were like bleeding, they were so dry. And my eyes were dry all day. When you'd wake up in the morning the sides of my mouth were completely- Say when you yawn

> or you move your mouth too quick it would just cut the sides of your mouth…. It would bleed a lot. Especially the corners.

Such has been the effectiveness of Accutane for treating her acne, and such was the pervasive impact of acne on her life, Heather felt, as Meghan did, that the extensive and painful side-effects she experienced while using this medication had been worthwhile.

Overcoming the Disordering Experience of Injectable Treatments

One aspect of the "disordering" experience of treatments that emerged around concerns about methods of administering medication, particularly the use of injectable pharmaceuticals, which a number of respondents undergoing treated for psoriasis had experienced. The use of injectable treatments has been associated with a range of concerns, such as difficulties with the act of injecting oneself (Heaton et al., 2016) or how a dependence on injections can affect social identity (Scambler, 2009; S. Williams, 2000) and may therefore be stigmatised. Modern biologic treatments for the treatment of psoriasis involve the injection of medication into the skin, which individuals carry out at home. Self-administering injectable treatments require an interaction with the body that some respondents found intimidating at first, but which over time had become more habitual, despite the discomfort of performing these injections.

Jennifer speaks about the pain involved in using the injectable treatment, how 'it's not nice' and 'it's quite horrible every time you do it, 'cause it's a bit weird to be injecting yourself and it can be painful, but you only hold it in you for 10 seconds'. Jennifer highlights the act itself of applying this treatment as being particularly unpleasant, yet emphasising that the act takes just a few seconds to complete and she found the treatment effective, Jennifer accepted her discomfort with the injection process as being tolerable. Jennifer says, 'it's worth it, in that you only do it once every two weeks, it's over in 10 seconds. It's not impacting your life. It's very chill'. The brevity of the treatment procedure and the substantial amount of time between uses are such that Jennifer feels the self-administered use of injectable biologic medication does not act as an insurmountable burden. The self-injection method of application of biologic medication was a cause for initial reservation for some, however, for many of the respondents living with psoriasis, the overwhelming effectiveness of treatment often far outweighed these concerns.

As Jennifer's experience demonstrates, the self-administration of injectable medication retains a degree of "weirdness" despite its repeated use. However, its fortnightly administration requires only a short process of injecting the medication and is infrequent enough that it can become normalised as part of lived routines. While it has been found that adherence to medical regimens for skin disorders is often limited (Storm et al., 2008), the experience of Jennifer and others agree with prior research findings (Basra & Hussain, 2012) that people are often able to cope well with the use of injectable biologic medications as part of their psoriasis treatment regimen. Moreover, the experiences of Monica, Meghan, Heather and Jennifer exemplify how the "disordering substances" repertoire is demonstrated in the evaluation that a medication being "worth it" because of its effectiveness, despite the side-effects it produces.

By contrast, in some cases, the severity of side-effects that emerged through using a pharmaceutical treatment overwhelmed any beneficial experiences of effectiveness. While the potential benefits of using a medication meant that it was worth *trying*, side-effects sometimes proved intolerable. In these cases, the difficulties of maintaining the "balancing act" (D. L. Hansen & Hansen, 2006) between effectiveness and the experience of side-effects were not viewed to be worthwhile, which often meant that respondents stopped using a particular treatment.

Suffering hair loss and an array of other uncomfortable bodily side-effects resulting from her use of medication to treat psoriasis, Michelle speaks about the disappointment she felt not only concerning the development of these side-effects but about the lack of effectiveness of treatments prescribed for her psoriasis. Michelle says:

> I started having um awful migraines. Some days I couldn't lift my head off the pillow. Um, my sleep was affected badly, and also I suffered hair loss… So, my hair was coming out quite badly, so at the next appointment then I discussed it and we decided that I wasn't benefiting. There was no improvement in my skin, and in fact I was aching more taking the medication than I was before…. so we decided to stop treatment… I did look at the other side- possible side effects, and I knew that hair loss was possibly one, which was something that did bother me… but I talked about it with my husband and with my parents and then they said, you know, well, given how you're going, you know, you're experiencing with your skin now, then would it be worth giving it a go? So we weighed it up, and we thought it would be worth giving it a try, because otherwise I would never have known.

The impact of losing her hair, a substantial component of aesthetic presentation, played a role in the decision Michelle made to cease treatment with Methotrexate. Michelle says, ‘So yeah I was very, very disappointed because I'd hoped that um, that this was going to be the solution, and it was disappointing, and I think upsetting, the fact that I was losing my hair’. The disappointment that Michelle felt about the failure of this treatment was amplified by a range of difficult side effects. The hair loss other distressing forms of bodily experience, including migraines and bodily pain that she suffered compounded her disillusionment at the realisation that despite the hope she had invested in this treatment it was not ‘going to be the solution’ for Michelle’s psoriasis. The “disordering substances” repertoire is characterised by hope attached to the potential benefits of using a medication weighed against any unwanted corollaries. As Michelle’s experience illustrates, the presence of hope often meant that respondents believed a medication was “worth trying” in spite of its risks and failure as treatment.

Long-Term Pharmaceutical Concerns

Concerns about side-effects and the long-term safety of treatments were a frequent source of ambivalence about treatments. Many respondents conveyed apprehension about the potential damage they believed their treatments may cause to their health in the future, as well as the side-effects they had experienced as part of their treatment practices. For some, the side-effects of medication use had been both distressing and debilitating. Those taking part in the study were often highly concerned about the long-term risks of particular medications, such as the potential for organ damage or the development of cancer, and weighed these risks against the benefits of the treatment for their overall wellbeing.

While many respondents spoke about their ambivalence towards the use of medications such as oral or topical steroids, as will be discussed in due course, the rapid efficacy of steroids for the drastic reduction in the intensity of symptoms such as itchiness was clear. Rather, ambivalence often stemmed from uncertainties about long-term efficacy, and even more so, experiences of and concerns about side-effects. The considerations made about medications often involved a process of “weighing up” possible side-effects and long-term risks against the potential for beneficial impact. Many respondents had needed to make difficult decisions about treatments in the course of their illness. Moreover, reaching a balance between negative side-effects and beneficial impact was often a perpetual process throughout the period of treatment as medications that respondents had proceeded with trying sometimes proved untenable through the experience of use.

It is known that many people with eczema have concerns about the side effects of using topical steroid creams and ointments to treat their skin (David, 1987). Concerns often focus around the risk of the skin thinning through topical steroid use, but also include fears about the accelerated appearance of ageing of the skin, changes in skin colour and becoming dependent on these drugs. Taken together, these and other concerns contribute to what has been termed "topical corticosteroid phobia". This phobia has been found to influence acts of non-compliance with the use of topical steroids as part of treatment recommendations from dermatologists and GPs (Charman et al., 2000). Notably, the two issues of temporary effectiveness and impactful side-effects of thinning the skin were commonly cited together surrounding the use of topical steroids. Respondents who spoke about the use of topical steroids were often concerned that these medications could cause a "thinning" of their skin, particularly if used for extended periods of time. Fears about the risks presented by use of topical steroids were common among those who used these drugs, which included the majority of respondents with eczema. Christopher, who has eczema, illustrates features of "topical steroid phobia" in his account of using these treatments. He says:

> they give me sort of cortisone again, hydrocortisone to, er, to apply to the eczema, and that would sort of temporarily fix it. I became quite dependent on using it, which was not a good idea because it does thin the skin if you use it too much.

Prescribed a topical steroid to manage his condition, Christopher found that the drug would 'temporarily fix it' before work stress would cause its return. Christopher had concerns both about long-term habituation to the treatment and this "thinning" of the skin that he understood may result from long periods of use. The "dependence" that he speaks of may refer to either a bodily reliance or a dependence on pharmaceuticals framed in psychological terms.

Similarly, Brooke raises concerns about how topical steroids are only effective for a short period of time after they have been applied and have skin-thinning side effects. Brooke says:

> Steroids will make it better but as soon as you stop it's going to get ten times worse, or you become resistant to them and they make your skin really, really thin. They're no good [laughs], but it's the only thing that the doctors are going to give you. They're like "here, this will help you". They'll help while I'm ON IT [laughs].

Noting concerns about the thinning of the skin and the possibility of becoming “resistant” to their effects, analogous with Christopher’s concern about “dependence” on these medications, Brooke’s experience with using topical steroids to treat her eczema is another illustration of “topical steroid phobia”. In addition, the experiences of Christopher and Brooke illustrate a concern about pharmaceuticals held by many of the respondents, that any effectiveness in relieving symptoms was only transient. Together with concerns held by these respondents and many others about the side effects associated with long-term usage of topical steroids and their limited effectiveness, the “disordering substances” repertoire was clearly represented.

In contrast to prior examples, many of the respondents also held concerns about the long-term risks presented by the use of medications which had in fact proved effective for them as treatment. These cases illustrate another variation of the “balancing act” (D. L. Hansen & Hansen, 2006) involved in negotiating treatment that was common among those who used the “disordering substances” repertoire.

Fears about the long-term risks associated with treatment led Jennifer to stop using the biological drug Humira, despite her experience of the effectiveness of this drug in minimising the impact of psoriasis. Jennifer says, ‘right now I've stopped having treatment completely because I got to the highest, the highest, what's the word? The most strongest treatment that's possible for severe psoriasis. It's not really good for you long term’. None of the other treatments that Jennifer had used in her lifetime of psoriasis had proved remotely as effective as Humira, yet such were her concerns for her long-term health that she took the action of ceasing treatment. Indeed, it was in part the escalation in her treatment trajectory to using a medication she acknowledged as being the most potent available for her condition that caused Jennifer a great deal of concern. However, in stopping her use of this treatment, Jennifer had experienced an intense recurrence of her psoriasis symptoms:

> And now I've got it bad again, and I'm like dealing with it again on a severe scale. So yeah it's quite, I've been through like lots of ups and downs throughout my whole life, trying a range of different treatments.

The relative modernity of this treatment also added to the uncertainty about how the drug might affect her health should she continue to use it for many years. As Jennifer says:

> It's only been out for about fifteen years. They tell me all the time that there are risks, you know, unknown, and they could be quite detrimental, blahblah blah. So I decided, you know what, it's starting to worry me now. I stopped it.

Negotiating the treatment trajectory is experienced as a complex process where no option is ideal. Jennifer points out that all of the pharmaceutical treatment options available to her present a differing range of possible side-effects and risks through their use. Deciding between a return to the newer injectable biologic medication (Humira) and the older oral immunosuppressant medications (methotrexate and cyclosporine) she took years previously presents a dilemma. Jennifer says:

> So, cyclosporine and methotrexate, I took a long time ago. They're oral tablets and they suppress the immune system, but they don't-, they suppress the entire immune system. And what they're used for usually is people who are going through organ transplants, so that they accept the organ and their body doesn't reject it. So that's what they're used for. And they give it to people with psoriasis just to dampen the whole immune system. Now they have stronger risks than the injections that I'm on now. They also gave me side effects that I wasn't, just quite small side effects. Like

> I'd get colds and cold sores and viruses more often. And they're just not something that you can be on forever. Now the injections are for people that have severe psoriasis, and they're really expensive, and the NHS don't want to give them to that many people. But the injections suppress the skin part of the immune system, not the whole immune system, so that's better in that it only targets the specific T cells. So in theory that should be better and decrease the risk. But actually what they say is that it's harder for them to assess the risk, in that those injections are very new, and so it, with cyclosporine and methotrexate they know the risks and they're not good. With the biologic injections, on paper they should be lower risk because they're not affecting the whole immune system. But at the same time they do not know what it's doing. That's what's unsettling I think for me.

While the older medications, which act on the 'whole immune system', that Jennifer had used previously are known to present serious risks to health, injections using the newer medication offer a 'lower risk' as they are more targeted in their approach, in that they 'suppress the skin part of the immune system, not the whole immune system, so that's better in that it only targets the specific T cells'. Speaking about the implications of this more targeted approach, Jennifer says that 'in theory that should be better and decrease the risk'. However, on the issue of risks associated with the biologic drug, Jennifer was told by dermatologists that in fact 'it's harder for them to assess the risk' because these injectable medications 'are very new'. Speaking about how the risks associated with the newer medications are lower 'on paper', there is a clearly a level of uncertainty based on an absence of information about the long-term impact of their use, an aspect that Jennifer says she finds 'unsettling'.

In addition to her broader concerns about using a potent medication in the long-term, the treatment action taken by her dermatologist to remove freckles that might have been cancerous was a further “trigger” for Jennifer to cease her use of Humira. As Jennifer explains:

> the other thing that triggered me to stop it was that my doctor, my dermatologist, removed some freckles from my body, and they weren't even moles, they were freckles. Um, and I was like “what, what do you mean? Why are you doing that?”. And she's like “oh, because, you know, I don't like the way they look, like they might be cancerous”. But she wouldn't have taken them off somebody my age that had never had the treatment that I'd had. That kind of shook me up a little bit and I thought oh god. So I think that was another reason for me to stop.

Jennifer believed that her dermatologist would not have been wary of these freckles had she not been using the biologic medication, and so through action taken from a position of medical authority added further legitimacy to her concerns about the risk of developing cancer.

Pharmaceutical concerns held by many of the respondents centred on the perceived potency of medications. For example, several respondents spoke about their concerns about the prescription of a medication for the treatment of their chronic skin condition, methotrexate, as this drug is also used in chemotherapy. Highlighting concerns associated with the potency of this medication, Sandra says that ‘Methotrexate is a horrendous chemical however as well as being a chemotherapy drug in higher dosages’. Sandra’s extract illustrates how the use of a pharmaceutical for treating their disordered skin that is also used for the treatment of life-threatening conditions, including some forms of cancer, appeared to attach an elevated level of seriousness to their own condition in a way that led respondents to reflect with concern about this treatment approach.

Developing an understanding about the seriousness of potential side-effects of methotrexate, as well as its use in chemotherapy prompted Barbara to reconsider her treatment. As Barbara explains:

> The dermatologist, the only thing that he could suggest was systemic therapy… Well he said with systemic therapy… I'd have to have my liver blood test done it's so strong. So I said well I'll go away and think about it and I did some research I realised it was chemotherapy basically. And I thought no, there's got to be a better way.

Sandra and Barbara had clear concerns about using a drug that is also used as chemotherapy for the treatment of cancer, a life-threatening illness. It appeared that the use of this "horrendous" drug attached a heightened sense of severity to their illness owing to a prevalent public association with its use in cancer treatment, which is understood to be arduous and to carry the risk of difficult side-effects (Seymour-Smith, 2002). Moreover, learning about the necessity of monitoring her liver function were she to undergo this treatment signified to Barbara an amplification in the degree of risk, which she found unacceptable. These extracts illustrate how perceptions about the potency attached to the use of particular pharmaceuticals, and the seriousness of conditions which they are used to treat, formed an important part of how respondents used the "disordering substances" repertoire.

Pharmaceutical Treatment Trajectories of Ever-Increasing Potency

Developing a "dependence" on pharmaceuticals was of great concern to many of the respondents because of risks attached to their use, illustrating another key aspect of the "disordering substances" repertoire (Dew et al., 2015). Respondents were often uneasy about the ongoing progression within their pharmaceutical medication usage towards ever-greater potency and the increased potential for serious and long-lasting side-effects.

Jennifer outlines the huge variety of different pharmaceuticals and types of treatment she has used since the time when psoriasis developed in her childhood, illustrating a progression from older therapies to more advanced pharmaceuticals she has experienced in the course of her trajectory with psoriasis:

> I’ve started, with being 7, and having tar baths and strange like very old methods, to then having UVB light treatment for about two years, to then taking methotrexate, which is oral tablets, then cyclosporine, creams the whole time the way through, and then now, finally, injections.

Along this trajectory, Jennifer has experienced periods during which the psoriasis was relatively subdued by treatments and periods when the psoriasis was particularly exacerbated, often during what Jennifer describes as the ‘transition between treatments’, that is, times between the ending and beginning of different treatment modes or drugs. At the time of speaking with Jennifer, she was in just such a transitionary period. However, there was a sense that this transition was different to any of those previously. Owing to her concerns about the progression of her treatment to using potent biologic medication, Jennifer had decided to put a temporary halt on using pharmaceutical treatments altogether. As Jennifer says:

> So what's difficult is, I'm very rarely the way I am now…. Right now I have it quite bad, and this is new to me really. The only time I ever get this bad is in between treatment, and pretty quickly I'll have started a new one and I'll be fine. But I've exhausted all options.

Jennifer’s observation about having ‘exhausted all options’ available to her through medical treatment demonstrates a vivid illustration of the concerns about dependency on pharmaceuticals that are part of the “disordering substances” repertoire. Given the progression in the potency of her treatment, Jennifer is concerned that there are no further treatments to move on to, should the biologic treatment no longer prove effective or diminish in its effectiveness. This concern about what would come next only add to the uncertainties about long term risks associated with a dependence on this medication.

Roshan outlines a strategy for adapting his medication use to address his concerns about dependence and potency. Speaking about how this adaptation applies to oral prednisolone, Roshan says, ‘I’ve learnt how to taper down off the prednisolone. My body is perfectly fine with me going on pred, then coming down. We know how to adapt’. While Roshan is able to modify the dosage of an oral medication, he reflects on how this strategy is not applicable to adjusting the dosage of topical steroid creams. Outlining his concerns about dependence on steroid creams and the limitation of his strategy for different medications that he has been prescribed, Roshan says:

> The difficulty is actually, oh I'll just have to go back on steroid cream. That's the thing. The problem is, with creams, there is actually no way to taper down. If you think by oh applying less cream. It's the same strength though, isn't it. So yes, you've applied less cream, but it's the same strength as you put when you put more cream on, so how do I actually taper down. Because the whole point of tapering down is you do it by strength. There's no way to get a non-strong Elocon or a non-strong Dermovate. So how do I do that? I just don't think that's possible. I don't think it's possible to be able to taper down off of creams…. That's when I see difficulties. If they put me back on the cream or I have to use the cream.

Roshan makes a point which illustrates how different modes of pharmaceutical treatment provoke different concerns in relation to the “disordering substances” repertoire. While he is able to modify the dosage of oral steroids that he takes in accordance with his illness, Roshan feels that there is no corresponding way to ‘taper down’ when using creams. That is, Roshan expresses how he feels powerless to ‘adapt’ his treatment to in response to nuanced changes in his illness or take a treatment trajectory that meets his needs when he uses pharmaceuticals in cream form. In this instance, Roshan conveys how the use of oral medications allows for a greater sense of agency over treatment for his eczema than when he uses steroid creams, despite the concerns that he has with the use of pharmaceuticals generally.

Like many of the respondents, Roshan and Jennifer's experiences represent concerns about a trajectory of progression with pharmaceuticals towards increasingly potent treatments. The extracts demonstrate ways that respondents acted on their concerns to reduce their reliance on medications. For Roshan, this involved a strategy of attempting to "taper" down the potency of medications through reduced dosing. By contrast, after feeling uneasy that she has 'exhausted all options' for treatment, Jennifer had stopped using her biologic medication entirely and was taking a "holiday" from its use. These concerns illustrate a particular focus of the "disordering substances" repertoire (Dew et al., 2015) on health risks associated with the use of medications. For the respondents in the present study, concerns about the "disordering" consequences of medications were elevated when they were associated with uninterrupted use over long periods. The actions of both Roshan and Jennifer demonstrate strategies for negotiating health concerns they had about long-term use by varying or temporarily halting their use of treatments.

A "drug holiday" or "medication holiday" is a 'deliberate interruption of pharmacotherapy for a defined period of time and for a specific clinical purpose' (Howland, 2009, p. 15). Given the effectiveness they had experienced with biologic medications, the vast majority of patients who were asked to take a "drug holiday" from the use of biologics by their doctors for a range of rheumatic illness conditions, were shown to have negative feelings about the possible consequences of halting this medication (Kosevoi et al., 2014). By contrast, Jennifer has proceeded to take a drug holiday from biologic medication, despite the effectiveness she had experienced with this treatment, and against the advice of her dermatologist. These strategies of modifying treatment regimens can be considered in relation to “non-adherence”, notable among dermatology patients (Storm et al., 2008). However, it may also be argued that such strategies demonstrate a nuanced and creative approach to the long-term self-management of illness.

Pharmaceutical Use as Disordering Society

Conventional medicine formed the mainstay of treatment approaches tried by many respondents in what was typically an ongoing pursuit. The physical, social and emotional factors involved in the experience of skin disorders made the assessment of treatment options a complex and highly personal task. Many respondents outlined the wide variety of medical treatment modes they had been prescribed by general practitioners and dermatologists at various times, as well as progressions in the intensity of treatment within each type, such as the use of increasingly potent topical steroids. However, the treatment trajectory, which often involved moving between medications or combinations of medications in search of effective relief, was found to be frustrating and exhausting. While the possibility for “cure” remained a hope for some despite the chronic nature of their disorder, the majority of respondents accepted that they would need to manage their condition long into the future. Nevertheless, many found the extended process of trial-and-error involved in consultation with those they had considered expert sources – dermatologists or general practitioners – to be a source of disappointment in the conventional medical system when the results of using prescribed treatments did not meet their hopes or expectations. Many respondents believed that there was an over-reliance by doctors on the prescription of pharmaceutical medication in the treatment of their illness. These concerns reflected the use of a discursive repertoire that (Dew et al., 2015) termed “disordering society”.

In the “disordering society” repertoire, pharmaceuticals evoke a society in an unnatural state and people are ‘made anxious by the fear-mongering and marketing of the pharmaceutical industry and the health experts who promote their products’ (Dew et al., 2015, p. 274). A stance of "active resistance" or, as a minimum, passive distancing is taken to the consumption of pharmaceuticals. This repertoire has a strong sense of agency and resistance is attainable where it is possible to avoid the 'disordering effects of a society distanced from nature' (Dew et al., 2015, p. 274). However, this repertoire forewarns that with the further distancing of society from nature comes an increase in the reliance on pharmaceuticals. Marketing is seen as a pathological influence on pharmaceutical consumption and therefore pharmaceutical companies play an important role in creating societal disorder through the marketing of drugs to doctors.

