

The Experience of Psoriatic Arthritis Patients Receiving Biological Treatment:
An Interpretative Phenomenological Analysis

by

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Abstract

The recent development of biological therapies has revolutionized medical treatment for psoriatic arthritis. To date, research studies have focused on the treatment effects of biologics from a quantitative perspective using generic quality of life measures. An understanding of how treatment with biologics is experienced in the lives of psoriatic patients themselves therefore remains lacking. This study investigated the lived experience of psoriatic arthritis patients receiving biological therapy by employing Interpretative Phenomenological Analysis (IPA) to access this experience. Analysis of the data highlighted that receiving biologics for psoriatic arthritis was experienced as life-changing, but also required participants to make sense of the many unknowns surrounding treatment in regard to future effectiveness and long-term side effects of biologics. Participants experienced a biomedical focus on disease and treatment effects alone as not taking into account the significant psychological impact that having psoriatic arthritis and being treated with biologics can have on sufferers' lives. Three master themes were identified: new lease of life, living with the fear of the unknown, and the importance of seeing the disease and the person. It is argued that this research extends the current knowledge base in counselling psychology on the psychological aspects of skin conditions such as psoriasis to what it is like to have both psoriasis and arthritis, whilst also being relevant to counselling psychologists working with psychological aspects of medical conditions, which is proposed to hold a promising future for the field.

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Glossary of Terms

Biological therapies (biologics): Biologics is the umbrella term given to a class of treatment drugs that are genetically engineered proteins derived from human cells. First licenced in the UK in 2004, biologics have revolutionised treatment of a number of inflammatory diseases. Biologics consist of highly selective agents that compromise the immune system by targeting specific internal events in the body that trigger the inflammatory response. Biologics are sometimes also referred to as anti-TNF or anti-tumor necrosis factor therapies, because these work by targeting a substance in the blood called Tumor Necrosis Factor (TNF)- alpha, which is a cytokine (specialized protein that promotes inflammation). It is this overproduction of TNF-alpha that has been linked to inflammation, which target by blocking the TNF-alpha activity by binding it to cell membranes and blood cells.

Methotrexate: is a type of immunosuppressant drug known as disease-modifying anti-rheumatic drugs (DMARDs). Methotrexate is prescribed to treat several auto-immune diseases including rheumatoid arthritis and psoriatic arthritis. Methotrexate works by blocking enzymes in the immune system but can cause serious side-effects to liver, lungs, and kidneys. Methotrexate is usually taken in tablet form.

PUVA: PUVA stands for psoralen combined with ultraviolet A (UVA) light therapy that is used to treat psoriasis. Psolaren is usually taken orally 1 hour before UVA treatment, but can also be applied topically in some cases. PUVA is usually given 2-3 times per week for 12 weeks in a light box.

Psychodermatology: Psychodermatology is a subspeciality of dermatology, which focuses on the interplay between dermatology (skin) and psychiatry/psychology (mind). The field has emerged as a response to there being a high

prevalence of psychological and psychiatric comorbidity in people with visible skin conditions, but also to findings suggesting that emotional states, especially stress, are implicated in the aetiology, maintenance, and exacerbation of several skin conditions. Psychodermatology is thus concerned with the interrelationship between the mind and skin and how treatment for skin conditions may include psychological interventions such as stress-reduction techniques, cognitive-behavioural therapy, mindfulness, etc. to reduce the psychosocial impact of disease and potentially physical symptoms of disease.

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Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obligated, at least for a spell, to identify ourselves as citizens of that other place.

—Susan Sontag (*Illness as Metaphor*, 1988, p. 3)

Reflexive Preamble

The inspiration behind this thesis arose at a clinical placement at a National Health Service (NHS) trust, which pioneers the use of psychodermatology – an emerging field concerned with the interrelationship between psychology and the skin.

For me, working with dermatology patients constituted the most formative experience as a counselling psychology trainee. It was one that led me to develop a profound interest in holistic patient care, the mind-body relationship, and how psychological therapy can be applied to patients