Issues of Agency in Accessing Effective Treatment

People living with a chronic illness often feel vulnerable and dependent on both medications and health care systems (Doran et al., 2005; Frank, 1991). Those who are ill are often faced with dependence on a health care system that is difficult to negotiate, and then the further difficulty of finding treatment that is effective.

The distress which Pavana experienced in developing eczema was compounded by medical treatment which she felt did not address her illness concerns with the urgency or seriousness which they warranted. Pavana was disappointed that the approach used by doctors in her treatment was based around pharmaceuticals, which she felt did not address the multifaceted impact of illness on her wellbeing. Pavana says:

> when I got that referral, it was, it was really all over and by that time I'd starting losing hair, I've lost about 15 kilograms in weight, and then um I'd got the, the dermatologist appointment. They did a few blood tests. They said, oh, you've come up high as being allergic to a few foods… I mean, desperation because the impact of it is so major you don't understand why no one, why it's not taken seriously. I don't get, I mean I've been in with things way more minor and got action, and I'm coming in with this, which is, you know, I'm not sleeping, I'm losing weight. There's many overall

> symptoms. Losing my hair. There's so many things going on and yet they're not moving forward with it, to hand you a topical steroid.

During the period of waiting to see a dermatologist Pavana experienced unwanted weight loss, lost hair and had trouble sleeping. She felt as though despite the impact it was having on her body and her life, her condition was not taken seriously by medical professionals. For example, Pavana believed that her eczema was also exacerbated by sunlight. She raised the possibility in medical appointments to no avail and lived with the concern that her skin condition had been misdiagnosed for three years. Pavana was eventually seen by a dermatologist who determined that she did indeed have light-exacerbated eczema, 'but by then then skin was so damaged, and I'd used so many steroids’, she says.

Pavana’s experience illustrates her frustrations with depending on a health care system that she felt did not consider her illness from a holistic perspective, with an approach to treatment that undermined the seriousness of her disordered skin and compromised her sense of agency. These experiences illustrate an aspect of the “disordering society” repertoire (Dew et al., 2015), as Pavana felt that there was an overly simplistic approach to treating her illness with pharmaceuticals when there were other factors that may have contributed to its development but which were not investigated. These experiences also illustrate the importance all respondents attributed to a sense of agency, which is often compromised through the treatment of those who are chronically ill (Frank, 1997).

As part of their treatment trajectory, many of the respondents had been prescribed a range of different pharmaceutical treatments, each in turn more potent than the last, in an attempt to find treatment that proved effective. For some, this “stepped” programme of medications of increasing potency found treatments that were effective, however, the process often took a great deal of time. Each step entailed a period of waiting as respondents tested a medication for effectiveness, and further waiting for medical appointments where the effectiveness of each treatment could be discussed. Given the chronic nature of these forms of illness, and the fluctuations in how they presented, navigating these stepwise treatment trajectories was often a source of frustration. Illustrating the difficulties of navigating a stepwise medical treatment pathway, Sandra says:

> Unfortunately I am now suffering from it in my inner thighs which has been an absolute nightmare so I'm currently under the care of the dermatologist at the hospital now, um, and it's one of those sort of stepped programmes where they start you on various different creams working through different types of steroid creams getting stronger and stronger and stronger come out without much relief, to then start on methotrexate it's been difficult to get to the point I'm at now because when you go to the doctors if they have to go through various creams and lotions and potions for them not to work. So then eventually a few months later to then refer you to the hospital. So then hospital goes through various lotions and potions. So sometimes it can take maybe I don't know six, seven months before you start to get some sort of treatment that works. I'm guessing that after the likes of methotrexate then you’re going down the root of biologics which I don't think it's probably as severe that it needs the biologics yet.

Sandra’s experiences of treatment for her psoriasis represents how negotiating the stepwise process involved to find effective medical treatment for disordered skin was often tortuous and frequently disappointing. The trial and error involved for each of the ‘lotions and potions’ of increasing potency that were offered to Sandra by GPs and specialist dermatologists, had been a lengthy and difficult process which left her with limited hope about the treatment pathway ahead. While Sandra believes that the treatment protocol she is undertaking with methotrexate may be effective and that a step on to biologic medication, which she classifies as being required in more ‘severe’ cases, will probably not be necessary, her knowledge about potential future treatment options illustrates a sense of uncertainty that the experimentation involved in each state of the stepped programme of treatment will yield effective treatment.

Medical Reliance on Prescribing Potent Pharmaceuticals

It was notable that some respondents alluded to a feeling of obligation placed on them from dermatologists to manage their condition using medication. Speaking about a particular exacerbation of her pompholyx eczema, Tanya felt a time pressure from her dermatologist to produce effective results using topical treatments she was relatively comfortable with in order to avoid what she perceived as the wish of her dermatologist to prescribe more potent, systemic forms of medication at her next consultation. Tanya says:

> I saw my dermatologist last week and she said, because it hasn't cleared up, and I've got a lot of secondary spread on my arms and legs that I've got 'til September to control it myself, and then I'll have to look at either a low dose of steroids or immunosuppressant drugs. But I don't like the sound of those…. The last two or three weeks, I've been using the steroid cream constantly, because I had a dermatologist appointment and I thought no, she'll just put me back on steroids if I don't clear it up myself.

Tanya felt an imperative placed upon her as a patient to produce changes in the state of her skin as judged by her dermatologist or face an escalation in the potency of her treatment that made her uncomfortable. Similarly, Roshan spoke about how the doctors that he has consulted with over many years of living with eczema often ‘seem to put the medicine first’ with their focus on pharmaceuticals. Roshan says:

> I get that doctors try to get you to think about all this when you're younger as well, but they seem to, how can I put it, they seem to put the medicine first. Like they'll say "take the medicine. Don't worry about it".

Roshan raises concerns not only of what he considers an over-prescription of medication, but also about the habituation of institutional practices, both in the reliance on drugs and in the acceptance of norms of drug use and biomedical discourse. With his comment, ‘doctors try to get you to think about all this when you’re younger’, Roshan infers a process of habituation in the acceptance of medical discourse as a social norm. Furthermore, in a critique of common medical advice about the use of pharmaceuticals given by doctors, which Roshan summarises as “don’t worry about it’, he illustrates a concern about trust in medical authority being used as justification for pharmaceutical consumption. Critical of the use of language by medical doctors in their advice about how treatments should be used, Roshan felt that medical discourse encouraged an over-use of pharmaceutical medication and under-represented the risks of using such treatments. As a telling and recurring example, Roshan speaks about the incidence of medical guidance for treatments to “use as and when needed” and how this phrase was emblematic of a pharmaceuticalised approach pervasive in his experience of conventional medical practice. Illustrating the impact of this discourse in encouraging a reliance on a potent topical steroid, Roshan says:

> So that pushed me to basically use steroids for a whole decade or so, or over a decade…. I think it led to the mentality that if you always have a rash, you can just throw some Elocon on it. That was the way I was treated. "Use as and when needed" is something that I remember being told, and they still say that to this day. "As and when needed”.

Reflecting on the medical treatment he received, Roshan felt that advice to use drug treatments “as and when needed” belies the potency of medications and the risks to long-term wellbeing presented in their use. Roshan is critical of what he perceives to be the ingrained institutional underrepresentation by medical doctors of the risks associated with pharmaceutical treatments. Roshan says:

> I thought they had my best interests. I thought they told me everything there is to say about the risks and so on and so forth…. So through that it implied to me that this wasn't a big deal. And then some other years later I was to find that this was, literally, the biggest deal of my life at the moment. Because the steroid withdrawal, steroid addiction cancelled out- I still have the after-effects now…. Because they create skin damage and addiction…. Due to the skin damage and addiction that they've created, and the power it took my own body to recover from that, which was… one of the most draining experiences.

Outlining the impact of what he perceives to be an irresponsible over-prescription of steroids, Roshan feels that the persistent use of these drugs caused addiction and long-lasting damage to his health. Roshan is not averse to the use of steroid medications for treating eczema when this is appropriate. However, as the following extract illustrates, Roshan believes that the use of such drugs should only be used for treating exacerbations of illness that surpass a threshold of much higher severity than they may typically be used. As Roshan puts it:

> It's when you get a rash, and you know, you itch it, then you just put some on. But's that's not how you use it. It's mainly made, or in my opinion, it's mainly made for when, you know when you're just completely- well, you're just like "this arm's fucked". Like this ain't getting better by using, um, I don't know, just whatever. So you're like, let's use some steroids now. It's not built for when there's "oh, there's a little scratch there, I was scratching while I was watching TV, I'll just go and get some Elocon". I don't think it's made for that, but by saying "as and when needed", I think that that's literally what they're promoting. Then use it whenever the hell you want. That's basically what it sounded like to me.

Roshan describes what he feels was an inappropriate prescription of medication use in his treatment for eczema from doctors, because of language that he interpreted to mean 'use it whenever the hell you want’. More broadly, Roshan’s experience of what he felt was an “as and when needed” approach to the prescription of treatment represented a model of treating chronic skin conditions through the perennial use of potent and risky medication in response to each bout of exacerbation, which Roshan says is ‘not the right way’. ‘They were just throwing them at me’, says Roshan on the prescription of steroid creams, while for a prescription of tablets of prednisolone, Roshan says, ‘I got given like a bagful of it’. In the following extract, Roshan speaks about his concerns about the over-prescription of potent medication, as well as a perceived medical justification of this prescription on the basis of Roshan’s experience and understanding of his own medication needs. Roshan feels that proceeding with treatment on this intuitive basis can overlook the risks of such treatments. Roshan says:

> That is not what you should say to patients that you are giving powerful medical grade steroids to. They're strong stuff. It's not a joke. You know, if you just swallow a handful of prednisolone for example, that could mean like your death, couldn't it, if you were to do that. 'Cause they said the same thing to me for pred. "As and when needed". And then they go, oh "you know your dose". It's just that I know my dose "as and when needed", and I got given like a bagful of it. You're like hold on a sec. All I have to do is get one small box out and punch them all out. And that could mean you being dead…. But given that much strong, strong drugs, and it wasn't regulated either. I could have literally like sold them and then gone back a certain amount of weeks or months later, and then just asked for more. So it was literally, I was- and the same with the creams. They were just throwing them at me and I was given loads of tubes.

This extract reflects a critical perspective on the over-prescription of medication. It highlights what Roshan views as the responsibility placed on individuals by doctors to use potent medications in ways that are appropriate for managing their illness, to “know their dose” and use treatments “as and when needed” without sufficient guidance or safeguards. Building on this argument, the following extract draws attention to a view held by a number of respondents that there is a dearth of information presented in medical settings to those who have chronic skin conditions about the potential for serious and long-term health problems as a consequence of using these pharmaceuticals. Roshan says:

> They keep escalating your steroid use. They don't tell you that you're becoming tolerant, they just escalate and escalate, until it reaches a peak and then you're absolutely fucked when you get to that peak, and I was really close to the peak, because I was using Dermovate, which is the strongest steroid there is in terms of the creams…. And the doctors only wanted to admit to it at the end of it, that it was an issue. All the way up, while I was going through it, while I was suffering, they kept trying to put steroids on me again. And I kept saying, "aren't you listening?". I was getting into arguments with loads of doctors…. why didn't you tell me about this which is steroid withdrawal? Why didn't you tell me this was a thing? They didn't speak about that at all? They talked about uh skin scarring. I didn't care. Because I had scars anyway, because you're itching….That doesn't bother me. But the thing that bothered me was that I don't want to itch, I don't want the pain…. But there was no talk about the fact that you could get addicted to it and it damages your skin. Your skin is an organ. Every time you put it on you're damaging an organ, you know. If you were doing that to any other organ in your body, you would stop, because that's what we've been taught, isn't it. All your life you've seen people applying creams or adverts about creams. So it's like normalised inside your head to put creams on. It's just normal.

In addition to his concerns about the insufficient information from doctors addressing the risks presented by medications, Roshan also outlines a view that the normalisation of applying creams to the skin, combined with a seamless escalation in the potency of medications offered to patients, may contribute to serious long-term health implications which could have been avoided.

Industry Pressure on Doctors

The targeting of doctors by the pharmaceutical industry is well established (Conrad, 2007). In a House of Commons Health Committee report (2005) on the pharmaceutical industry it was stated that although the ‘pharmaceutical industry cannot be blamed for creating unhealthy reliance on, and over-use of, medicines, it has certainly exacerbated it’ (p. 4). Many respondents shared ethical concerns about the role of the pharmaceutical industry as an influence on the treatments recommended and prescribed by doctors.

James speaks about his concerns that pressure may be applied to doctors by the pharmaceutical industry and that this may affect how they treat patients. James says:

> I'm of the view that biologics doesn’t work for everybody, you know? You're on a biologic, it'll work, you know? But obviously not. And a lot of it I think is to do with the drugs company. And my dermatologist, when I stopped the Humira that time said to me, "oh, there's some really good biologics on the market". I thought, are you under pressure from the drug companies to… prescribe a new biologic…. Humira's an old drug. It's been around a long time. But I think they're under pressure to buy some of these new drugs that are on the market obviously…. You don't get to hear of it, but I think they're under a lot of and, she tells me she isn't but she's quite keen for me to get off Humira, and I said "look, it works for me, let's stick with it". And obviously, they do listen to the patient, because I thought they would just say, "look, we're stopping it. This one's better". But no.

James poses his concern that despite the effectiveness he has experienced in his current treatment for psoriasis, using a product called Humira, pressure may be placed on dermatologists by pharmaceutical companies to recommend newly developed drugs that yield greater financial profits. However, as this extract illustrates, in spite of his concerns about pharmaceutical industry pressure on doctors, James acknowledges the influence he has had within treatment discussions with his dermatologist.

Industry Influence Over Patients

As Conrad (2007) points out, the public have increasingly become targets for pharmaceutical industry promotion. It was of interest that a few of the respondents, particularly those who had experienced pharmaceutical advertisement in countries such as the United States, framed their own illness experience in relation to how illness was represented through direct-to-consumer commercial portrayals.

While uncertain about how the injectable biologic medication that she has begun to use will affect her, Margaret is hopeful that this drug will help in the treatment of her psoriasis. ‘Maybe it'll go good. It's only been two shots on the Humira. You know. So maybe it'll be wonderful. I don't know. They certainly get better on the ads!’, she says. Only further ‘shots’ of this medication and the time needed for the effects of the drug to present themselves through bodily reactions will enable any more certainty about its efficacy for Margaret’s psoriasis. Margaret’s experience illustrates a critical response to pharmaceutical promotion targeted at members of the public in the US where direct-to-consumer advertising is permitted. That is to say, while her optimism for the effectiveness of treatment may have been bolstered by the adverts she saw, her response to the images presented through pharmaceutical advertising do not suggest at an acquiescence to the consumerist messaging directed towards her (Conrad, 2007; Conrad & Leiter, 2008). Margaret’s use of dry humour about the apparent effectiveness of Humira for characters in its direct advertising campaign in the US where she lives suggests any optimism for efficacy resulting from her use of this treatment is coloured by a sense of reserve, in part from a critical stance she intimates through her ironic inflection about the promises of pharmaceutical advertising.

Pharmaceutical companies were often focus for critique as part of the “disordering society” repertoire. Several respondents voiced concerns about the power that pharmaceutical companies had to influence treatment practices, both for medical professionals and the public (Conrad, 2007). In a critique of the power held by large pharmaceutical companies, Sandra raises her concern that drug companies sometimes cease production of treatments that people have found helpful for the management of their illness. Sandra says:

> And there was a cream that I used to use. And like many things GSK pulled the plug on it. They even did it with Polytar shampoo…. It's back on the market. After about a five- or six-year absence, it is back.

Sandra’s extract draws on the “disordering society” repertoire in this critique of a pharmaceutical company halting production of creams and other medications that she previously used as part of her psoriasis treatment. Highlighting the capacity of drug companies to “pull the plug” on medications that she and others had found helpful in managing illness, Sandra’s extract illustrates a critical position on the moral standing of the pharmaceutical industry.

Pharmaceutical Use as the Result of a Disordering Self

In the “disordering self” repertoire, the use of pharmaceuticals signifies a ‘moral failing of the individual or a stigmatised failing of the body or both’ (Dew et al., 2015, p. 275). In this repertoire, pharmaceuticals are viewed as an inconvenience that the user must endure. Given that access to the pharmaceuticals needed to manage illness can be controlled by health professionals, this repertoire produces a stance of “regretful dependence” which is embedded within pharmaceuticalised governance. Owing to this reliance, obstacles to access of pharmaceuticals from health professionals may be resented. With a sense of moral failing at being unable to retain control over illness without pharmaceuticals, use of this repertoire denotes a compromised view of self.

Regretful Dependence Despite Personal Decision to Halt Treatment

During a period in which he had stopped using steroid medication due to his concerns about dependence on pharmaceutical treatments in the form of “steroid addiction”, Roshan took the action of discarding all of these drugs from his home to reduce the ‘temptation’ to begin taking them again. Roshan says:

> I won't have it on me anymore. I chucked it all out of the house. What you do now is when you need it you go and get it. You don't stick around. You don't just leave it lying around…. Because when you're at your lowest moments, the temptation to have it will be increased, because it's there. That's people. When we experience low moods, low areas of life, we'll do what's there, 'cause it's easy. Don't make it easy for yourself.

Illustrating a response to his concerns about a regretful dependence on pharmaceuticals, Roshan speaks about the importance that the physical removal of medication held during this period. Roshan acknowledges how his emotional mode and overall wellbeing would affect his likelihood of reaching for the steroids that he was attempting to avoid. That is, at times of low mood and when facing difficulties, ‘we’ll do what’s there’, Roshan says.

Speaking about the importance he attributes to enduring the symptoms of his illness without intervention, Roshan says:

> You'll know after suffering for a few days whether you actually need the steroids or not. So when I went back on them, end of 2016 right, or last quarter of 2016, I gave it a week. I suffered for a week with reactions. Straight up, couldn't sleep. It was, oh man, I was like "shit, I'm fucked again". But I wasn't actually that bad. Because everything had healed by then. So it was just rashes and reactions.

Roshan took an approach of ‘suffering’ through the exacerbation of his condition for a period of time as this would allow him to gauge whether or not he ‘actually’ required the medication. Only after a severe and prolonged exacerbation of his eczema during his break from conventional medication did he begin to use oral steroids again. Moreover, it is interesting to note that Roshan attributes his period of abstinence from the medication as “healing” his condition to the extent that this exacerbation was not representative of his eczema more broadly, rather the exacerbation was, as he put it, ‘just rashes and reactions’. Roshan’s perspective on the meaning of this exacerbation as being less serious than it initially appeared is consistent with a critical position on the use of conventional medication for treating illness. Consistent with the “disordering self” repertoire, this extract further illustrates the view that reliance on pharmaceuticals signifies a moral failing.

A number of respondents had faced circumstances in which doctors had advised them to stop their use of particular pharmaceutical treatments in their regimen for medical reasons around side-effects or long-term risks, or respondents had made the decision themselves to stop using these treatments for similar reasons in spite of the effectiveness they had experienced through their use. Ambivalence was often apparent under these circumstances - misgivings about the risks to their health of the continued use of such treatments occurred alongside a notable sense of temptation to continue using treatments that offered relief from their symptoms. With her psoriasis in a state of acute exacerbation, Jennifer speaks about the “temptation” she feels ‘to reach into the fridge and take the injection’ and how she “misses” the effectiveness of the drug. However, keeping in mind the potential long-term risks and her decision not to return to using this drug for the time being, she has resolved not to succumb to this temptation. Jennifer asks:

> I stopped it in August, um, and now I'm covered and I don't like it and I'm very tempted to reach into the fridge and take the injection, but, and I really miss it, and I

> just think it's so easy, but at the same time, um, I am aware of, you know, there's horrible risks out there involved, and how long can I be on it for? I'm only 25, so how long can I really be on it for?

Such was the effectiveness for the management of her condition however, that despite possible side-effects and any long-term health risks, Jennifer may ultimately return to using this medication. Jennifer says:

> But for what they do for the here and now, I'm really annoyed that I'm not taking them and I really want to take them. So I guess what needs to happen is for me to be in such a bad state with my mental wellbeing, my social life, how I feel physically, for me to believe that it's worth it if something were to go wrong. So if something were to go wrong and, I don't know, in a few years' time if I was to get cancer, I want to be able to have said, well I had to take it and it was worth it.

This extract demonstrates a view that if Jennifer experienced circumstances in which her overall wellbeing suffered so intensely from the recurrence of psoriasis exacerbation that she considered using Humira again, she would hope that its use felt justified, even if she were to develop cancer as a result of returning to the drug. That is to say, given the moral failing she attaches to the use of a drug, from which she has resolved to abstain, Jennifer is hopeful that returning to its use would feel worthwhile when weighed against the suffering of her psoriasis.

Regretful Dependence Despite Medical Advice to Halt Treatment

While respondents who had made the decision to stop using a pharmaceutical treatment experienced a sense of agency in their management of illness, by contrast, those whose cessation of treatment had been advised by dermatologists or other health professionals felt a loss of agency over illness that had been offered by the talismanic qualities of their pharmaceutical treatment. James speaks about the "temptation" he felt to use medication during a period when he had been advised to stop by his dermatologist because of an infection that had developed following surgery to repair a hernia. The effectiveness that this medication had demonstrated for treating his psoriasis, and the realisation of his fears about how debilitating the re-emergence of bodily symptoms affecting his skin and his joints would be meant that being told not to use the medication provoked a great deal of anxiety for James. James spoke about his medical consultations and email correspondence with his dermatologist and the unrelenting effort it took to resist the temptation to use the treatment:

> when I went to the dermatologist and they saw the infection, she said "you need to stop the Humira", and I said, "but I'm reluctant to do so, because what's going to happen to the joints and the skin?" And she said, "no, you have to stop, because the infection needs to be cleared". It was a massive infection, it was quite big. So I stopped obviously, but as I said to you, it's very difficult to be sitting at home in agony, when you've got a fridge full of pens…. I was fine for a month, it was the fifth week, got a massive flareup in terms of the joints. Terrible. Agony. Again, had to call them and- but, hospital- what's so frustrating is I had the pens in the fridge, I'm in agony, and you're very tempted just to get one out you know. It's difficult…. So tempted. So tempting. I said this many times on the email. I was losing the will to live in the end.

Knowing that he had a supply of injectable Humira pens stored in his fridge at home presented James with a constant temptation to use a treatment that might relieve his suffering from psoriasis but would potentially cause a great deal of damage to his health as its suppression of the immune system would disrupt healing from the infection.

Despite the reasoning behind a cessation of treatment, halting the use of a treatment which respondents had found to be effective was accompanied by a temptation to resume. These extracts served to illustrate the “disordering self” repertoire as respondents described experiences in which they felt a “regretful dependence” (Dew et al., 2015) on particular medications. These extracts about the temptations that respondents felt towards medications illustrate a complex picture of responsibility and dependency in the use of these pharmaceuticals. There are also shifts between pharmaceuticals being experienced as ordering and disordering in their effects on illness, and frequently experiences of ambivalence and uncertainty concerning the impact of treatments over the course of the illness trajectory.

Pharmaceuticals as Re-Ordering Substances

While scholarship on medicalisation has often taken a polemical tone, authors such as Lupton (1995) stress the importance of nuance and complexity on this issue. Similarly, Parens (2013) advises caution against understandings which overlook the subjective realities of experience and see medicalisation as either good or bad. Parens (2013) points out that while medicalisation can individualise systemic issues, there are also ways that medicalisation can alleviate suffering. A repertoire of “re-ordering substances” (Dew et al., 2015) represents pharmaceuticals as substances to sustain or restore order. Using the re-ordering substances repertoire, Dew et al. (2015) write, pharmaceuticals can signify ‘obedience and conformity for what is a taken-for-granted good provided by a beneficent pharmaceutical industry and expert health providers, or they can even have a magical talismanic quality of keeping illness at bay’ (p. 277). As part of the repertoire of “re-ordering substances”, agency and responsibility are limited to complying with the advice of others who hold responsibility for health. Therefore, the duty of the individual is to be a responsible consumer and adhere to the guidance of health professionals, who are viewed as experts. Within this repertoire, institutions with a cultural authority over health and illness are sources of trust (Dew et al., 2015).

Magical Qualities

While pharmaceutical concerns were highly prevalent in respondents' accounts, the beneficial qualities of medications were also a feature through their powerful effects in treating illness. Speaking about the effectiveness of Accutane for the treatment of her long-standing acne, Heather says:

> My whole skin feels different…. The whole texture. I don't feel like I'm playing with fire anymore. It just feels like a normal face…. it feels like I can do things or put something on my face…. like I can actually use moisturisers and... just normal things.

The effectiveness that Heather experienced with her use of Accutane for treating her acne is illustrated by the impact this medication had on returning a sense of "normality" to the skin of her face. While the process of undergoing drug treatment for her acne had been difficult for Heather, the overwhelming benefits of the medication for how her skin demonstrates the capacity of pharmaceuticals to re-order. This return to normality was presented in terms of how her skin feels to touch, the sensations that emanate from her skin, and how robust her facial skin felt to "normal" daily skincare routines, all of which made a substantial difference to how Heather felt about her skin.

The effectiveness of biological treatments such as the medications Humira was often found to be "life changing" and like "magic" by the respondents whose psoriasis was being treated with these drugs. Illustrating this "magical" quality of biologic treatments he has used, James recalls:

> the last time I was at the dermatology unit, and I only go back every six months now, last time I was at the dermatology unit there was a young guy sitting next to me, and my dermatologist came out and said to him, "have you had the magic stuff yet?", and he was like, "yeah, it's great, it's great", you know, he was really- you could tell- It's life changing. I'm saddened when I read stories where it hasn't worked for people,

> because I'm not quite sure what- I know there are other biologics on the market, and there's now tablets that work, but for me, Humira's been, you know, amazing, it's amazing…. it's great for me, but, you know, I'm pretty much clear. I've got a bit on my legs, but compared to being eighty percent covered it's quite remarkable. It's just amazing, this drug, you know? Tiny, what is, one point five mils or something every two weeks. And it's life changing…. And you still get a bit of psoriasis, but when I saw the dermatologist last I said "I've got a bit of psoriasis on my legs. Is it normal to have a bit of psoriasis?" And she said "yeah". I'm thinking, should you be completely clear on this drug or should you have- and of course I don't expect to be completely clear, but when I just look at those photographs that were taken before I even started Raptiva, there's a massive difference.

In this extract, James highlights the capacity for these "magic" substances to restore the condition of his skin from a state of broad psoriatic coverage to near clarity from the disorder. While he acknowledges that medications may not be effective for everyone who uses them, James describes the impact of this drug on his skin as 'life changing'.

Fears That Effectiveness of Treatment Will Diminish

Respondents who had experienced positive effects from using particular pharmaceutical treatments for their skin condition were often fearful about the possibility that the effectiveness of this treatment might wain in the future. Having experienced Accutane to be effective in treating her acne, a notable source of concern for Heather is the possibility that the symptoms of her acne may return. Despite assurances from her dermatologist that other treatments could be effective, Heather is uneasy about any potential return to treatments that had proved ineffective and painful in the past. As Heather recalls from a conversation with her dermatologist:

> I said “if it comes back what do I do?". She said "your skin should be more receptive to other treatments that haven't worked before now"…. But I would be too scared. 'Cause that's what scarred my face. Where they gave me such strong creams at a young age it burnt my face…. they used to give me creams that were so strong, the smell would make your eyes water.

Heather’s concern about a return of symptoms manifests in daily practices of vigilance where she checks her skin for the visible signs of acne.

Heather’s ongoing grooming practices illustrate a mentally demanding component of skin work. She says:

> Well I'm just scared now that it's going to come back…. So the first thing I do in the morning, I jump straight out of bed and look in the mirror. Every morning…. I'm too scared to do anything. Where it's good I'm just leaving it. But not putting make-up on unless I'm going "out-out". I'm just keeping it neutral.

This extract from Heather addresses the fear that respondents held towards losing the near-magical effects of treatment. Drawing from their embodied knowledge of their condition, respondents were sensitive to any indications that a treatment was no longer as effective or their condition was becoming exacerbated. Illustrating the work of Dew et al. (2015) around the “re-ordering substances” repertoire, the responsibility that respondents took on as diligent patients who used treatments as directed by their dermatologist was often driven by a fear of their skin disorder returning to severe levels of exacerbation.

Tangibility of Treatment

Medications can be a focal point for efforts to take action in response to illness. Van der Geest et al. (1996) note that ‘Medications are tangible, usable in a concrete way: They can be swallowed, smeared on the skin, or inserted into orifices – activities that hold the promise of a physical effect’ (p. 254).

As a focal point for illness treatment, the ongoing “circular” practices that Lafrance and Carey (2018) identified were common among respondents. This was frequently illustrated by the perpetual application of creams and ointments into their skin, which was a mainstay of treatment for many respondents. These circular practices, in which medicines were physically applied to the skin, offered respondents a tangible activity which offered the promise of physical effect, as identified by Van der Geest et al. (1996). Speaking about her treatment routine, Helen says, ‘I kind of moisturise every morning, 'cause it seems to keep my skin in better nick. So I moisturise all over’. Helen’s experience illustrates how the act of moisturising the skin with cream offers a tangible practice that holds the promise of physical effect in how it appears to produce effective physical changes in the treatment of her eczema.

Further illustrating the tangible value of applying creams as part of the circular treatment process, Pavana says:

> I keep my moisturisers nearby so that I can always just keep topping up to stop myself from scratching, because I keep breaking the skin and I can't scratch too much otherwise I will cause too much damage so er I keep moisturising every five minutes and keep it near me.

While Pavana’s circular practice of using moisturisers offers a similar benefit to that which Helen identified in managing the health of her skin, the ongoing act of applying this treatment to the skin is implicated in this end-result via effects on reducing sensations of itchiness and avoiding the subsequent “damage” that scratching the skin would cause to the body. A focus on keeping moisturising creams close by her illustrates the importance Pavana attributes to this tangible product and the circular practice of moisturising for the treatment of her eczema.

Valuing Medical Expertise

By contrast with a number of other respondents who have experienced problems in negotiating access to effective treatments, James speaks about his own experiences of access to consistent health care services in a positive light. However, James also reflects on how the inadequate provision of healthcare services would add to the suffering of living with illness when compared with his own experiences:

> some people are suffering bad, and around the country. It's very hit and miss. Well I know this from my own experience, but around the country it's very hit and miss on treatment and services. London seems to be brilliant. And I must admit, I've had the same dermatologist now for about fifteen years. Absolutely brilliant. And although I've moved here I'm still a patient at (hospital name). But if you haven't got a good dermatologist I think it just makes it worse.

The inadequacy of health care access, James suggests, contributes both to this sense of isolation and the need for people with this condition to find alternative sources of information for themselves, often through forums online. James' experience illustrates the importance that he and others attributed to having consistent access to health care services for the ongoing treatment of their skin. However, the suffering that inadequate access contributes to experiences of illness must also be noted.

While the use of pharmaceuticals was often presented with a sense of ambivalence, there were also instances when the overarching experience of a drug treatment had been one of profound beneficial change. These extracts from James and the other respondents featured here illustrate their use of a repertoire of "re-ordering substances" (Dew et al., 2015) in relation to the beneficial effects they experienced with particular medications for treating acne and psoriasis respectively. Each speaks about the life-changing, talismanic qualities of these pharmaceuticals for greatly improving the condition of their skin, returning their skin to what they perceive as “normal”.

Conclusion

Research by Simon Williams and Michael Calnan (1996) and others has demonstrated that people have complex and often ambivalent views about pharmaceuticals. The use of drugs is often ‘permeated with ambivalence – simultaneous and contradictory feelings of attraction and repulsion’ (Martin, 2006, p. 285). Drawing on Gilbert and Mulkay’s (1984) use of “repertoires” as the resources used to justify understandings and achieve something, Dew et al. (2015) identified a range of repertoires that people use to justify their understandings and achieve moral positioning on their use of pharmaceuticals. The four repertoires Dew et al. (2015) identified were those of “disordering society”, “disordering self”, “disordering substances” and “reordering substances”. Despite the importance of medical treatment regimens in the ongoing management undertaken by people living with chronic skin disorders, there has been little exploration in the literature on the question of how this group relate to treatments which they use. This chapter has set out to understand the treatment practices that people with disordered skin engage in, the implications of these treatments for everyday life and how respondents view these treatment needs in the context of their illness. In this chapter, the framework developed by Dew et al. (2015) based on the use of pharmaceutical repertoires has been used to better understand the relations with medical treatments held by respondents. It was found that each of the four repertoires identified by Dew and colleagues (2015) were apparent in respondents’ data, albeit to different extents and in particular illness contexts.

Drawing on the repertoire of “disordering substances” as discussed by Dew et al. (2015), pharmaceuticals were presented by a majority of respondents as a threat to their physical or mental equilibrium. Looking beyond the balance within embodied experience, respondents often expressed their treatment needs as a threat to the equilibrium of daily life. That is to say, the labour of treatment often added an arduous burden to the course of everyday living. This finding is in agreement with those of Jobling (1988), who demonstrated how restoring the state of the skin to "good order" often requires practices which are strict and ritualised and may be experienced as punitive. Indeed, reflective of other work about experiences of treating chronic skin conditions, such as Wahl et al. (2002), the efforts required just to remain on an "even keel" often led to a sense of despondency among respondents.

Moreover, this burden was seldom rewarded with improvements in the condition of the skin that respondents felt warranted the efforts expended. As illustrated in prior sociological research on disordered skin, notably Jobling (1988), the treatment of a chronic dermatological condition can feel like a Sisyphean effort. The Sisyphean quality of treating disordered skin as experienced by respondents in this study may be of value for understanding why non-adherence is found to be notable among people undertaking treatment for dermatological conditions (Storm et al., 2008).

It was also apparent, however, how respondents valued and attempted to maintain agency across other aspects of their lives, despite the necessities demanded by regimens of pharmaceutical treatment for their illness. Consistent with other chronic illness research, such as work by D. L. Hansen and Hansen (2006), respondents in the present study performed a perennial "balancing act" of managing their treatment, with considerations of their past experiences and their hopes and concerns for the future. In agreement with Mollerup et al.'s (2013) work on experiences of managing dermatitis, the sustainability of treatment regimens across each skin disorder represented in this study was subject to an analysis of costs and benefits.

In addition to the practical burden of treatment, there was a great deal of concern about the side effects associated with using pharmaceutical medication. As Dew et al. (2015) identified, the side-effects of medication can produce a deep sense of disorder and a feeling of being unrecognisable to oneself. Managing the side effects of treatment entailed a balancing act of weighing up the benefits of their use against the problems they posed. Under some circumstances, the side effects associated with using pharmaceuticals would be tolerated given their effectiveness. These findings support the notion put forward by Gabe and Lipshitz-Phillips (1984) that pharmaceuticals represent a "necessary evil". Given the findings, it is worth noting that the etymological origin for "pharmaceutical" means poison as well as remedy. For many of the respondents, the benefits of particular medical treatments did not outweigh the adverse effects they experienced with their use. This often meant that respondents were faced with moving from one pharmaceutical treatment to another in the hope of greater effectiveness or more tolerable side effects.

There was a lot of concern among respondents about the serious or long-term risks associated with using pharmaceuticals, whether or not individuals had used these drugs themselves. This was consistent with studies that have demonstrated fears about the risks associated with medication usage for skin disorders. For example, widespread concerns about risks posed by the use of topical steroid creams preceded the development of a notion of "topical corticosteroid phobia" (David, 1987). This was illustrated in the findings of the present study, particularly among those with eczema, for which topical steroids were a commonly prescribed treatment. The prescription of a particular drug, methotrexate, was another prominent source of fears among respondents concerned about the potential for serious side-effects. Supporting findings by Seymour-Smith (2002), the use of this pharmaceutical, which a number of respondents framed as a very potent drug used in chemotherapy, was a particular source of concern.

Addressing concerns associated with the “disordering substances” repertoire, it appeared that respondents adapted their treatment approaches in order to limit their exposure to pharmaceutical risks. With medical guidance, some of the respondents, particularly those with psoriasis using biologic medication, had taken a “medication holiday”, which is a planned interruption of pharmaceutical treatment taken for clinical reasons (Howland, 2009). However, in accord with findings by Kosevoi et al. (2014), respondents had concerns about the consequences of halting their use of medications they had found effective as part of these medication holidays, despite medical justification for taking these actions. Acts of non-compliance with topical steroids prescribed by doctors have been related to fears associated with side effects (Charman et al., 2000). Respondents adapted treatment protocols, diverging from medical recommendations based on their needs and their own understanding, preferences and concerns about treatment.

For the “disordering society” repertoire, a reliance on the use of pharmaceuticals evoked a society in an unnatural state. In support of Dew et al.'s (2015) conceptualisation of this repertoire, the reliance by doctors on the prescription of potent medication was a prominent source of concern for the majority of respondents. It has been reported that the pharmaceutical industry has exacerbated a reliance on and over-use of medicines (House of Commons Health Committee, 2005). Moreover, it is known that medical doctors are targeted by the pharmaceutical industry (Conrad, 2007). There were clear concerns among respondents about the role of the pharmaceutical industry in putting pressure on doctors, and that that these pressures may have influenced their treatment decisions. As well as the potential for influencing the decisions of doctors, there were also concerns about the power of the pharmaceutical industry as an influence over patients’ views. As discussed by Conrad (2007), the pharmaceutical industry has increasingly targeted the public with promotion for new medications.

Added to concerns about an unnatural reliance on pharmaceutical medication, difficulties with accessing effective treatment through health systems raised questions of agency among respondents. In a similar vein, respondents had concerns about the power of pharmaceuticals to curtail the production of particular medications, limiting access to treatments which respondents had found to be effective. These data add to the argument that the complexities of finding effective treatment can lead people with chronic illness to feel dependent on health care systems (Frank, 1991). Moreover, reflective of Arthur Frank's (1997) work, these findings demonstrate how the difficulties of navigating treatment for chronic illness can lead to a compromised sense of agency for patients.

Using the repertoire of "disordering self", the use of pharmaceuticals was viewed to signify a moral failing of individuals, a stigmatised failing of the body or both. A key aspect of this repertoire is what Dew and colleagues (2015) refer to as a "regretful dependence" on pharmaceuticals. In line with this conceptualisation, respondents often illustrated what appeared to be just such a "regretful dependence" on the use of pharmaceutical treatments which had been prescribed to them. This was highlighted by incidences when respondents were acting to reduce their use of drug treatments, whether by medical advice or by their own volition. Adhering to decisions about limiting the use of a drug as part of a treatment regimen was commonly a difficult process subject to feelings of what respondents often described as temptation, illustrative of the moral framing inferred by the "disordering self" repertoire.

Parens (2013) argues that while there are legitimate problems with the overuse of pharmaceuticals, medicalisation can alleviate suffering and should be considered with nuance for understanding subjective realities. Within a repertoire of "re-ordering substances", pharmaceuticals are framed as substances that sustain or restore order and medical institutions are viewed as a source of trust (Dew et al., 2015). For respondents invoking this repertoire, medical expertise and the use of pharmaceuticals held the power to transform skin to a state of normality.

In agreement with the findings of van der Geest et al. (1996), pharmaceuticals were sometimes conceptualised by respondents as tangible products with the promise of effectiveness in treating illness. This use of medications formed a ritually important part of what (Lafrance & Carey, 2018) term the “circular” practices of managing the skin. Moreover, for those whose treatment had been beneficial in the management of their illness, the effects of pharmaceutical use could feel magical. Given the profound benefits they could confer, in line with Dew et al.’s (2015) conception of the “disordering substances” repertoire, treatments took on a talismanic quality as part of daily routines. Furthermore, respondents were fearful of the possibility that any effectiveness produced through using a pharmaceutical might diminish over time.

In this chapter, deploying a conceptual framework developed by Dew and colleagues (2015) in the study of treatments used for disordered skin, it was demonstrated that respondents drew on a range of repertoires concerning the use of pharmaceuticals. Most prominent were the use of repertoires of “disordering substances” and “disordering society”. The heavy use of these two repertoires appeared to reflect the difficulties respondents experienced with accessing effective treatment for their chronic skin conditions, combined with problematic side effects and concerns about implications associated with the use of pharmaceuticals, both for the individual and wider society. Concerns about an over-reliance on the prescription of pharmaceutical medications were shared by many respondents. However, these concerns about the medical reliance on pharmaceuticals was not limited to those who had experienced difficulties resulting from their medication use. Even among those who had experienced some therapeutic effectiveness from using pharmaceutical treatments, concerns emerged as part of the trajectory of illness and treatment, often focused on the long-term safety of medication use.

While there were examples of how respondents drew on the “disordering self” repertoire in the form of concerns about a “regretful dependence” on drugs, and drew on the “reordering substances” repertoires when medications were viewed for their restorative, magical or talismanic qualities, these repertoires were represented to a far lesser extent. It should also be noted that individual respondents often drew on a variety of the repertoires cited here. Together these results provide important insights into different ways that respondents related to the use of pharmaceuticals as part of medical treatment for their skin conditions.

Findings: Experiences of Treating – ii. Autonomy and Alternative Approaches

The purpose of this chapter is to assess the role of alternative treatments in the regimens of people living with disordered skin conditions. While there is a body of research concerning the use of alternative treatments for chronic illnesses (see for example Thorne et al., 2002) there has been very little research into how alternative treatments are conceptualised and used in the treatment of chronic skin conditions. An initial aim for the chapter is to explore why people living with chronic skin disorders may turn to the use of alternative treatments in relation to the conventional treatments prescribed by medical professionals. The chapter will explore notions of autonomy, consumerism and patient expertise and their relation to the use of pharmaceuticals. An argument will be made that the use of alternative substances often appeared to represent, in part, a response to the difficulties of navigating health care systems in search of effective treatment, as well as illustrating the importance attributed by respondents to having autonomy over how they treated their illness.

In the remainder of the chapter, it is hoped to gain an understanding of the role that alternative sources of knowledge and treatment hold in treating chronic skin disorders, and what implications these alternatives have for respondents in the management of their illness experience. Attention will be drawn to the importance attributed to "natural" approaches to treatment in managing illness in respondents' desire for alternative products and therapies. It will be demonstrated that respondents often engaged with a spectrum of alternative treatments and sources of knowledge as a means to manage their chronic skin conditions, oftentimes in pursuit of what they viewed as more natural approaches to treatment than what conventional medication offered. As the data will show, in line with what is understood about how health-related information is accessed (Nettleton, 2004), much of the exploration of alternative treatment knowledge that respondents engaged in took place online, and frequently involved the use of online discussion communities.

There will then be a focus on the concept of “dermatologisation” (Lafrance & Carey, 2020) to build an understanding of how aspects of lifestyle may become targets for treatment, and the implications this holds for the experience of illness. However, along with other aspects of alternative approaches to treatment, the dermatologisation of diet and exercise was often challenged. It will be shown that in spite of concerns and any adverse experiences with conventional medical treatments, respondents did not view alternative treatments uncritically.

Autonomy of Treatment

Much has been discussed about the prominent role of consumerism in western health care (Henderson & Petersen, 2002; Hudak et al., 2003; Nettleton et al., 2005). Within medical sociology, consumerism describes the process of patients playing an active role through informed choices about their health, and the demands that they should do this (Gabe, 2013). It was very apparent that respondents strived for agency in their interactions within the health care system. Indeed, several respondents spoke about the importance of maintaining “independence” as part of the health care they received in the management of their illness. Some of these respondents took on attributes of “expert patients” (D. Taylor & Bury, 2007), often becoming more informed about their treatments, questioning the recommendations of health professionals and seeking out alternative sources of knowledge.

Patient Expertise

In common with a number of other respondents, Thomas alluded to a critical stance he took in interactions with medical professionals and asking questions during medical appointments as a means of maintaining a level of autonomy in decision-making about treating his skin. While Thomas had tried using a variety of medical treatments for his eczema, he also spoke about the importance he attributed to having 'independence' from the medical system. Thomas says:

> in the case of disease if there's one thing I have discovered it's, um, if you want a cure, it's very important to become your own doctor in terms of becoming as independent as possible. Of course, use some solid evidence that's out there. And that's the great thing about the Internet today. You can do your own research. Even though you may not be a- you know, you don't have any scientific training you can basically do your own research and find your own cure, so the idea being to find a lot of independence. I think it's great that we have a medical system to diagnose, to use surgery for instance when there is trauma and things because obviously you can't cut yourself up if you've just had an accident or something like that, or if you have a tumour to remove, but pharmacologically, if you need to treat different diseases there are all sorts of options that mainstream medicine cannot use at this point, so it's interesting to be able to experiment. You have no guarantee. You will always be a guinea pig, but it's probably the best way, at this stage in the evolution of medicine.

Thomas argues for the value of individuals in seeking ‘independence’ in treating their illness. As illustrated in this extract, Thomas advocates for the importance of people conducting their own research online and experimenting with different forms of treatment as opposed to being limited to what conventional medicine currently offers.

In another illustration of respondents advocating for the value of becoming well-informed about treatments, Barbara drew on strategies for the negotiation of treatment approaches which she had developed through her previous experiences of other types of illness. Speaking about the ‘investigation’ she carried out into the systemic methotrexate treatment suggested by a dermatologist for her psoriasis, Barbara says:

> I looked up what the side effects were of it and also the fact that it may not cure or help the problem and a lot of people who have been on that say it comes back when you come off it…. I have an enquiring mind, I think most people do, but you know it's

> whether you choose to think about what you're doing and I thought well it's my body, my body is telling me something is wrong here so what's the harm in investigating? And just looking to see you know if there is anything that can help, and then I thought if I can't get myself better then I will have to go back, maybe consider the systemic therapy.

Barbara’s approach involved being receptive to sensing what her body was “telling” her in the progression of psoriasis symptoms, investigating and evaluating the implications of medical treatments, and then planning for possible treatment pathways using the expertise she had developed. In a similar vein, Roshan had developed practices of conducting research about his illness, conventional and alternative treatments over the course of his experience living with eczema. Speaking about the changes in his relationship to what medical treatment could offer and to medical practitioners as his understanding has developed, Roshan says:

> I was extremely sceptical, because they weren't giving you the answers that I wanted. It wasn't treating me the way they were supposed. Now I'm part of it again. But now I think carefully. I research carefully. I talk to people…. When I was younger it was blind faith, because I didn't know any better, and nor did anyone else around me…. Even now, the answers I've ever got, they're only through pain-staking research and pain-staking experience. Otherwise they weren't really out there. I had to earn them. So I've earned it…. But… the system itself, I'm happy with it. I'm happy with it because at the end of the day I have needed it when it was there…. But now I tell them that I do what I do. They don't like it. The dermatologist didn't like it. They like it NOW. For some reason when I went a couple of weeks back they didn't mind hearing that I went to an Indian herbalist. Before they'd be like haha, or scoff at you, or go ohhhhh. So we just used to keep it to ourselves, me and my family. But now, they're all like really- there's this new one, and she's amazing. I don't know if it's her

> or if it's the department that's changed. But anyway, she is great. She was happy that I found something that was for me.

As this extract demonstrates, Roshan was wary about whether he should be open with medical doctors about his use of conventional, complementary and alternative therapies. Speaking about the nuanced approach he has taken to disclosure of his treatments to doctors, Roshan says:

> But now, I said it, and I thought, fuck it. Because I didn't say it to them before this whole time. I told them about the acid. I didn't tell them about the herbalist. We just continued, just continued with it… every now and then, with the Indian herbalist when needed. And then, this time round, I thought to myself- I was sitting by myself out there in the waiting area, and I was thinking to myself, ok, what do I do know? Do I tell her? 'Cause I'm not going to lie. In the period where I had a load of reactions, for them to die down and be killed off, I needed something. High doses of pred didn't work…. Do I lie and just go, "oh, my reactions have died down a lot and shit's cool now", or do I tell her the truth? That I was on steroids, and I couldn't continue taking them because I've got side-effects? So I asked my dad. I went, "can we go back to … the Indian doctor…. And my dad's like "yeah", so he takes me there.

Unlike Barbara, who first developed disordered skin as an adult, Roshan's eczema developed during his adolescence. Roshan's understanding about his illness and possible treatments grew over a period of time in which he grew from childhood into adulthood. Parallel to an increasing knowledge about the relationship between his illness and treatments, Roshan's relationship to the health care system and health professionals also changed. Roshan viewed his early relationship to conventional medicine as one of "blind faith", but as he matured into adulthood his experience with the management and treatment of his eczema also grew, and

Roshan took on a role of increasing expertise and agency in his interactions with the health care system.

Each of these respondents took on attributes of the “expert patient” (D. Taylor & Bury, 2007). Differences in factors such as stage of life and history of illness experience appeared to affect how attributes of patient expertise were presented. These respondents demonstrated approaches that was proactive in developing an understanding of their treatment options and critical of medical recommendations for treatment. Williams et al. (2011, p. 717) outline a complex relationship between patient expertise and pharmaceuticalisation:

> On the one hand the rise of the articulate or information rich consumer, and associated forms of patient expertise, suggest the potential for various challenges or forms of resistance to pharmaceuticalisation. On the other hand, however, these developments may themselves fuel or facilitate further processes of pharmaceuticalisation, including patient-driven demand for pharmaceuticals… with or without the aid of DTC advertising and other forms of “marketing” on the part of the pharmaceutical industry.

Illustrating complexity in the relationship between patient expertise and processes of pharmaceuticalisation, a number of respondents spoke about how they used their knowledge and experience with using medications in their interactions with health care professionals. This was often more pronounced in respondents who had long-standing experience with their disordered skin. Speaking about some of the strategies she has used in the course of many years of experience of interactions with doctors concerning her skin eczema, Helen says:

> I do go and see the GP. I have been referred to dermatologists in the past. I have had patch testing. I have had various interventions, various different types of drugs. Not very strong drugs. Steroids occasionally. And I, they kind of don't get... the dermatologists do, the GPs are so... undereducated I guess that it kind of makes me... I

> understand that they do a very short amount of training, um, but they're usually quite good if you've done your research and they know that they have to prescribe you this, and you tell them, this is what you want, and you can give them good justification and they will, especially when you've found the website which says what everything costs per 100ml [bangs hand on table three times as she talked about the cost] and kind of go, I want this and I want this and I want this. And you say I have tried them myself, you're not wasting the prescription, it's not going to sit there. So they're quite good, they're quite good at that.

Like many of the respondents, Helen feels that GPs are not well informed about skin disorders. In order to access medications, Helen demonstrates her own expertise through her detailed knowledge about treatment during medical appointments. She outlines how she presents a level of understanding that goes beyond embodied lay experience and includes understanding of factors that GPs may take into consideration, such as the financial cost of a treatment to the NHS. Using this approach, Helen addresses potential barriers to access this medication by demonstrating her awareness of elements that may factor into the decision-making process adopted by an NHS GP, in the hope that the medication she is seeking will be prescribed. It may be argued that the strategies that Helen and other respondents harnessed, using their experience and knowledge of illness to aid their access to effective medical treatments for their disordered skin, support Williams et al.'s (2011) argument that patient expertise can facilitate pharmaceuticalisation.

As these accounts have demonstrated, many of the respondents involved in this study perceived that their skin conditions were not treated with the level of urgency or seriousness that their illness warranted by medical practitioners. Helen reflected on difficulties she had experienced with doctors who did not appear to treat her eczema seriously, despite the suffering caused by her illness. However, Helen found that in cases where she drew attention to a severe visual exacerbation of her eczema, which successfully ‘ticked the that’s impressive box’, the doctors she has consulted with about her skin often responded to by prescribing an array of different treatments. Helen says:

> the thing is, with GPs, whenever it gets really, really bad I go, and I show it to them, and they make the right noises and they go, OH MY GOODNESS, and they make a kind of sympathetic noise and like oh, you know, and you think GREAT, I've ticked the that's impressive box, now they're going to take me seriously…But you kind of know... it has to get really bad [bangs hand on table in time with speech] and then they'll throw... last time I went when it got really bad they threw steroids at me, they threw antifungals and steroid creams, and they gave me oral steroids, and they gave me an antifungal, and you're not supposed to take, put antifungals on with... but they gave me all three, and I thought ok, so you don't even, you're kind of saying that it might not even be eczema. Or you really don't understand skin. And I still don't know what made it flare so badly. Absolutely no idea.

Helen’s experience of medical treatment consultations illustrates difficulties faced by many of the respondents during such medical interactions. In addition to what Helen felt was an inappropriate and overzealous prescription of different medications, Helen suggests at how doctors may not always view skin disorders with a level of seriousness that takes the impact of these chronic illnesses into account. It can be inferred from Helen’s extract that it sometimes takes for disordered skin to be in what is clearly a severely affected state, and for patients to emphasise this severity, in order to be taken seriously during a medical consultation.

Self-Medicating

As a further illustration of patient expertise, Helen speaks about incidences of self-medicating that were made possible through her knowledge about the availability of medicines without a prescription in other countries she has visited, by contrast with the UK. Recalling how she had made use of the availability of oral steroids while on holiday in Spain, Helen says:

> I'm afraid to say I did find out that you can get Prednisone and Prednisolone in Spain, over the counter, for about 50p…. So when I last went on holiday to northern Spain and it started flaring again, I thought I'm not going to have it 'cause that, THAT tends [bangs hand twice to rhythm for emphasis] to be a flashpoint. Holidays [bangs hand on table twice] can be kill or cure. They can be, great, sunshine, sea, can be great, or you can just like, you start tearing your skin apart and you're like I can't cover up in this heat. I can't. I can't. I can't. So yeah, so I did um self-medicate [knocks on table twice] with that which I felt a little bit bad about. But then I thought I've done all the research. I understand it, you know.

Helen has feelings of ambivalence about self-medicating. On the one hand, there is a sense that buying medicines abroad that would be prescribed in the UK only under medical authority is in some ways “bad”, owing perhaps to a discourse of risk that may be raised, for example, by the act of ingesting pharmaceuticals without consulting a medical doctor. On the other hand, Helen feels justified in her actions, given her previous experience of using oral steroids and other forms of knowledge she had accessed about these medications, as well as the urgency for effective treatment demanded by a severe exacerbation of her eczema while she was abroad.

As illustrated by Helen’s strategic approach, several respondents demonstrated how aspects of patient expertise could be deployed to help gain access to pharmaceuticals for the treatment of their disordered skin. By contrast, the experience and knowledge gained during through the management and treatment of disordered skin also often influenced respondents to challenge the use of pharmaceuticals as treatment.

Exploring Alternative and Complementary Approaches to Treatment

There is a dearth of sociological knowledge about the use of complementary and alternative (CAM) treatments for skin disorders. However, more widely, it has been argued that people turn to alternative treatments for several reasons. One motivating force may be a dissatisfaction with health outcomes of conventional medicine, which Siahpush (1998) terms the “medical outcome hypothesis”. Another motivation may be the ‘recent emergence of a new value system that is congruent with the philosophical underpinnings of alternative medicine’, which describes what Siahpush (1998, p. 50) terms the “postmodern hypothesis”. Drawing on the postmodern hypothesis, it has been suggested that the trend for ever-increasing demand for CAM services is likely to continue (I. D. Coulter & Willis, 2004). This trend towards greater use of CAM would align with expressions of Rose’s (2001) concept of “somatic individuality”, and fits with understandings about the use of CAM in relation to lifestyle and “self-assembly” as predicted by theorists of postmodern or late-modern society (Rayner & Easthope, 2001).

Many respondents had used alternative forms of treatment, including complementary medicine and over-the-counter remedies for their chronic skin disorders. It has been demonstrated that proponents of “green” social movements have developed preferences for “organic”, “natural” solutions rather than chemical solutions (Eastwood, 2000). In support of this claim, there was commonly a belief among respondents that alternative medicines were more “natural” than conventional treatments, safer for long-term health and would result in fewer and less severe side-effects in use. Alternative treatments were often seen as taking a more holistic approach to treatment than conventional medication and tackling root causes of illness unique to every individual.

Seeking Natural Alternatives to Conventional Medicine

Respondents often took an experimental approach to the incorporation of alternative forms of knowledge and treatment for their disordered skin. This experimentation often drew on a range of sources of information as respondents took on increasing responsibility for their treatment trajectory. Many participants talked about how in their attempt to find solutions to the management of their skin condition they would "try everything" in terms of complementary or alternative treatments available to them.

Tanya feels that the treatment she receives from dermatologists is often heavily focused on treatment using pharmaceuticals, whereas she would prefer to use more 'natural' products for managing her pompholyx eczema. 'It's too drug-related. I'd rather try and find some natural remedies really. I don't want to put those into my body really' she says. Tanya differentiates between pharmaceutical treatments and what she refers to as 'natural remedies' that she would be more comfortable taking. There is a sense in this extract that the ingestion of pharmaceuticals represents a chemical contamination of the body reminiscent of arguments used by proponents of green social movements (I. D. Coulter & Willis, 2004; I. Coulter & Willis, 2007). Tanya's extract exemplified a common experience among many of the respondents for the need to try to seek out alternative treatments that would be effective for managing illness but which also fit with their identities as active and informed consumers within a marketplace of health products (Coulter and Willis, 2004; 2007).

Similarly, Theo speaks about the frustration he felt at the apparent lack of conventional or alternative options available for treating his nail psoriasis suggested through consultations with a dermatologist. Theo recalls a consultation where he was advised to the effect that 'yeah yeah this looks like nail psoriasis, and there's nothing we can do about it'. Theo says, 'It's rare to be told there's nothing we can do. And I don't really want to accept that'. Elaborating on how these unsatisfying interactions with doctors nurtured a critical position in his views about conventional medical treatment, Theo says:

> I'm not the only one having psoriasis or nail psoriasis and I'm thinking why the doctors are not actually suggesting, even if there is not like drugs That would work, but why the doctors are not suggesting even some non-drug solutions. Maybe certain creams could help. You read things online like maybe olive oil or vinegar solutions, why don't the doctors mention any of that? So I don't get it. Or is it because none of these have been really validated?…. I was telling those doctors sometimes, I said is there- do you have any teas? Any of those grandma's remedies? They say no, I don't know anything. And I'm like, I don't get it, they are supposed to be specialists. Or maybe none of these actually work, maybe that's why, but you don't feel like they're even that aware of some other solutions, non-drug solutions, so I feel like there is a really lack of knowledge or willingness to make you try things that are may be less conventional in terms of medical treatment, because I think people are ready to try different things as long as it's legal means and something that you can do like place your fingers in a vinegar solution once every week or once every night. If you know or if it's validated that it's going to help you then I think people would be happy to try, right? And so I think there is a lack maybe of either knowledge or willingness to be a bit more open to those things.

Theo was critical of this position held by the dermatologist that there were no treatment options that he could try. He views the position of dermatologists on treatment advice as being one that lacks "openness" to try or recommend possible remedies.

Theo's experience illustrates a point noted by (Barker, 2008) and others about a growing medical uncertainty that has occurred alongside the development of a consumerist mindset around healthcare. Keen to try out a range of unconventional treatments, in addition to trying remedies for his psoriasis learned of through internet forums that involve use of household ingredients, Theo talks about searching for effective “natural remedies” that are available to purchase online. Taking an experimental approach to finding effective treatment, Theo outlines a process of submitting each remedy to a period of trial before deciding on its efficacy and then trying another. Theo says:

> But on my side, I'm going to try that, and after that I will maybe look at some of those websites where they sell natural remedies and I might try that olive oil, I might try the vinegar solution, And I guess you've got to stick to a routine for a while, see if it works or not, if it doesn't work then try something else.

These extracts illustrate Theo’s sense of disillusionment with the medical approach which developed through his consultations with doctors. Theo’s resolution to conduct personal trials of unconventional remedies appears to reflect both his hope that a market of alternative options may offer the possibility for effective treatment, as well as an understanding that he must be proactive in taking responsibility for his own treatment. These findings support arguments made by Nikolas Rose (2001), a social theorist whose work on postmodernity draws attention to an alignment between the somatic individuality of the current era and trends towards greater use of complementary and alternative treatments.

Costly Alternatives

Many of the respondents appeared hopeful in assessing the therapeutic potential for using complementary or alternative treatment options, often more so than for conventional medicine. Even for those who had tried a huge range of treatments, a marketplace of untapped options was always available that might provide an effective solution. However, the financial cost of accessing alternative treatments was often cited as a barrier to these explorations. Sandra talks about being put off using alternative treatments because of the financial expense. ‘It costs lots of money’, she says. As Sandra elaborates:

> So if you go to a Chinese herbalist, you know Chinese medicine has been around for thousands of years, but it's some of those things are cost prohibitive, you know, so I might go and spend £50 to kind of see somebody and get some tablets, so it's kind of weighing things up on your perspective, you know, and you don't necessarily know it will be worth it.

While Sandra had been deterred by the uncertainty about whether alternative treatments were worthwhile based on their financial costs, in their explorations of the plethora of options many of the respondents had spent a great deal of money, time and effort on alternative treatments and products. While for some respondents this was a source of financial strain, the impact of their condition on their lives had been such that they were willing to tolerate the burden of this expense. Illustrating the resources that respondents often dedicated to finding effective treatments, Michelle says:

> for years… if someone said, oh, buy this cream, me or my parents would dash off and get this cream or that cream. And underneath my um sink was just full of boxes of different things that we'd bought or I'd been prescribed.

Cupboards filled with both conventional and alternative remedies were evidence of the effort and expense Michelle and her parents went to in their search for any possible effective treatment for her psoriasis. As Michelle's extract demonstrates, taking an alternative approach to treating a chronic skin condition often meant engaging in a great deal of self-experimentation to find what would work. However, by contrast with the time-consuming process of waiting for an appointment with a dermatologist largely in control over access to yet another conventional treatment, having the power to choose from a vast array of treatment options held appeal.

Having written posts in online forums about his eczema, Roshan was given a recommendation to use a product sold in Japan, 'Dr Fukaya's lotion', which he bought at a substantial expense. ‘Using Reddit I found a blog’, Roshan says. After contacting the author of the blog, Roshan received a reply telling him ‘you’ve got skin damage from using steroids too much… use this lotion to combat the effects of steroid cream’. Having a sample of the product shipped from Japan, Roshan describes how the lotion cost a ‘fucking fortune. This much [indicates a small container size with his fingers] cost me fifty pounds… Thirty mil. Fifty quid. I was like, shit. 'Cause our Customs ended up putting money on it as well.’

After testing the hyaluronic acid product on his neck, and finding it to be effective, Roshan then undertook a complicated process of negotiation in order to get access to the product more affordably than was the case for his first sample. He speaks about his communication with the company that produced the lotion, through which he was connected with a person distributing the product in the UK, which reduced the expense a little. Describing the elaborate and unconventional process he undertook to sourcing ‘Dr Fukaya’s lotion’, Roshan says, ‘I then went to contact them on the website. You know you click "contact form", then emailed the team. And just asked them, "I can't afford the Customs charge here in England". In response, Roshan was told about a distributor based in the UK from whom he could buy the lotion at a lower price. ‘So it was, erm, ninety quid. A hundred and fifty millilitres for ninety pounds’, says Roshan.

Despite the high cost, even after his efforts to source the product more affordably, Roshan felt the financial burden was made worthwhile because there seemed to be no conventional treatment that he felt could be sustainably effective for him. In hyaluronic acid Roshan had found what he felt was a ‘miracle’ treatment which enabled him to feel more certainty about his ability to cope without using steroids. Roshan says:

> So ninety-something pound for that fucking miracle lotion. That's what I'd call it. 'Cause it really was. 'Cause that period of life was either ON steroids, or OFF steroids.

> No in-between. You know, you can't- There's no in-between. So you were either on them or you were off them.

Roshan felt that although the cost of paying for a bottle of the hyaluronic acid treatment each month was substantial, this remedy formed an important part of his new alternative treatment regimen, given that he aimed to stop using steroids. Roshan says:

> you'd get through about a bottle, one bottle a month… So ninety-something quid a month. Which ain't bad. 'Cause I stopped everything else anyway. I wasn't going to the Indian doctor then. I wasn't going to the German doctor then. It was just straight THAT. Get a moisturiser from the GP, which I can get on the NHS. Massive tub, yeah? So that will last you one or two months. And then get his thing. And that's it. So altogether ninety-something quid for their lotion, per month, which is basically the price of private or cheaper than private health care anyway.

As these extracts illustrate, Roshan had tried a range of alternative treatments, some of which had been very expensive. Given the impact of his eczema on his life, and the effectiveness he found through his use of a treatment he learned of online - which he described as a ‘miracle lotion’ - for Roshan, these expenses were justified and in line with other forms of alternative treatment. Through their ongoing pursuit of effective alternative treatments, respondents took on consumerist practices that aligned with the “postmodern hypothesis” (Siahpush, 1998) and an enactment of “somatic individuality” (Rose, 2001). The extracts of both Michelle and Roshan illustrate how many of the respondents would go to great lengths in the hope of finding alternative treatments that were effective. This often meant that respondents would expend a great deal of time, effort and money to research, source and buy alternative treatment for their illness.

Online Explorations of Alternative Treatments

The increasingly active role patients take in their own healthcare is reflected and reinforced through health policies that construct patients, particularly those with chronic illness, as experts who work in partnership with healthcare professionals (D. Taylor & Bury, 2007; S. J. Williams et al., 2011). There has been growing sociological attention to users of pharmaceuticals as reflexive and knowledgeable actors who assess the risks and benefits associated with treatment options to make informed decisions (Stevenson et al., 2008; S. J. Williams & Calnan, 1996). However, it has also been noted that there exists a context of growing medical uncertainty in which lay understandings of health and illness have increasingly gained influence in relation to professional expert knowledge (Barker, 2008; Brown et al., 2004). Factors including the increase in access to health information online, growing mistrust in the medical profession and expanding market forces have contributed to the development of what Barker (2008) terms “patient-consumers”. It has been well established that people use the Internet for accessing information about medications and other treatments (Nettleton, 2004). These developments reflect wider trends towards a society in which health-related information and products are readily available online (Nettleton et al., 2005). It has also been noted that in addition to accessing medical information online, the increasing access to information available online has also fuelled practices of seeking out alternative forms of treatment (I. D. Coulter & Willis, 2004; Nettleton, 2004)

Furthermore, electronic support groups provide virtual spaces for members to share their knowledge and experiences with others who live with the same illness. Indeed, Kristin Barker (2008) argues that in the current biopolitical age electronic support groups are a ‘ubiquitous feature of the illness experience’ (p. 20). Barker (2008) suggests that the development of electronic support groups has accompanied a substantial shift in experiences of illness, in that ‘the process of understanding one’s own embodied distress has been transformed form an essentially private affair between doctor and patient to an increasingly public accomplishment among sufferers in cyberspace' (p. 21). In support of this claim, it was found that in addition to using the internet as a resource for information about conventional and alternative treatment approaches, many respondents drew on a range of online spaces and support communities dedicated to the discussion of treatment strategies and concerns.

Facebook is a social network that many of the respondents had used for accessing online support communities of people who shared the same skin disorder. A common theme of the Facebook groups used by respondents in relation to their illness, is the sharing of advice for treating skin disorders that does not involve the use of pharmaceuticals. Speaking about the critical position she and other members of a Facebook group that she joined takes towards medical approaches for treating their eczema, Tanya says:

> I've read a lot on the internet about long-term steroid use and I really don't want to take them if I can help it…. I have joined some forums on Facebook as well. So that's been quite useful actually, 'cause I've had some good tips from people on there about how to control it, without using drugs. That's my main thing. I don't want to take steroids or anything else particularly. I really don't.

Tanya, Brooke and a number of other respondents cited the importance of Facebook groups in learning more about the risks of using steroids. While Tanya's desire for 'natural remedies' led to membership of a Facebook group for people living with the same skin condition, Brooke's critical position on conventional medical treatment in the treatment of her dyshidrotic eczema, particularly the use of steroids, appeared to stem primarily from her membership of a similar Facebook group. Brooke says:

> I've come to find out since then and joining the Facebook group with steroids how bad it is, and that's all the doctors are going to do, is give you steroids, so I really don't

> necessarily WANT their help, I just want the patch testing done to find out what it is that triggers mine, so that I can try and stay away from it, because avoiding it there's nothing they can do.

This extract from Brooke is illustrative of how several respondents engaged with Facebook groups which shared information about the side-effects of steroid use. Moreover, it is also illustrated how alongside a developing understanding of critical perspectives on pharmaceuticals, access to online communities accompanied a shift in how Brooke she related to medical doctors and the treatment services they offered.

Other members of the Facebook group that Brooke joined share their experiences of different treatments they have used in managing their condition and learn about options others have experiences of using. Brooke says, ‘I’m still trying to find what works best…. and I've tried different things that people have done on there that work for them’. Like Brooke, a number of respondents used Facebook groups as a resource for learning about alternative treatments to explore, some of which they proceeded to try as part of their own treatment regimen. Tanya says:

> It's something I've turned to with my skin really. I've never really been on any forums before, or anything like that. And I've been on Facebook for a while, but only because I've got family all over the world. I've resisted it for ages because I'm not a big fan of Facebook. But that's been quite useful. The forums on there have been very useful, because they're worldwide. So you've got so much information coming from people. And help. And that's why I took red meat out of my diet, because that was suggested on a forum, that possibly the protein in red meat could cause problems with eczema. But I don't think it's made a difference, but, I'll carry on.

While in the past, Tanya was not an avid Facebook user - indeed, she is ‘not a big fan of Facebook’ - it is since the development of her skin condition she has taken greater interest in this online platform. The ‘worldwide’ spread of users of a various Facebook groups means that there is the possibility for Tanya and others to receive a broad range of alternative treatment recommendations, despite misgivings about online forums held by some of the respondents. These findings support Barker's (2008) contention that in light of the growth in use of online communities of support, the understanding which individuals develop about their illness has become an accomplishment that is increasingly public.

Critical Evaluations of Alternative Treatments

As Nettleton and colleagues (2005) have shown, individuals demonstrate an awareness of concerns about the trustworthiness of the Internet as a source of treatment advice, drawing on a range of “rhetorics of reliability” in their evaluations of information. With reference to a prevalence of viewpoints sceptical of health claims broadly, particularly those made online, Erica feels that there is ‘a lot of doctor bashing that goes on, and some fear mongering I think’. Erica speaks about the importance of people being selective in what information they view and her own critical approach. She says ‘there are a lot of these people who are willing to make money out of you and so you have to sort of pick and choose what you look at, and I remain sceptical when I read things’. This extract demonstrates concerns that respondents often had about the intentions of those offering health information online and illustrates, in line with the work of Nettleton et al. (2005), how respondents purposefully evaluated the information available to them for trustworthiness.

Roshan was acutely concerned about side-effects he experienced while he had been using topical steroids, when he felt his skin had become thinned by the medication and prone to infections. Describing his reliance on steroid medications as an ‘addiction’, Roshan could no longer tolerate the impact its use he felt was having on his health and ended this treatment. Moving away from conventional medicine and the use of topical steroids, Roshan speaks about a careful process of learning about, acquiring and cautious initial applications of a product bought from a person whose blog about non-drug eczema treatments Roshan had found online.

> Using Reddit I found a blog…. and the guy was just OPEN. He was open to chat about it. He was like, "oh, add me on Skype”…. I was like, shit, what is this guy up to? He was willing to give out his real name, real thing.

The man was offering ‘advice, for free’, Roshan says. Illustrating his scepticism about the man and the legitimacy of his offer of information without asking for payment, Roshan says:

> I was like, wait, hold on. 'Cause then I was like sceptical. I was like- Some random internet dude. What the fuck am I going to learn off of this dude? Like this is shit. I've been to doctors, who have asked me for thousands…. What's some random internet stranger going to do for me?

He initially considered the proposal with some wariness because of a perception that this source may not be trustworthy and the man may have had an ulterior motive to take monetary advantage of Roshan’s position. Roshan had been forthcoming to the man about looking for alternative treatment options, feeling let down by the conventional medical system and its approaches to managing his skin condition. Roshan was encouraged by what he felt was a level of ‘openness’ in the conversations he was able to have with the blog’s author about alternative treatments, by comparison with more didactic conversations Roshan had experienced as part of conventional medical consultations.

Illustrative of a watchful approach to assessing trustworthiness, Roshan speaks about there being a need to ‘protect yourself’ when communicating about or buying alternative treatments from the internet, in order to avoid being caught by a “scam”. However, he also emphasises a view that it is important for those with chronic illnesses to ‘take risks’. Speaking about his experience with finding and using the hyaluronic acid treatment, Roshan says ‘I took the risk. And in the end it turned out to be the best risk of that entire period’.

Fearful of using the hyaluronic acid lotion for the first time because of a concern that the product may be harmful, Roshan says:

> I just used it on my neck. I was really scared to use it, 'cause you hear the horror stories where people put stuff on, and it burns them. And then I was like ohhhh. So even just to use it I was so afraid.

Speaking about how he decided to use the lotion on this part of his body for the first use, despite his concerns, he says, ‘I chose the neck as a testing region, because my neck was bad’. Roshan reasoned that the high severity of the eczema on the skin of his neck relative to other parts of his body made this area a good place to begin the ‘test’, as any improvement would be noticeable, and would also avoid worsening the state of other areas of skin on his body. However, after experiencing its effectiveness in treating his skin Roshan describes the product he found through his online research as a ‘miracle lotion’.

Demonstrating a watchful, ongoing surveillance of the material and sensory functions of his skin (Lafrance & Carey, 2018) Roshan outlines a detailed awareness of how his skin changed in response to stopping steroid treatment and experimenting with an alternative treatment which he learned about online. Roshan’s initial scepticism and cautious manner of trying the product demonstrates a critical evaluation of the trustworthiness of claims about the effectiveness of this alternative treatment. In support of findings by Nettleton et al. (2005), these results illustrate how Roshan and other respondents who engaged with support forums were often highly aware of the need for careful evaluation of information found online.

While people who are ill gather about treatments from an increasingly wide range of sources, this is not to deny the ways in which health professionals can, and often will, play a central role in determinations and practices of treatment (P. Bissell et al., 2001). People may remain dependent on medicine, but may also, through their use of alternative treatments and a wide-ranging search for information, ‘engender a sense of agency or lay expertise over the body and its maintenance’. For example, as Nørreslet et al. (2009) found, seeking out alternative treatments, moderating or avoiding completely the use of medicines as prescribed for eczema, may be conceived as acts of empowerment and resistance to the use of pharmaceutical treatment. However, while many people attempted to avoid the use of pharmaceutical medications, the need for treatment to relieve symptoms means that many had ‘eventually been forced to accept’ (Nørreslet et al., 2009, p. 1412) these treatments.

A minority of the respondents were sceptical about the utility of alternative treatments. For example, Sandra speaks about concerns she has about the use of complementary or alternative forms of treatment in the management of her psoriasis. ‘I’m cynical with things like that’, she says. Sandra outlines a range of concerns she has with alternative treatments, which she frames through comparisons with conventional medicine, in which she has more confidence. A quantification of risks for conventional medicine treatments, provided by having been ‘tried and tested’ through clinical trials, in addition to the known expertise of the practitioner, help Sandra to feel confident that a medicine is ‘legitimate’. As Sandra puts it, ‘I think with the sort of complementary therapies you know I think medicines that you don't know what they are a hundred percent, you don't know that they’re legitimate, you don't know’. By contrast, illustrating her greater faith in the legitimacy of conventional medications, Sandra says:

> when you get medication you get your sheet and as always the most common side effects and then there's the one in a million person will get this, but a lot of the treatments have been there for years and you know if you have ten thousand people using the specific type of medication who are benefiting from it, that means it is probably quite a good medication. You know they've gone through all the clinical

> trials, they'll have done the bits where they've had the placebo you know so they are tried and tested.

Sandra points out that by comparison with conventional medicines alternative treatments have not received the same level of testing and so they may not be as effective or safe as conventional treatments. Addressing another factor in her evaluation of trustworthiness, Sandra refers to the importance of expertise and the qualifications of the practitioner or the person dispensing a product. Raising concerns about the level of expertise of people selling alternative therapeutic products, Sandra says:

> to be honest I don't know that I would feel confident, because even if you go to like a health food shop, how well qualified is that person to be able to impart sort of advice…. The people that are selling them you don't necessarily know what they are qualified to sell whereas if you go into a chemist and speak to a pharmacist you know that they are educated to degree standard and beyond, you know that they're regulated and licensed, you know so therefore there's less likelihood of something going wrong.

While Sandra is sceptical about the use of CAM products, she is more comfortable with the idea of using alternative therapies to help with the mental and emotional aspects of managing her condition. Sandra explains:

> I mean I know for me one of my main triggers is stress so it's always going to be there but how inflamed and how bad it is I guess depends on how stressful my life is at that particular moment in time, and whether or not the complementary thing I don't know yoga, doing meditation, you know, doing the whole mindfulness stuff, whether by doing those it then helps to lessen the stress which in turn would lessen the psoriasis, to a point yes, but in terms of products, no. Obviously it lowers the mood when I'm on a total downer and I'm stressed and there are things going on and sometimes it's things beyond your control, that's for me when it flares, but in terms of I don't know there's

> not very much I can do about it, you just kind of you know, huuhhhh [exhales], there's nothing I can do to make it particularly better, you know, and even if I gave up drinking alcohol and turned vegan and meditated for an hour every day, there's nothing to say my psoriasis would then just disappear. It might lessen or it might not be as bad. Or it might just even disappear temporarily but then what happens when the next blip comes along and something disastrous happens that then causes distress to come back, then the psoriasis comes back.

Sandra's experience has been that there is 'nothing I can do to make it particularly better'. Uncertainty about whether the changes she would be making to her life would prove worthwhile for sustainably improving the state of her skin condition in spite of distressing events and emotions that will likely occur, means that Sandra feels little incentive to try these alternative approaches.

Many of the respondents stated a preference for trying alternative treatments, but also questioned their effectiveness. Speaking about her experience with alternative and complementary treatments for pompholyx eczema, Tanya says:

> I have done a bit of research on the internet, and I've found, you can actually buy these little [inaudible] things from B&M and Home Bargains. They've got tea tree oil and- I can't think what it is now- and they're a foot soak, and they're really good. So I'd rather try and use natural remedies if they work. That's if they work. If they don't work then it'll have to be the route of taking steroids again. But I'd rather try and alter my diet and maybe, I don't know, people have suggested that I should have maybe some reiki or something like that. But I don't know how much I'd be into that, but- I'd give anything a try. The worst thing that can happen is it won't work, but- I dunno.

For Tanya, who has bought a range of "natural" treatments and is interested in trying others, these alternatives would be preferable to using steroids for treating her pompholyx eczema, but their efficacy is source of uncertainty. Similarly, while Brooke would consider herbals treatments and essential oils for her pompholyx, she has found it difficult to source reliable information about how to approach the use of such treatments. Brooke says:

> I would consider like herbal things, like, my mum- well, and not even necessarily herbal, but essential oils are really popular and seem to help a lot of people with a lot of things, so that's something that I would consider if, you know, I could figure out [inaudible]. But I don't even know where to start. My mom's got a big book of what oils to use for what but it's- there's nothing that really pinpoints that it will be helpful for this condition. I've asked around on the Facebook group and I haven't gotten a duplicate answer yet [laughs].

When asked about whether she had tried any alternative treatments in the management of her eczema, Patricia says ‘it’s easier if you ask me what I haven’t tried!’. Patricia details the many alternative treatments she has used along her illness trajectory, driven previously by a hope that she might find a solution that could remedy her condition. However, having tried a vast array of treatments Patricia expresses that she now tries treatments in the hope only that she is not further debilitated by her disordered skin. Outlining her experiences with a multitude of alternative treatments, Patricia says:

> I have done… homeopathy, Chinese medicine for ten years… Homeopathy again. Fasting. Elimination diets. I’ve been on the… diet where you don’t have any dairy, no, you don’t have any sugar or yeast… Candida diet, yeah, that sort of thing. I’ve done that… for a long time. And for me I just don’t think it IS about food… Tried too many things. I mean by the time I'd been on the Candida diet for maybe a year and I wasn't eating meat at the time, and I can't eat fish, I went to a nutritionist who said I was completely undernourished and I'd better start eating properly again… Yeah. Done lots. Lots and lots of… alternative ways of trying to get rid of, 'cause you do,

> don't you. You would. But I'm sort of, I'm not resigned to it, maybe I've got a minuscule, tiny, tiiiny, no maybe I haven't. Have I got hope that it'll go? No, not really. I've just got a hope that I can manage it and it doesn't debilitate me like it has done this year.

Although she continues to explore alternative modes of treatment, Patricia has not found any of these alternatives to be effective in treating her eczema. Like Patricia, many other respondents had tried using a wide range of alternative treatments without a great deal of effectiveness, albeit when compared with the results of using conventional pharmaceutical medicines.

Speaking about his experiences with both alternative and pharmaceutical treatments for psoriasis, James says ‘I have had acupuncture. I have tried homeopathy as well. I've tried most things. Believe me, I've tried most things over this journey. Some things worked but nothing clears your skin like biologics I'm afraid. Not for me anyway’. While James has been open to the use of many different alternative treatments across his long-standing experience with psoriasis, he acknowledges the effectiveness that pharmaceutical treatment can bring.

Hybrid Treatment Practices

Drawing on Latour's (1993) notion of “hybrids”, Dew et al. (2014, p. 28) argue that homes are ‘hybrid centres of medication and therapeutic practices’ in how households cut across and assimilate mainstream and alternative health care practices, linking an array of networks including family, friends, health practitioners and the Internet. In the home, practices and beliefs which have been “purified” in health practice spaces such as the consultation rooms of medical practitioners or alternative healers are mixed up and reassembled in hybrid form. Responses to illness and wellbeing ‘involve pragmatic decision-making based on what seems to work or what might work rather than purified rule-following’ (Dew et al., 2014, p. 29). Through these processes of research, experimentation and observation, people engage in truth-production and develop their own understandings about – and practices for – managing their wellbeing. This can be viewed as a form of resistance to institutional discourses concerning health and illness. Dew and colleagues (2014, p. 29) argue that lay beliefs and practices are ‘inherently a challenge to the power of medicine, in particular because they are not readily visible and therefore not readily disciplined’. Rather, the products of institutional medicine, including pharmaceutical treatments and clinical advice are hybridised through combination with alternative forms of knowledge through the activities of daily practice within the home.

Experiences of powerlessness and ambivalence about treatment and management practices often led respondents to feel apathetic towards institutionalised medicine and the practices they undertook as part of their illness management. It could be argued that the ambivalence and powerlessness these respondents experienced may have contributed to subsequent acts of resistance to institutionalised medicine such as seeking out alternative treatments (I. D. Coulter & Willis, 2004)of exacerbation to enacting out daily practices to future plans and expectations about managing their skin condition, a number of those involved in this study had looked to alternative approaches and practices for wellbeing, either instead of using pharmaceuticals or, in many cases, in combination with them.

It has been shown that people “hybridise” wellness practices. Dew et al. (2014) demonstrated that householders take suggestions from different sources and recombine these in relation to their own understandings, needs and resources. Individuals often deviate from the treatment recommendations of others, engaging with them tactically by adapting them to their own interests (de Certeau, 1984). Deviations from recommendations include stopping the consumption of a medication, rejecting a medication and ignoring warnings about usage (Dew et al., 2014). Through their use of medications and processes of experimentation, people become experts in how and when it is best for them to use treatments and when not to.

Their home becomes sites of truth production. Dew et al. (2014) found that advice about treatment practices may be ‘supplemented, modified or rejected’ (p. 36) based on processes of reconciling advice from alternative sources with personal experiences and understandings about the effects of prescribed medications. This process of reconciliation demonstrates a challenge to normative expectations of the use of medication through what Latour (1992) calls “anti-programmatic practices”.

Inspired by de Certeau’s (1984) analysis of “tactics”, Dew and colleagues (2014) conceptualised ways that people negotiate normative frameworks of therapeutic practice in everyday life. The discourses provided through therapeutic spaces, including those of the general practice clinic, the pharmacy, the alternative therapist’s consultation room and the health food store may be viewed as “tools” that can be actively manipulated by users, rather than passively consumed. Respondents often demonstrated a hybridisation of practices and sources of knowledge as part of their overall treatment regimen as different forms of treatment were used in combination or at different times.

Erica’s account of her treatment demonstrated a pragmatic use of both alternative treatment approaches and pharmaceutical medications. While she had experienced some success in treating her eczema with natural products, Erica found that a period of stress produced an exacerbation of her condition. Erica says:

> I was so stressed, and that's when it started to happen. So yeah, I've got it on my hands and arms, and um, intensely itchy, and also quite sore, which was a new characteristic for it…. I’d just been using natural products before, just literally coconut oil and a really clean diet, and a much better mind, much better sort of emotional fitness I guess…. But then when I got this sort of hurdle, there was a few sort of external factors which made me more stressed. So I started using, er, obviously I used some topical steroid as well as trying to clean up my diet even more.

Returning to topical steroids to treat the exacerbation of her eczema, Erica combined this use of a pharmaceutical with further “cleaning up” her diet. Erica’s simultaneous use of these treatment protocols, drawing from both medical and alternative understandings of illness and deploying each pragmatically, illustrates a hybridisation of therapeutic practices (Dew et al., 2014).

Similarly, Roshan emphasises there being a need to use different treatments depending upon the context of illness at different points in time, particularly the level of exacerbation of his eczema. He is also highly aware of the limitations of each treatment. Roshan outlines his reasoning for taking a nuanced regimen that combines conventional and alternative treatments and discusses his process for deciding on which treatments to use under which circumstances. Roshan says:

> sometimes the Ayurvedic stuff isn't strong enough and you do need steroids, so you go out and get steroids then. And then when the steroids have done their bit, like steroid withdrawal, clearly I can't use steroids anymore, so then you have to go to some alternative, right? So then you pick up the Ayurvedic, or you pick up some other natural stuff… You've got all these different types of treatments in front of you. Just jump at them all whenever the time is right or the context changes…. In Asian culture they always go to their private doctor, and they have the natural guy. Chinese people do the same thing. They go to the Chinese medicine. Indian medicine. I've had both in my life. Western, kinda lab-made medicine, that goes through the official channels, and then on this end I've always had the Indian doctor, and you'd used to go and visit them whenever the hell you want.

Roshan has tried numerous alternative forms of treatment across the trajectory of his illness experience. Elaborating on his experience of numerous forms of treatment and the need to be open to using a range of treatments, Roshan explains that ‘I’ve used them all. There’s no one method that works best'. As this extract demonstrates, Roshan uses a hybridised approach to treatment based on the specific context of illness and treatment at any time, taking into account the strengths and limitations of each type of treatment. Alternative or complementary treatments are not taken up uncritically. Rather, as Dew et al. (2014) found, the 'manipulation and production of practices applies as much to the frameworks of alternative practitioners as it does to the frameworks of orthodox medicine' (p. 41). Roshan regards each treatment as a "tool" (Dew et al., 2014) that can be put to use according to the unique situation, illustrative of Latour's (1993) contention that practices are often rather more "pragmatic" than they are "purified".

The Dermatologisation of Lifestyle as Treatment

As the work of Rose (1999, 2001) demonstrates, an emphasis on discourses of self-management and self-improvement, characteristic of contemporary society, have intensified the moral significance of the body. Rose's (2001) concept of "molecular politics" was developed to understand how in contemporary times life 'appears open to shaping and reshaping at the molecular level: by precisely calculated interventions that prevent something happening, alter the way something happens, make something new happen in the cellular processes themselves'. However, the possibility of reshaping life through conventional and alternative treatment interventions impels a responsibility on the individual to do so. Lafrance and Carey (2020) note that in this 'neoliberal age, having bad skin means having to do a lot of good work on it' (p. 10). This "good work", Lafrance and Carey explain, puts into action innovations in biomedical knowledge through learned habits which can affect the material composition of the skin. These transformations can create what Rose (1999) terms "somatic individuals" who act on their bodies, including their skin, in ways that align with neoliberal projects of medicalisation.

Rabinow and Rose (2006), argue that medicalisation acts primarily through the body and aims to instruct people in how they must ‘work on themselves qua living beings’ (p. 215). By focusing on the actions that individuals can take to modify and optimise the body, it is suggested (Rail & Jette, 2015) that medicalisation obscures systemic forms of inequality. Focusing on “life itself” (Rose, 2001) as the source of disorder, it has been argued that medicalisation constructs bodily parts and processes as problems to be solved for health to be achieved. In a development of theory that considers the role of medicalisation in practices around disordered skin, (Lafrance & Carey, 2020) highlight how the ways that individuals with acne act on the surface of the body not only consolidate medicalising projects, but also complicate them. Therefore, rather than framing skin-related practices in terms of a “medicalisation of skin”, Lafrance and Carey (2020) develop a concept of the “dermatologisation of life” to better understand the ‘embodied experiences of acne sufferers in the biopolitical age’ (p. 10). Lafrance and Carey (2020) assert that ‘from bacteria, cells and genes to stress levels, consumer habits and work schedules, everyday life is increasingly assigned a dermatological significance’ (p. 10).

Food can leave what Lafrance and Carey (2020) term a “dermatological aftertaste” which is ‘sensed through the impact that it is likely to have on both the feel and the look of the skin’ (p. 17). This results in the development of an embodied knowledge about the “epidermal effects” of dietary choices. Acne sufferers in the present study were found to organise their eating practices using information provided by doctors, dieticians and other health experts, and a range of lay sources, experimenting with their diet despite a lack of scientific consensus on whether acne and eating practices are connected. This sometimes involved eliminating “unhealthy” foods that had been “processed” or contained high quantities of sugar from their eating practices. Eating “right” was also shown to involve adding foods deemed healthier, more socially conscious and more “natural” than industrialised foods options, including products described as local or organic. As well as considering expert opinions, people with acne were found to use “skin sensing” practices as a means to determine if foods affect their skin condition, such as whether a food appears to increase or decrease the emergence of pimples. As Lafrance and Carey (2020), put it, ‘they become their own experts by combining what they have learned from medical professionals with what they have sensed from their skin in order to gain insight into diet and nutrition’ (p. 17). Moreover, the findings and recommendations which originate from these different sources of knowledge may not always align. As Lafrance and Carey (2020) note, the knowledge that individuals develop through “skin sensing” may confound conventional understandings of healthy and unhealthy diets.

Dietary Change as Alternative Treatment

In some cases, diet and exercise were cited as means of treating the skin. Michelle spoke about engaging in exercise and dietary changes as ways to treat her psoriasis when an oral steroid treatment proved ineffective and caused painful side-effects. Michelle says:

> it made me ache quite a lot, so we decided to stop treatment, and um, and then um that's when I realised that I needed to do something because um... pfff [exhale with pursed lips], there wasn't a next stage then…. I didn't know where I was going from that point, so that's when I decided to look at diet and exercise…. I think my diet um being improved, and the exercise, has helped me to become um much better in myself. I know from a physical state of my skin being much better, and also from the mental state of feeling, well, it's my wellbeing, I feel much better…. I wish I'd done it before, and, um, people did suggest it to me before, but I was quite negative really, and I thought that I'd tried absolutely everything to help my condition, that I was very reluctant to believe anything that anyone said, and I was very, very negative, and people would make suggestions and I just thought that I'd tried everything that you

> could possibly try and that exercise would make no difference at all. In fact it would probably make the situation worse 'cause I do have aches and pains in my joints, so I said I couldn't exercise. I used it as an excuse. I can't exercise because it'll make me ache more and I'll be more tired [slight laughing tone] than I already am [slight laughing tone].

Despite prior reservations about the value of diet and exercise changes, experiences of side effects from pharmaceutical treatment were cause for Michelle to turn to diet and exercise to treat her skin.

In the pursuit of finding effective treatments for her eczema, Erica has made many changes to the types of food she eats, which she frames in terms of “cleaning up” her diet. Erica explains that these changes were made on a dietary understanding about the basis of many forms of illness she has learned about through her exploration of non-pharmaceutical treatment practices and the “functional medicine” model. Erica pinpoints the focus of a functional medicine approach as treating the “root cause” of illness, in contrast to conventional medical pharmacy, which focuses on treating “downstream” manifestations of illness without tackling this “root”. From a functional medicine perspective, the root cause of illness then remains active in the continued progression of illness, which Erica believes to contribute to the recurrence of flared skin following pharmaceutical treatment.

Dietary changes included removing foods that contained gluten and ‘massively’ reducing the amount of dairy products she was consuming. ‘I don’t drink any cow’s milk at all, cow’s products at all anymore’, she says. ‘There’s a whole leaky gut theory’ Erica says, which is widely held within the community of practitioners of functional medicine because of a belief that various illnesses are related to the permeability of the gut. ‘Particularly in functional medicine, doctors recognise this form of intestinal permeability…. That's one of the theories about what triggers allergies and eczema’, says Erica. Erica believes that this dietary approach will ‘treat my gut better’ and ‘make my gut happier and absorb better’ and in turn may be beneficial in the treatment of her eczema.

Erica’s process of cleaning up her diet also including adding certain foods. For example, Erica ‘started to do things like a bone broth’. As part of her process of dietary change, she talks about having her levels of vitamin D checked, and began taking various supplements including ‘B vitamins’. However, ‘the key’ to what Erica has found to be an effective dietary approach has been the addition of ‘probiotics’ and fermented or “cultured” foods for their probiotic qualities. ‘So I started to take on good quality probiotics as well as cultured food, which is better – has better bioavailability for probiotics’, she says. Erica cites eating foods such as kefir, a fermented product made with cow’s milk, but clarifies that to be congruent with her reduction in reducing her consumption of cow’s milk products she chose a variety that didn’t use cow dairy. Rather, ‘most of the time it's cow's milk, but I actually used to get goat's milk kefir’.

In efforts to maintain “balance” with her food practices, Erica strives to eat in a way that broadly adheres to her “clean diet” but also limits the emotional consequence of eating something that falls outside of her perception of what is “clean”. Erica says:

> I have as clean a diet as possible… I think it's a delicate balance between, um, you know how some of the most "healthy people" in inverted commas eat organic and are very strict about their diet, they can sometimes be the most sick people because they're just stressed about if they've had something that's not organic today they'll get stressed out [laughs while speaking] and I think it's a balance.

While Erica focuses on a pragmatic application of “clean” eating, based within a framework of functional medicine and “leaky gut” theory, she also emphasises a need for people who are ill to ‘pick and choose’ between treatments, and feels there is a need for ‘trying for yourself’ in a process of ‘trial and error’ as ‘not everything works for everyone’. That is to say, Erica believes that the efficacy of different treatments varies between individuals. As Lafrance and Carey (2020) observe, such is the social importance of the skin, people with “bad skin” have a responsibility to do “good work” on their skin. Drawing on the implications of Erica’s extract, given the variability of what each person may find to be effective in treating their disordered skin, the process of researching and undertaking what constitutes “good work” work may be considered a near impossible task.

While Jennifer is sceptical of many alternative treatment methods such as reflexology and acupuncture, she is experimenting with dietary change as a non-pharmaceutical method for treating her psoriasis. With reference to her decision to stop using Humira, a biologic pharmaceutical, and taking on dietary advice, Jennifer says:

> I've decided not to continue with [the pharmaceutical treatment] for now, and I kind of wanted to look at another way of treating my psoriasis. I only started it on Monday. Like literally Monday. So it's just gluten and dairy free, and that was at the advice of a dietician.

Given her scepticism of the effectiveness of non-pharmaceutical treatments for her psoriasis, Jennifer has limited hope that dietary change will have a major impact on her skin. However, in pursuit of trying a more ‘natural’ approach to treatment, implored by her mother, Jennifer is willing to experiment with a period in which she applies advice from a dietician. As Jennifer puts it:

> And to be honest I'm quite... doubtful of other alternative methods. I think that's because I've been part of having medicine for so long. And um this diet and me stopping conventional medicine is partly to do with my mum as well, just to try and appease her and make her happy. Because she feels that there must be some hope for me, and some day it'll go naturally, and if I do the right things it'll disappear and I

> don't have to be… on horrible medicine…. And the only one of those options that my mum suggested, that I can see having a positive impact is diet.

Based on a scientific understanding of links between the immune system, psoriasis and diet, Jennifer is more willing to try the expert advice of a dietician as an alternative treatment than other types of alternative treatment which she views to require "faith" that she does not possess, for any chance at effectiveness. However, while she is trying dietary change as an alternative treatment for her psoriasis, Jennifer remains sceptical. She says:

> That's the only one I can kind of get my head around…. there's got to be some science about what you put into your body. I saw a dietician and she was saying that, obviously what you put into your body, your immune system has a reaction to it. If I'm putting things into my body that, um, my immune system is reacting quite severely to, then it would make sense that it would probably increase the reaction it has on my skin. Because obviously it's my immune system…. I kind of understood that and believed it. And another thing is, just giving it a go for my mum's sake I think, and I just don't feel like I could put myself through reflexology or acupuncture, 'cause I just do not have any faith in it or believe it, and it's costly as well, um, for something that I'm going to really dislike going to.
>
> Diet, I can change more easily. Um, and I'm only doing it for two weeks anyway, just to see what the reaction is of going completely gluten and dairy free. And then after two weeks I'm going to, like, eat a massive cheese board and see what happens. I'm just trying to hold off on the medication as long as possible, but in my head it's like I'm taking every day at a time. The diet, um, I don't know. I don't really have any expectation to be honest. I'm just gonna do it and see what happens. But… I have no expectation…. There is probably a placebo effect in there…. I need to believe it, but I can't really do that, and I don't really know why, because there was a time

> where I went to see a reflexologist about two months ago. I only went once and I just didn't want to go back, and um, I think the lady said to me, or my mum said to me, 'oh, you have to believe it's going to work'. I don't really get that, because if it's going to work it's going to work. I don't think about my injections working. I just do it and it's gone…. And I'm very scientific minded I think. I think that's probably what it is…. I'm just taking each day as it comes. And if this diet makes it a bit more subdued I'd be happy with that.

As this extract makes clear, Jennifer draws a distinction between the value of conventional and alternative treatments based on her scientific beliefs. While dietary approaches to the treatment of illness may resonate with those who would prefer to use "natural" or non-pharmaceutical methods, dietetic expertise maintains a basis of scientific knowledge familiar to people, such as Jennifer, with more experience of managing their chronic illness using conventional medicine.

Skin Sensing and the Dermatological Aftertaste of Food

Demonstrating a formalisation of the process of "skin sensing", Michelle keeps a written record of how food affects her skin. Michelle says:

> I did my own research and um because I was coming across conflicting information, so I thought that I would try to look at my diet, at what I was eating, and keep a food diary to find out if anything sort of aggravated it more, on days that it seemed good, so what helped it and what didn't help it. So I kept a food diary for a while.

By recording the "dermatological aftertaste" (Lafrance & Carey, 2020) of dietary elements in a food diary, Michelle created an innovate system to help find patterns in how her skin felt in relation to the foods she had eaten across time. Moreover, by making a longitudinal written record of her "skin sensing", Michelle's had access to data that could reveal patterns to help plan dietary practices to give a better dermatological aftertaste in the future management of her skin.

In the following extract, Patricia demonstrates a detailed understanding about the dermatological aftertaste that alcohol can leave through how her skin feels. Patricia says:

> I’ve done all of the diets and exclusion diets and, you know, I know for example that alcohol would dehydrate me quicker than it would dehydrate one of my friends, and therefore I don't like the feeling of it, and sometimes that can make you itchy if you get too dry. But that's alcohol…. If my skin's not in a good state, the alcohol will make it worse much quicker. If my skin's ok, I can drink a lot more….But if I drank a glass of wine now, before I've even finished it I would feel my hands drying out, just by one glass…. I think white wine's probably got lots of toxins in it that don't agree with skin problems. I don't know. But vodka, I drink. That's what I drink, vodka and tonic. So to me I know vodka's pure, and most of the time it doesn't cause a problem. But say I had six vodkas, then I would be more dry. I know I would.

Based on her skin sensing experience, Patricia outlines how different types and quantities of alcohol typically affect her skin through dehydration. In this extract, Patricia also demonstrates a nuanced understanding about how the differing severity of her eczema at different times influences how alcohol consumption affects the sensations of her skin.

Patricia and Erica’s experiences illustrate how skin sensing is used in their evaluation of how dietary choices can produce exacerbatory effects for their disordered skin. As demonstrated in her extract, Michelle’s system of using a food diary formalises “skin sensing” data that she can then use to discern how periods of exacerbation or reduced symptoms relate to her food habits over time. Each of these extracts demonstrate a keen awareness from respondents of the “dermatological aftertaste” (Lafrance & Carey, 2020) of the food and drink they consume. The extracts also highlight the extent to which dietary habits were shaped by their dermatological significance among respondents.

Topical Use of Food as Treatment

In addition to its bearing on what foods are considered healthy, the dermatologisation of life redefines the uses to which food can be put. Is it known that people with disordered skin may experiment with the use of food as a topical agent applied directly to the skin. Applying foods to the bodily surface, acne sufferers can 'sense it through the porous interface of the skin', find Lafrance and Carey (2010, p. 18), in a process of conducting experiments which generate 'new forms of both feeling and knowing' about the workings of the skin. While the application of food to the skin as topical treatments was limited among respondents, there were examples of food being used in this way for both psoriasis and eczema with mixed results.

Speaking about how her previous experiences of alternative treatments had contributed to her scepticism about using alternative treatments in the future, Michelle says:

> A friend of mine also suggested um some aloe vera based products which, to be honest, I dismissed, and I thought it was a load of hogwash, and, but I think I was in the mind state of I've tried everything and I knew best and nothing was going to work, because I'd tried all um like old wives' tales that older people were recommending to me, like boil some baby carrots and mash them up, and rub them on your skin and it'll make it go away. So I would do things like that.

In this extract, Michelle frames her experience of the topical application of foods as originating from "old wives' tales", suggestive of a relation to historic folk remedies. Having tried a recommendation for the application of mashed up carrots to the skin, Michelle had not found this traditional remedy to be effective and had become sceptical about the possibilities for finding effective alternative treatments.

By contrast, based on her understanding of functional medicine, Erica believed strongly in the potential benefits of the topical application of certain foods for effective treatment for her eczema. Erica speaks about how her use of topical and oral anti-fungal pharmaceuticals in treating a flare, just as with her use of topical steroids, would be effective in reducing the flare but only temporarily, before the skin flared again a week later. Following this course of anti-fungal treatment, in addition to her changed eating practices focused around cultured foods and other probiotics, Erica began to apply kefir, a fermented dairy product, directly on to her skin which 'made it feel much better'.

Having been thorough in her research into understanding applying the functional medicine model and gut health practices to the treatment of eczema, and as someone who has lived with eczema since infancy and who is also a medical doctor, Erica has both personal and professional interest in approaches to treatment. Reflecting on the potential incorporation of understandings of topical probiotic products into 'mainstream' medical treatment, Erica says:

> I definitely think, having researched so much about the role of the microbiome, about skin flora, about how eczema sufferers are more prone to skin infections, I think watch this space in terms of topical probiotics being a mainstay treatment.

Erica has used a process involving personal experimentation as part of her adoption of alternative treatments. She speaks about the empirical approach she has applied with her own use of topical kefir, which she tried despite her understanding that the kefir may not have 'the right bacteria' to be able to help with the skin. Erica says:

> And it's about selecting the right antibiotic- er, the right- sorry, bacteria too. I mean there's a question about that. And you could argue that I was putting stuff on my skin which was really for the gut, but I thought, well, sod it, I'll just try it anyway and see

> what happens [laughs while speaking] and it did actually help me. It definitely helped me. It was much less sore and felt much better, and felt a little bit less itchy.

Erica's topical use of kefir for treating her eczema illustrates an experimental approach to the application of food products to the skin as noted by Lafrance and Carey (2020) in their study of acne sufferers. Echoing those findings, Erica sensed a range of beneficial changes after applying the topical kefir to her skin in the form of reduced symptoms of soreness and itchiness.

Drawing on understandings about the use of fermented foods topically from doctors of functional medicine, as well as her knowledge and experience of living with eczema and as a GP who treats patients with disordered skin, Erica experimented with a type of kefir that may not have had recommended type of bacteria for this application 'just to see what happens'. In turn, Erica generated novel, embodied knowledge about the effectiveness of this type of kefir as a topical treatment.

Using Physical Exercise as Treatment

Exercise habits were often viewed by respondents as being important to manage their overall health as well as the benefits for their skin. Speaking about the benefits of exercise as a way to manage her skin condition, Meghan says:

> It keeps me happy, doing like the fitness classes and stuff. And I also get some exercise in, so, um. 'Cause I do, definitely, if I don't exercise my skin gets worse…. In exam time… I just know it will get bad, and I just sort of accept that.

For Meghan, exercise is presented as a means of managing her emotional wellbeing and for the beneficial effects exercise has for the state of her acne. Meghan has found that stressful periods, such as exam times, seem to exacerbate her skin regardless of any actions she may take to do things such as exercise.

Drawing on ideas around power, discourse and the body developed by Foucault (1976), Lafrance and Carey (2020) show that the dermatologisation of life produces a context where power both works on – and leads to new forms of knowledge about – the body. Lafrance and Carey (2020) found that the knowledge gained by acne sufferers through acts of skin sensing is also frequently challenged. For example, electronic support forum members questioned the value of positive thinking practices as a means of reducing stress when the skin is itself a source of stress. While exercise may also help to reduce stress, some acne sufferers found that exercise actually exacerbated their acne. Many respondents referred to difficulties they had faced in relation to their exercise habits which illustrate the notion of a "double burden" (Lafrance & Carey, 2020) in working towards both a healthy lifestyle and healthy skin.

The Double Burden of Treating the Skin

Respondents' accounts revealed a "double burden" in managing their skin in ways that fit with what they viewed as healthy lifestyles, with both exercise and diet being notable areas of concern. For example, many of the respondents mentioned the difficulties they experienced when they undertook physical exercises that caused them to sweat, itch or otherwise exacerbate their illness symptoms. In efforts to manage the exacerbation of their disordered skin, some respondents had greatly limited the physical exercise they undertook. In order to avoid exacerbating her eczema, Patricia limits her physical exercises to those which do not make her too sweaty or warm. Patricia says:

> sweating does make you itch. I went and did a hot yoga with a friend who teaches it…. Urgh, never again. And while I don't think we sweat as much, most people with eczema don't seem to sweat as much so someone said to me probably putting yourself in a massively hot situation is not good for you at all, because you're not able to release the heat from your body. And then sweat was making me itch, and apparently

> that's quite common. I didn't know that. But so I don't tend to do those kind of classes…. I do pilates and body balance which are never, you never get that hot and there's aircon which I need…. And if I did do anything in the gym I'd probably want to do weights or something. But I never, I never get boiling, I don't do anything that really heats me up anymore…. I never do anything that gets me too hot, 'cause it's just not worth it. 'Cause I'm gonna be itchy. Possibly.

Pavana greatly limits the physical activities she allows herself to do because of how the results of physical exertion impact her skin. She has found that running causes her to feel too warm, so she limits herself to walking on a treadmill to avoid discomfort and the time and effort required to cool her skin down. Pavana says:

> I don't go to the gym and do the running I used to do. I go to the gym and I use the walking machine and I do an hour's walk at a slow pace, and it's unbelievably frustrating 'cause you're like, you know, I used to in forty-five minutes do about three, four hundred calories. Now, you do an hour's walking and you do about two hundred calories or something, and it's, you know, it feels so minuscule and you just wanna um have a good run, and when I do sometimes just break into a quick run, the impact is that I have to go into the changing room, sit there for like twenty minutes, put on the cool moisturisers, wet towel, all this kind of stuff, and my feet get worse. So, yeah, I don't do that anymore. I don't do the runs anymore.

Not only did Pavana feel unable to exercise in a way that she had valued before the development of illness, limiting herself to walking meant that the time she dedicated to exercising felt less worthwhile for her health. A further limitation on physical exercise emerged after Pavana realised that her eczema was also exacerbated by sunlight. As a result of her photosensitivity, daytime fitness classes at the gym, which Pavana previously enjoyed, were no longer possible because of exposure to sunlight through windows at the gym. She says:

> Um, I used to do aerobic classes which were really nice because they…. actually do the stretches and do all the bends and twists and things so, I now have to think about stretch exercises at home that I try to do for neck-aches and things like that, whereas before I used to just go to use the gym a couple of time a week, do a class once or twice a week, and then I wouldn't have any aches and pains… whereas now, 'cause I can't do some of the things I wanna do I have to actually work out my own exercise programme and, um, because of the- it's sunlight triggered, I can't go just out for a walk like I used to be able to do. I have to wait until the evening, or I have to use, my husband goes to a gym, but I can't go to his gym because it's got windows.

Unable to attend these fitness classes, which provided a range of different exercises, Pavana has found that she now experiences more bodily aches and pains.

By contrast, a number of respondents felt that the value of physical exercise to their overall wellbeing meant that they would often tolerate discomfort with their skin rather than avoiding their preferred activities. Speaking about the impact of physical activities on her eczema, Erica says 'I'm quite a keen exerciser, so when I sweat that tends to irritate it'. Similarly, Helen says:

> I wouldn't say I choose not to, but you kind of know like if you go for a run, you're probably gonna, it's gonna make it itchy and you're gonna have to calm it down somehow. It doesn't STOP me going though if I want to…. As you sweat, and it just, it kind of, I think it's heat. With me it's a lot to do with heat, so I'll get eczema all down the back of my neck, and I'll maybe get it down my back, so, but it fades very quickly, but it's a temporary thing.

These experiences illustrate the "double burden" faced by respondents trying to manage their lifestyle practices as part of treatment for their skin condition. While respondents often valued doing exercise or felt that it was important to be physically active, the physical discomfort that was associated with sweating, to focus on an issue common among those with eczema particularly, often led to feelings of ambivalence about these practices. However, as these extracts make clear, for many of the respondents, the burdens of discomfort or exacerbation that followed exercise were outweighed by the benefits they experienced for their wellbeing in carrying on with the activities they enjoyed.

Critique of a Dermatologised Lifestyle Discourse

Diet was frequently an area of practice that contributed to the "double burden" that respondents faced in trying to navigate simultaneously the intricacies of a "healthy lifestyle" and "healthy skin". Highlighting the complex social background to dietary practices, an important component of lifestyle, Biltekoff (2013, p. 4) notes that:

> despite seemingly scientific origins, dietary ideals are cultural, subjective, and political. While its primary aim may be to improve health, the process of teaching people to "eat right" inevitably involves shaping certain kinds of subjects… and shoring up… identity and social boundaries.

The offence taken by respondents to suggestions that their skin condition was caused by being "lazy", eating too much chocolate or fried foods and not enough fruit or vegetables may be better understood by addressing Bourdieu's (1984) work on class and lifestyle.

Exploring dietary views and practices in relation to class status, Bourdieu (1984) found that a taste for light and refined foods with a focus on fruits, vegetables and exotic cuisines was indicative of higher economic and cultural resources. Meanwhile a taste for heavy and substantial foods, including greasy fast foods and "junk foods" high in sugar and fat, indicated access to fewer resources. Such divisions of food and resources have largely been shown (Atkinson & Deeming, 2015) to correspond with contemporary dietary patterns and views on health.

Many respondents were critical of a common discourse they had encountered that attributed skin conditions to lifestyle and the consumption of certain foods, and which proposed dietary and lifestyle changes as effective treatment for disordered skin. Christopher believes that there are misinformed perceptions about the influence of an “unhealthy lifestyle” and diet on acne, and that this leads to prejudice. Christopher says:

> when I was a teenager there was still this idea that if you ate too much fatty foods or too much chocolate that's a contributor to it. I think that since then there's been studies that say that's a load of rubbish. But there's still probably a perception that maybe you live quite an unhealthy lifestyle maybe if you're quite spotty. Whether that's true or not, it doesn't, there might still be that prejudice there, or that, not prejudice but that presumption that you live an unhealthy lifestyle.

Similarly, noting that she has experienced misperceptions that link acne with “laziness”, hygiene problems and eating junk food, Meghan says:

> people think you only get acne if you just are lazy, eat junk food and you don't wash your face, so it's just people thinking that I don't know how to take care of my skin, when actually I'm doing the best thing for it.

Finally, in relation to diet and her eczema, Patricia says ‘there are no cures. People put various things on my Facebook page saying about eating lots of fruit and oh... No’. Patricia is highly critical of advice that people have given her which purports the curative powers of dietary change.

Given the cultural and subjective nature of dietary and health ideals (Biltekoff, 2013), the dermatologisation of lifestyle presents particularly issues for people living with skin disorders. However, as these extracts illustrate, it was relatively common for respondents to demonstrate resistance to a discourse in which chronic skin disorders were presented as the result of "unhealthy lifestyles" comprised of "junk food" diets, a lack of physical activity or hygiene issues. As a means of adding validity to their arguments, several respondents made reference to scientific knowledge dispelling such ideas.

Conclusion

This chapter set out with the aim of assessing the role of alternative and complementary treatments approaches in the management regimens of those living with chronic skin conditions. Very little was found in the literature on the question of how those with disordered skin viewed alternative treatments. In this chapter, it has been demonstrated that the use of alternative treatments often represented a response to difficulties associated with conventional medical systems and illustrated the importance which respondents attributed to autonomy over their treatment. It has been shown that respondents engaged with alternative treatments and sources of knowledge in order to manage their disordered skin in ways they viewed as more "natural" than the pharmaceutical treatments offered through conventional medicine. It was then demonstrated how aspects of lifestyle have been medicalised through alternative treatment regimens for the skin, conceptualised as the "dermatologisation" of lifestyle. To finish, evidence was presented to illustrate how despite negative experiences and concerns with conventional treatments, respondents did not view alternative treatments and knowledge sources in an uncritical manner, and often resisted normative views perpetrated as part of dermatologisation.

Consumerism describes how patients play an active role in their health through informed choices, as well as there being demands that they should do so (Gabe, 2013). It has been demonstrated that consumerism plays a role of increasing prominence in western health care practices (Henderson & Petersen, 2002; Hudak et al., 2003). Health policies increasingly construct patients living with chronic illness as working partners of professional healthcare providers (S. J. Williams et al., 2011). Moreover, pharmaceutical users are increasingly viewed as reflexive, knowledgeable actors who make informed decisions about their treatment options (S. J. Williams & Calnan, 1996).

Reflective of these trends, in the process of negotiating pathways towards effective treatment within the conventional health care system, respondents oftentimes strived for agency and independence. Many of the respondents placed value in the importance of developing an understanding of their treatment options. This typically involved a great deal of investigation and experimentation to find treatments that proved effective in managing their illness. Taylor and Bury (2007) note that through processes of becoming more informed about their treatments, questioning professional recommendations and exploring alternative sources of information, people become “expert patients”. The importance that respondents attributed to developing expertise in the treatment of their illness was sometimes driven by a sense that doctors lacked understanding about how to treat skin conditions.

It was not uncommon for respondents to engage in self-medicating, using knowledge about the effectiveness of different treatment developed over the course of their illness trajectory. There is a complex relationship between patient expertise and pharmaceuticalisation. Evidence of self-medicating by several respondents add weight to claims by Williams et al. (2011) that while patient expertise can facilitate resistance to pharmaceuticalisation, it can also fuel further processes of pharmaceuticalisation through patient-driven demand.

With a prevalent sense of disillusionment with what conventional medicine could offer, respondents were often keen to explore alternative treatments. These findings support Siahpush’s (1998) “medical outcome hypothesis”, which describes how a dissatisfaction with health outcomes from conventional medicine can lead people to turn to alternative treatments. For many respondents, alternative treatments represented a more natural approach to managing their illness than using pharmaceuticals. Moreover, as options for conventional treatment were often limited, the array of possible alternatives was often welcomed. It has been suggested that preferences for natural solutions rather than chemical solutions have developed through green social movements (Eastwood, 2000). Moreover, drawing on the "postmodern hypothesis", Coulter and Willis (2007) argue that the increasing demand for complementary and alternative medicine is likely to continue, based on a congruence between postmodern values and the philosophical underpinnings of CAM services. Such trends towards a greater use of complementary and alternative medicine aligns with Rose's (2001) concept of "somatic individuality", and the postmodernist concept of "self-assembly" as outlined by Rayner and Easthope (2001).

A prominent point raised by respondents about alternative options for treating their skin conditions was that the financial costs of pursuing alternative treatments could be high. These financial burdens sometimes limited the extent to which respondents could explore the alternative options that were available. However, the affinity between contemporary values, lifestyle and the use of CAM services, in addition to a disillusionment with conventional medicine, may help to explain the substantial expenses respondents had been willing to incur on alternative treatments along their treatment trajectories.

Information about health-related treatments is often readily available and accessed online (Nettleton, 2004; Nettleton et al., 2005). Consistent with the literature, respondents frequently accessed online communities for support and knowledge about treatments. These findings reflect developments noted by Barker (2008) that online support groups are a ubiquitous aspect of illness experiences and that the understanding that people develop of their own illness is an increasingly publish accomplishment. Furthermore, as Barker (2008) identified, alongside the development of "patient-consumers" and online usage there has been a context of growing medical uncertainty. It was often through access to online resources and joining online support communities that respondents developed an understanding of alternative treatments, affirming findings by Coulter and Willis (2004) that the increasing access to online information has fuelled practices of seeking out alternative treatments. It appeared that the online communities accessed by respondents were generally critical of conventional medical treatment.

While many respondents were hopeful about the effectiveness of using alternative treatments in managing their disordered skin, these alternative treatments were not taken up uncritically. Indeed, respondents were often sceptical about the possible effectiveness of alternative treatments. These findings support the position of Nettleton and colleagues (2005), who argue that people draw on a range of "rhetorics of reliability" when they evaluate information. That is to say, respondents demonstrated a critical appraisal of the trustworthiness of information about treatments they accessed online. More generally in fact, whether online or in real world situations, as Dew et al. (2014) note, alternative treatments are not taken up uncritically.

Furthermore, while respondents had frequently developed a great deal of understanding about treatment, and some respondents appeared to have taken on aspects of the role of expert patient, the expertise of medical professionals often remained an important resource for many. This is consistent with the view of Bissell et al. (2001), who argue that despite the wide range of sources of treatment information that is available, health professionals play a central role in determining treatment practices. Moreover, in agreement with Nørreslet et al. (2010), it emerged that despite their concerns about pharmaceutical treatments and preferences for seeking alternatives to treat their disordered skin, many respondents found themselves returning to the use of conventional medicines for the effectiveness that they could offer.

Alternative treatments often formed a complementary aspect of overall treatment regimens alongside conventional medicine. These findings corroborate an idea developed by Dew and colleagues (2014) that households are “hybrid” centres of medication and therapeutic practices. That is to say, far from being passively consumed, the knowledge and resources of array of different treatments, conventional or alternative, become “tools” that users can actively manipulate (Dew et al., 2014). In this sense, treatment practices were often “hybridised” as respondents selected from a range of treatments based on their beliefs about different treatments and their embodied experiences of treatment effectiveness.

Drawing on de Certeau’s (1984) conceptualisation of “tactics”, Dew et al. (2014) demonstrated that people engage with treatments tactically, in that they adapt these treatments for their own interests. In their ongoing assessments of available and preferable treatment options from a diverse range of sources, both conventional and alternative, respondents appeared to demonstrate a similar tactical engagement. More broadly, these findings echo the ideas of Latour (1993) that Practices are often pragmatic, rather than “purified”, and that in reconciling advice from a range of different sources with personal understandings, people engage in “anti-programmatic practices” by challenging normative expectations about treating their illness.

Acts of treating the skin both consolidate and complicate medicalising projects (Lafrance & Carey, 2020). In the management of a broad array of skin-related practices, LaFrance and Carey (2020) suggest, there emerges what they term a “dermatologisation of life”. In agreement with LaFrance and Carey, it was found that there was a “dermatologisation” of life, or perhaps more precisely a dermatologisation of lifestyle, as part of the treatment regimens adopted by respondents in the present study. This dermatologisation of lifestyle may be understood as a response to demands of present-day society, and in particular, demands about the importance of the health and presentation of the body. As Rose (1999, 2001) argues, the body is attributed considerable moral significance in contemporary society, which is intensified by discourses of self-management. Acting through the body, medicalisation instructs people in the actions they should take to work on themselves (Rabinow & Rose, 2006). Focusing on the effects of these societal demands on relations with the skin, Lafrance and Carey (2020) argue that people with “bad skin” have a responsibility to do a lot of “good work” on their skin.

A prominent aspect of the dermatologisation of lifestyle centred on food. Diet was dermatologised as an element of treatment by many of the respondents. In their study of people with acne, Lafrance and Carey (2020) found that a dermatological significance was often assigned to food. Foods left a “dermatological aftertaste” that was sensed through their impact on the skin, or their “epidermal effects”. Consistent with those findings, respondents in the present study often engaged in an ongoing process of “skin sensing” in relation to their diet. The “dermatological aftertaste” of different types of food and drink was often noted. Moreover, in line with Lafrance and Carey's (2020) findings, “skin sensing” practices were considered alongside other source of knowledge as individuals developed expertise in their own disordered skin. Furthermore, in alignment with Lafrance and Carey’s (2020) work, the epidermal effects of dietary choices sometimes confounded understandings of what is considered a healthy diet.

Lafrance and Carey (2020) argue that the “dermatologisation of life” creates a context in which power works on the body, but also facilitates new forms of knowledge. They found that through experiments with the application of foods directly to the skin, people are able to sense foods through this “porous interface” and develop new ways to feel and understand their skin. Besides giving attention to the effects of diet on the skin and adapting their diet as a treatment modality, a number of respondents had used food as a topical treatment applied directly to the skin. In need of finding effective treatment for their disordered skin, often having become disillusioned by conventional treatments, and in accord with Lafrance and Carey's (2020) ideas about how the dermatologisation of life can facilitate new forms of knowledge, these respondents were open to experimenting with a wide range of treatment types and modalities of use, including the topical application of foods.

In addition to the dermatologisation of diet, there was also a notable dermatologisation of physical exercise, both in attending to the effects of different types of exercise on the skin and in how physical exercise could form a part of treatment strategies. While exercise was often seen as a valuable adjunct to other treatment strategies, and for some respondents benefited the condition of their skin, the relationship between exercise and the skin was often more complex. In a finding about barriers to effective health practices, Lafrance and Carey (2020) noted that people with disordered skin face a "double burden" of working towards health goals which may be asynchronous - those of achieving both a healthy lifestyle and healthy skin. In line with these findings, many respondents had experienced this double burden. Fulfilling expectations about a healthy lifestyle in terms of aspects such as diet and exercise habits as well as pursuing healthy skin sometimes presented a range of ongoing conflicts.

Illustrating resistance to these sources of power, it was of interest to find that the dermatologisation of lifestyle was not always accepted. Indeed, for some respondents, this dermatologisation of diet and other lifestyle components presented a source for critique. Critical arguments made by these respondents reflected the cultural, subjective and political nature of dietary ideals, as noted by Biltekoff (2013). In particular, points of critique that were made by a number of respondents, about an illegitimate association between "junk food" and the skin, supported ideas outlined by Atkinson and Deeming (2015), who pointed out that contemporary views on health and diet reflect cultural ideals that associate lifestyle and class with food choices.

This chapter explored issues around how respondents approached alternative and complementary treatments for their disordered skin. It emerged that there was often a profound sense of disillusionment with health care systems and the availability of effective treatments. Notions of patient expertise and medical consumerism were drawn on to help understand reasons for respondents to turn to alternative treatments. It was also found that there was often a hybridisation of treatment approaches as respondents drew from conventional and alternative treatment and knowledge sources as they navigated in hope of effective treatment. Attention was then directed towards respondents' explorations of alternative and complementary approaches to treatment, where it was found that respondents often accessed resources about alternatives online and participated in support communities. It was notable that much of the online content that respondents discussed was critical of conventional medical treatments and in favour of "natural" alternatives to pharmaceuticals. Lastly, it was demonstrated that there was notable "dermatologisation" of lifestyle as treatment, in which practices around diet and exercise became a focus of alternative treatment strategies. However, this dermatologisation of lifestyle was not accepted uncritically.

Discussion

The findings in this thesis have been differentiated into 3 sections that represent experiences of Being, Living and Treating for people who have chronic skin conditions. Experiences of Being centre on findings that help build an understanding of identity and relationships with respect to the social importance attributed to the skin, and how this is affected by a chronic skin disorder. Experiences of Living represent findings that explore the material realities of living with disordered skin, focusing on the everyday impact and practices required to manage the body through chronic illness. Finally, experiences of Treating focus on how people living with chronic skin conditions relate to the treatments which they have used as part of regimens for managing their illness.

Summary of Findings and Theoretical Contribution

By adapting the concept of "aesthetic capital" (T. L. Anderson et al., 2010) for application in medical sociology, and for the experiences of living with chronic skin conditions specifically, it has been shown in this thesis that concerns about the presentation of the skin were common among respondents. As the findings demonstrated, such concerns were often driven by the ways in which the physical manifestations of a skin disorder can affect aesthetic appearance and produce visible markers of a stigmatised illness identity that can affect many aspects of lived experience. It was notable, however, that incidents of enacted stigma were found to be relatively rare in adult experience for the respondents in this study.

In this thesis it was demonstrated that rather than being enacted, many experiences of stigmatisation were instead perceived in the absence of such enaction by others. Reflective both of Leder's (1990) conceptualisation of "social dys-appearance" and Scambler and Hopkins' (1986) work on "felt stigma", this thesis has shown that for people living with disordered skin conditions, the stigma they perceived very often reflected a sense of ambivalence around appearance norms. However, it was also highlighted in this research that norms of appearance were deeply ingrained, despite respondents' hopes to resist them. It was found that while concerns about aesthetic appearance were often derived from worries about appearing abnormal, there was also another side to these concerns.

In adapting Tammy Anderson et al.'s (2010) concept of "aesthetic capital" for the first time for application to the field of medical sociology, this thesis draws attention to the notion that living with disordered skin can damage possibilities for aesthetic distinction. That is to say, disordered skin appeared to diminish the access available to respondents in this study to the embodiment of valued identities based on the appearance of "normal" or "healthy" skin. Moreover, it was also demonstrated in this thesis that concerns which respondents held about their presentation were also often connected to how living with disordered skin undermined a sense of embodied capability, particularly in work roles.

Responding to calls to acknowledge the importance of embodied and socio-spatial experiences of chronic illness and disability (R. Butler & Bowlby, 1997; C. Thomas, 2004), this thesis has illustrated how aspects of these concerns about the capability of the body to enact roles can be attributed to the notion of "disabling spatialities" that lead to the development of "time-space tactics", in an adaptation of Hawkesworth's (2001) ideas about how people living with acne negotiate across numerous aspects of everyday life. In this thesis, it was demonstrated that people living with a range of different skin disorders used such time-space tactics in the face of a variety of disabling spatialities in many areas of their lives.

For all of the individuals in this study, access to empathetic social networks and the relationships which comprise them were found to be an important source of support in coping with their illness. Respondents also sought networks of people offering knowledge about their skin condition and treatment options. It was notable that access to such resources for respondents appeared to be helpful in fostering valued identities as well as in the management of their illness needs. Support was not always perceived as being well-intentioned and it was not necessarily always welcomed. It was demonstrated, for example, that family and friendship networks could not always offer appropriate and welcome support, and in many cases, respondents had experienced interactions within personal networks which imposed identities that were unwelcome or undermined valued identities. Furthermore, it was noted that the illness management needs of disordered skin often added strain to personal relationships.

Few of the respondents had experienced attending illness support groups in person, so most of those who wished to engage with illness support networks had accessed these online. These online networks provided access to collective knowledge about treatment options and management strategies and offered opportunities for individuals to interact with other people who were able to relate to the concerns raised by their illness. Respondents often valued a sense of connection with support group members, particularly as any advice given was based on personal experience, which was often not available from anyone else in respondents' social worlds. For a number of respondents, the opportunity to contribute their own experiences within a community of support was also important, and they attributed a sense of value to being able to support other people in navigating experiences of illness and treatment which many found incredibly isolating.

An important theoretical contribution made by this thesis centres on the application of Leder's (1990) concept of "corporeal dys-appearance" to experiences of chronic skin conditions. Chronically disordered skin was found to emerge into awareness as an alien presence which forced a disruption between body and self. Illustrating Leder's (1990) conceptualisation, upon the exacerbation of the skin, distressing sensations such as itchiness or pain were found to become the focus of attention and demanded resolution. This attentional focus of dys-appearing skin was found to disrupt intentions that respondents held towards valuable projects in their life outside of the immediate focus on their body. It was also notable that the disruptive qualities of corporeal dys-appearance often took on distinct temporal qualities. Symptoms of illness often took on fluctuating trajectories in which periods of exacerbation were interspersed with periods of quiescence, highlighting the differential between these periods in both bodily sensations and management needs.

Practices of scratching, picking off psoriatic scales or squeezing spots were a perennial area of concern for respondents. Indeed, such practices, and the awareness of these practices and the need to relieve sensations were found to occupy a substantial amount of focus in everyday life. Building on the conceptualisation of Lafrance and Carey (2018), these can be considered acts of "skin work" performed by those with disordered skin. It was clear within the findings that across all accounts of such acts, respondents regarded grooming with a sense of ambivalence. It was shown that this ambivalence often stemmed from a consideration of the implications of performing such acts on the body, which were often presented as assaults on the skin. Given this framing, acts of grooming were frequently evaluated in moral terms as being transgressive in relation to norms about appropriate bodily behaviour. Moreover, given that obligations towards the management of external appearance are heavily gendered (N. Wolf, 1990), grooming represented a particular transgression for women, as the engaging in these non-conformist acts could put claims to beauty in jeopardy.

It was demonstrated that there was a notable extent of concerns around sleep as a focus of bodily experiences. Indeed, the associations between sleep and corporeal dys-appearance were often complex. Developing on a conceptualisation of sleep by Williams (2007) through adaptation to experiences of chronic skin conditions, it was shown that through the agentic "absence" engendered by sleep, respondents experienced themselves as vulnerable to bodily dys-appearance and the possibility of unwanted grooming. When this vulnerability to the dys-appearing body, was combined with the consequences of “damaging” the body while asleep through scratching or picking at the skin, it is argued that the processes required for achieving the “ontological security” necessary for sleep can become incredibly difficult. Respondents were often distressed by concerns about breaching aspects of “sleep etiquette” (S. J. Williams, 2007) in which daytime sleepiness and night-time wakefulness are problematised. As such, respondents often had concerns about the impact of taking naps on perceptions of their productivity and capability. Furthermore, using a concept developed by Kroll-Smith and Gunter (2005), it was shown in this thesis that people living with disordered skin often “put sleep to work” through making use of sleeping time as an opportunity to treat their skin with creams and ointments.

A new concept of “containing” has been demonstrated in this thesis as a type of skin work to be added to those of “concealing”, “grooming” and “medicating” within Lafrance and Carey’s (2018) model, which was based on acne alone. It has been shown that when applying this concept to other skin conditions such as eczema and psoriasis, managing disordered skin often demanded that the exudation of organic substances associated with the disordered skin had to be contained in order to avoid soiling the environments in which they have been shed. Furthermore, it was demonstrated that this work of “containing” also demanded constant reflexive awareness of the body that was producing these “dirty” substances.

Adapting Ben Anderson’s (2010) concept of “anticipatory action”, which describes how orientations are ‘made and lived in the name of pre-empting, preparing for, or preventing threats’ (p. 777) for application to the lives of people with disordered skin, it was notable that respondents commonly took on dispositions and actions in how they approached their everyday lives that could be described as “anticipatory”. Drawing on the work of Dew et al. (2014), it was argued that in addressing the material environment of the home for the management of illness, domestic environments became hybrid treatment spaces. Moreover, anticipatory dispositions were apparent in planned orientations to routine elements of everyday life that were focused on the assessment and negotiation of risks associated with disordered skin.

Dew et al. (2015) identified a range of repertoires used by people to justify their understandings and achieve moral positioning in how they use pharmaceuticals. The four repertoires identified were those of “disordering society”, “disordering self”, “disordering substances” and “reordering substances”. In the repertoire of “disordering substances, pharmaceuticals are presented as a threat to physical or mental equilibrium. For the “disordering society” repertoire, a reliance on the use of pharmaceuticals evokes a society in an unnatural state. Using the repertoire of “disordering self”, the use of pharmaceuticals represents a moral failing of individuals, a stigmatised failing of the body or both. Finally, within a repertoire of “re-ordering substances”, pharmaceuticals are framed as substances to sustain or restore order, and medical institutions and health professionals are viewed as sources of trust. The use of Dew et al.’s (2015) framework in this thesis is a new application of conceptualisation to medical treatments used for treating chronic skin conditions which was originally developed to represent perspectives on the meanings ascribed to household usage of pharmaceuticals.

It was demonstrated that people living with disordered skin drew on a range of repertoires concerning the use of pharmaceuticals. Most prominently, respondents drew on the use of repertoires of “disordering substances” and “disordering society”. It is argued that the prominent use of these two repertoires by respondents in this research appeared to reflect the many difficulties respondents experienced in their attempts to accessing effective treatment for their disordered skin. The use of such repertoires also represents concerns with effects and about implications associated with the use of pharmaceuticals, both for the individual and broader society - particularly in how the use of pharmaceuticals represents a move away from what is “natural”. A small number of respondents drew on the “disordering self” repertoire in relation to their concerns about developing a “regretful dependence” on medications. Meanwhile, for a few respondents, notably those respondents living with psoriasis who had tried modern biological injectable treatments, such medications represented “reordering substances”. For the respondents using such medications, it was noted that the use of treatments presented restorative, magical or talismanic qualities.

Reflective of consumerist developments in recent decades (Gabe, 2013), in the process of negotiating pathways towards effective treatment within the conventional health care system, it was demonstrated that respondents often strived for agency and independence. It was found that this often involved a great deal of investigation and experimentation to find effective treatments, through which respondents had often become “expert patients” (D. Taylor & Bury, 2007). More critically, it was notable for some respondents that the importance they attributed to developing expertise in the treatment of their illness was driven in part by a sense that doctors lacked detailed understanding about how to treat skin disorders. Moreover, it was not uncommon for respondents to engage in self-medicating, applying knowledge they had developed about the effectiveness of different types of treatment along the course of their illness trajectory. This evidence of self-medicating by numerous respondents corroborates claims by Williams et al. (2011) that although patient expertise can produce resistance to pharmaceuticalisation, it may also fuel further processes of pharmaceuticalisation demand that driven by patients.

Illustrating Siahpush’s (1998) “medical outcome hypothesis”, which describes how the dissatisfaction with health outcomes from conventional medicine may lead people to turn to alternative treatments, for many respondents, alternative treatments represented a more natural approach to managing their illness than using pharmaceuticals and an array of possible alternatives was often welcomed. However, it was notable that a prominent point raised by respondents in relation to alternative options for treating their skin conditions was that the financial costs of pursuing alternative treatments could be too high, which sometimes limited the extent to which respondents could explore alternative options, despite their preferences for doing so.

Consistent with the work of Nettleton et al. (2005), respondents frequently accessed online communities for support and knowledge about treatments, as information about health-related treatments is often readily available online. These findings also reflect developments noted by Barker (2008) that online support groups have become a ubiquitous aspect of illness experiences amid a context of growing medical uncertainty. However, it was also notable that in agreement with Nørreslet et al. (2009, 2010), it emerged that despite their concerns about pharmaceutical treatments and preferences for seeking alternatives, many of the respondents returned to the use of conventional medicines for the effectiveness that they could offer in treating their skin, whether solely using conventional medicines or developing complementary practices of using both alternatives and conventional medicines.

Lafrance and Carey (2020) argue that in the management of a broad array of skin-related practices, there can be what they term a “dermatologisation of life”. It was found in this thesis that just such a dermatologisation of life appeared to develop as part of the treatment regimens adopted by respondents, which may be understood as a response to contemporary expectations about to the importance of a healthy and presentable body. A prominent aspect of the dermatologisation of lifestyle for respondents in this study centred on diet. It was shown that items of food and drink were dermatologised as part of treatment by many of the respondents and the “dermatological aftertaste” sensed through food’s impact on the skin. Respondents in the present study engaged in an ongoing process of “skin sensing” related to their diet. There was also a notable dermatologisation of physical exercise, both in monitoring the effects of different forms of exercise on the skin and how physical exercise could play a role as part of treatment strategies. However, in agreement with Lafrance and Carey (2020), it was found that respondents often faced a “double burden” of working towards health goals which appeared to be asynchronous. To fulfil expectations about healthy lifestyles and pursue healthy skin sometimes presented a range of conflicts that were inescapable.

Implications for Policy and Practice

In addition to the conceptual contributions of this research, the findings presented in this thesis in relation to understandings about the experiences and demands of disordered skin have a range of practical and political implications. Many aspects of these findings would be pertinent to policy makers and employers, as well as to health professionals. Of particular relevance to the practice of policy makers and employers, this research acknowledges the serious impact and broader life implications of the burden of managing a chronic skin condition.

This thesis has drawn attention to the impact of disabling spatialities of illness in relation to bodily presentation and the functions of the skin. The concerns and difficulties demonstrated by respondents in how they related to particular physical and social environments highlight the impact of perceptions about environments on overall wellbeing. As the findings illustrated, the organisation of working environments or public settings that were perceived as unsupportive of the management of illness, or of the maintenance of valued identities, often contributed to the burden of illness. This raises questions about the challenges presented for moving towards more enabling and inclusionary spatialities in ways that could assist people living with chronic skin conditions at work and at leisure.

This research gives recognition to the complications presented for acts of disclosure and accommodation by the erratic presentations of illness, such as fluctuations in severity, that were so commonly an experience of respondents, and which often created concerns about access to institutional support. Given the impact of such concerns about public perceptions of whether the illness caused by a skin condition would be perceived with requisite seriousness on respondents' willingness to disclose their illness, this recognition is important. It may be argued that the erratic presentation of illness could be better acknowledged and accommodated for in interactions with healthcare professionals, employers and other institutional bodies through policy.

Relevant to broader political considerations, it has been highlighted in this research how access to resources, conceptualised in relation to different forms of capital, often has a bearing on experiences and actions in relation to illness. Whether in the form of financial resources for seeking further advice, the support of family and friend networks, or knowledge about treatment options, inequalities of access often contributed to the burden of managing illness. The broader policy implications of these findings relate to the acknowledgement of how capital inequalities affect experiences of illness and how these inequalities may be addressed in ways that assist those with limited access to resources vital for managing wellbeing with chronic illness.

The practical implications of managing a chronic illness have been a central focus of this thesis. This research gives comprehensive recognition to the amount of consideration, time and effort people living with chronic skin conditions must dedicate to their skin. Moreover, this research recognises the additional laborious practical demands of washing and cleaning that many must undertake each day as part of managing their skin disorder. It emerged clearly that the constant need for attending to the skin, and managing the consequences of exudations from the skin, both physically and in terms of mental and emotional focus, often greatly limited social participation across broad swathes of experience from employment to intimate settings. This knowledge can be used to help identify ways of acknowledging and accommodating some of the additional labour of life with a chronic skin condition through broad policy measures, so that such social limitations can be ameliorated.

Finally, the thesis gives recognition to the ways that sleep is often compromised in those living with disordered skin, with clear implications for the ways that those who are ill navigate daily tasks and their overall wellbeing. Given the importance of sleep for health, it would be valuable to consider whether there can be improved policy recognition of the impact of sleep problems for people living with chronic skin conditions so that these additional needs may be better accommodated in relation to the many social roles which individuals fulfil.

Of particular relevance for the practice of healthcare professionals, this thesis demonstrated that people living with disordered skin often held deep concerns about their use of pharmaceutical treatments. Research findings illustrated an ambivalent - but often notably critical - perspective from respondents on what they considered to be the over-prescription of medications which they considered to present substantial side-effects and long-term risks. Moreover, respondents often felt that these concerns were not adequately taken into account by healthcare professionals, particularly alongside experiences of poor pharmaceutical effectiveness. This research raises questions about the extent to which ambivalent perspectives about pharmaceuticals held by those with disordered skin are acknowledged by health care practitioners and how these concerns can be better addressed or accommodated in health care practice.

This thesis highlighted ways in which treatment often appeared to leave respondents feeling like they were undertaking a Sisyphean effort, in which any success in treating the skin was difficult to achieve and often temporary. Perennial fluctuations of illness and a succession of pharmaceutical treatment protocols were often a source of emotional exhaustion which added to feelings of disillusionment with medications and the conventional medical health care system. While the complex nature of dermatological conditions understandably makes treatment a difficult and often slow process, these findings suggest that further attention could be afforded by healthcare institutions and medical professionals to the acknowledgement of such Sisyphean experiences and consequent disillusionment with medical treatment, as well as ways in which the difficulties of accessing effective treatments might be eased.

Parallel to concerns about the use of pharmaceuticals, this research highlighted the importance which respondents attributed to having agency within their treatment. An important aspect within the findings was how those living with disordered skin were keen to experiment with treatment protocols, and that this sometimes involved self-medicating with pharmaceuticals, using alternative treatments or complementing conventional treatments with alternatives. These issues raise queries about whether the desire that people with disordered skin have for agency in their treatment, particularly around the use of alternative treatments as a means to achieve more “natural” protocols, could be better acknowledged and accommodated by healthcare professionals and institutions.

Of relevance to the practice of healthcare professionals, but also of institutions like the NHS, this thesis recognised a desire for more social support in living with a chronic skin condition from people who could relate to shared experiences. As the findings demonstrated, there was often a sense of isolation and a great deal of uncertainty associated with navigating life with disordered skin. Social connection was often sought online through support forums and much of the knowledge that respondents developed about their illness and treatments were sourced through such forums. The prevalence of online support forum usage appears to be indicative of a lack of availability and access to supportive communities. Online support forums were often critical of conventional medicine and its institutions, yet as was shown in this thesis, alternative sources of knowledge and treatment were not taken up uncritically.

These findings could be used to develop resources through which people living with chronic skin conditions could access more welcome support from people who understand what it means to live with these illnesses. Furthermore, given that online support forum usage was often associated with critical perspectives on medicine among respondents, it may be of value for the use of such online resources to be more closely acknowledged and concerns understood within conventional healthcare practices.

Limitations

One area in which the study may have been particularly limited was in the selection of respondents. There was a notable disparity in representation between the different skin conditions that the study aimed to represent through respondent sampling. There were far fewer respondents with acne than those who have eczema and psoriasis, which in some ways limited the scope of involvement of data representing acne experiences. However, it must be noted that the data gathered from those respondents with acne was often rich and featured prominently within the findings.

There was also a limitation in sampling in terms of the locations of respondents. While the initial plan was to draw on respondents based solely in the UK, the nature of sampling by advertising online could have made clear that UK respondents were being sought. However, given the international spread of respondents, while this may have implications for their experiences of health systems and medication usage, it was decided that the rich data gathered from all respondents was of value to the project.

Future Research

As has been demonstrated, the findings of this research have a number of implications for policy and practice, as well as for the development of theory, that could impact the lives of those living with chronic skin conditions, and which present valuable directions for future research. Building on these broad and varied findings and contributions, it would be of interest to develop research that explores experiences of managing disordered skin in relation to sociologically germane components of experience around gender, ethnicity, age and social class.

While this study has focused on material, sensory and social implications of living with these conditions, future research could explore these topics in more concise focus. Leder (1990, p. 97) recognises, for example, how historical and cultural power discrepancies associated with constructions of gender mean that the bodies of women do not disappear in the same ways as the bodies of men. “Social dys-appearance” can limit access to tacit embodiment for women (Leder, 1990, p. 99), who as a result of gendered expectations about beauty (N. Wolf, 1990) are faced with particular societal demands to give scrupulous attention to their external appearances. Developing on the notions explored within this thesis for a detailed examination of how gendered expectations impact women with disordered skin, for example, would make a valuable contribution to the literature.

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Appendix 1: Participant Information Sheet

School of Law
Royal Holloway, University of London
Egham, Surrey, TW20 0EX

Participant information sheet

PhD research study: An exploration of life with a chronic skin condition

This research is being conducted by:

Khalid Al-Muhandis
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This research is being supervised by:

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Aims of the research

This research aims to study experiences of living with a range of chronic skin conditions, such as acne, psoriasis and eczema, focusing on how people cope with and manage the physical, psychological and social difficulties that these conditions present. The findings from this research will provide valuable real-world understanding about life with a chronic skin condition from the perspectives of people affected.

I'm keen to find people who would be interested in speaking with me about their experiences. In addition, I am also interested in finding people interested in making some short video accounts exploring the impact of their chronic skin condition on day-to-day life.

If you decide you would like to be a part of this research, your participation will be entirely voluntary and you may withdraw from the research at any time, without giving a reason.

What your participation means in practice

Stage 1: Interview

We would find a time that is convenient to meet for a one-to-one interview at your home or another place suitable for a private conversation. The interview would last around an hour. We could also do an interview by Skype or by phone if a meeting in person is not possible.

The interview will provide an opportunity to have a conversation about life with a chronic skin condition. We will cover topics such as your personal history with the skin condition, what advice or guidance you have taken about treatment in this time, how you manage your skin day-to-day, and whether your skin condition impacts on your way of life.

Stage 2: Video accounts

Following the interview, I may invite you to take part in the second stage, which involves recording a few short video accounts of your daily life over a period of around a month.

I will supply you with a portable video camera, guidance about how it works and some suggestions about what you could record. This could include “video diary” type entries in which you talk about your feelings about any current treatment you may be undergoing for your skin, or a demonstration of how you use different creams, ointments or other medications to manage your skin condition. After around a month, I will arrange to collect the video camera.

Stage 3: Follow-up interview

With your agreement, we would then arrange to meet for a follow-up interview. In this second interview we will review and discuss some of your video clips together and talk about your experiences of producing video accounts related to your skin condition.

Inclusion and exclusion criteria for this research

If you are aged eighteen and over and have a chronic skin condition, such as psoriasis, eczema or acne, you are eligible to take part in this research. If you are under the age of eighteen and those who do not have experience of life with a chronic skin condition you will not be invited to participate.

Risks, inconvenience or discomfort that you may experience as a result of taking part

While it is hoped that your experience of participation in this project is a positive one, there is the possibility that discussing some aspects of life with a chronic skin condition may be lead you to feel distressed.

You will have the right to end an interview at any point without giving a reason. If you are taking part in the second stage of the research, there will be no obligation for you to make video recordings of any situation that causes you distress and you will have the right to delete any video recording without giving a reason. I will provide details of counselling services who can provide psychological support if required.

How this research can benefit you

You will receive an initial report of findings from the research and will then be given an opportunity to provide feedback. All feedback will be taken into account for a final report.

The findings produced with your participation will help to build an understanding about life with a chronic skin condition that will benefit others who share these conditions presently and in the future.

It is also hoped that you will find the experience of participation to be personally rewarding, and one which provides the opportunity to reflect upon your skin condition and the practices involved in its management in ways seldom presented in everyday life.

Privacy and confidentiality

Your anonymity and confidentiality will be maintained throughout the research, which will be conducted according to principles outlined in the British Sociological Association Code of Ethics and Social Research Association ethical guidelines. Ethical approval has been sought from the School of Law research ethics committee, Royal Holloway.

All data will be held in a password-protected computer in the form of electronic recordings and transcripts. Only the researcher and academic supervisors will have access to these data. All data gathered during this research will be anonymised for the purposes of publication or any other use, such as presentations at academic conferences.

Data will be held for a period of up to five years following completion of this research before being destroyed.

Your consent form will be stored separately from the responses you provide.

You may retain this information sheet for reference and contact the researcher with any queries.

Appendix 2: Interview Topic Guide

An exploration of life with a chronic skin condition

1. What does it mean to experience life with a chronic skin condition?

    - Tell me about your skin condition
    - What does it mean to you to have a chronic skin condition?
    - What impact does your skin have on your life?
    - How long have your experienced living with your skin condition?
    - Do you think there was something that caused it in the first place?
    - Would your life up until this point have been different if you did not have a chronic skin condition?
    - Does your work affect your skin?
    - Does your skin condition affect your work?
    - Are there positive aspects to living with a chronic skin condition?

2. What practices and strategies are used to manage a chronic skin condition?

    - Are there things that relieve your skin condition or make it worse?
    - What treatments do you use?
    - Where do you go to be treated?
    - How do you obtain the products used for treatment?
    - How have you learned about managing your skin condition?
    - Have your treatments changed over time? If so, what are your experiences with different treatments?
    - Have you experienced any side-effects from any treatments you have used?
    - Are there any risks associated with your treatments?
    - Have you tried any alternative treatments or therapies?
    - Are there any adaptations or decisions you have made in your lifestyle that take your skin into account? Why did you make these adaptations/changes? Were they effective?
    - Do you envisage that the way you manage your skin will remain the same in the future?
    - Are you hopeful about the future in terms of how you will manage your skin?

3. To what extent are experiences of chronic skin conditions embodied?

    - What do the symptoms of your skin condition feel like?
    - How does your skin condition make you feel emotionally?
    - Do your emotions affect your skin condition?

4. How does the management of a chronic skin condition relate to self-identity?

    - Does your skin condition play a role in making you who you are?
    - Does having a skin condition affect your social life / others around you?
    - Do other people notice your chronic skin condition? How do they react?

Appendix 3: Participant Consent Form

School of Law
Royal Holloway, University of London
Egham, Surrey, TW20 0EX

Participant Consent Form

PhD research study: An exploration of life with a chronic skin condition

Please take your time to read each statement carefully and put a tick in the corresponding box if you agree. Feel free to ask the researcher for any further information if required. After you have considered each statement, please go to the next page and

- **sign and print your name**
- **add today's date**

Thank you!

- I have read the Participation Information Sheet describing the nature and purpose of the research project. ☐
- I understand the purpose of the research project and the nature of my involvement in it. ☐
- I understand that I may withdraw from the research project at any stage and that this will not affect my status within the project, either now or in the future. ☐
- I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential. ☐
- I understand that data will be held confidentially, in a password-protected computer in the form of electronic copies of audio recordings and transcripts. These data will be accessible to the researcher only. ☐
- I understand that I may contact the researcher if I require further information about the research, and that I may contact the academic supervisors of the project if I wish to make a complaint relating to my involvement in the research. ☐
- I have had the opportunity to ask questions. ☐
- I have received satisfactory answers to my questions. ☐

- I agree to participate in this study. ☐

Signed ....
(Research participant)

Print name ....

Today's date ....

NB:This consent form will be stored separately from any other data you provide.

Signed ....
(Researcher)

Khalid Al-Muhandis

Today's date ....

Contact details

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Academic supervisors:

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Appendix 4: Participant Details

Pseudonym	**Gender**	**Condition**	**Age**
Amara	F	Eczema	31
Anthony	M	Eczema	50
Barbara	F	Nail psoriasis	56
Brooke	F	Dyshidrotic eczema	34
Christopher	M	Eczema & Acne	32
Erica	F	Eczema	36
Heather	F	Acne	26
Helen	F	Eczema	53
James	M	Psoriasis	42
Jennifer	F	Psoriasis	24
Margaret	F	Psoriasis	65
Matt	M	Contact dermatitis	44
Meghan	F	Acne	18
Melanie	F	Psoriasis	35
Michelle	F	Psoriasis	41
Monica	F	Psoriasis	25
Patricia	F	Eczema	53
Pavana	F	Eczema	49
Rebecca	F	Eczema	30
Roshan	M	Eczema	26
Sandra	F	Psoriasis	43
Tanya	F	Dyshidrotic eczema	46
Theo	M	Psoriasis & acne	39
Thomas	M	Eczema	53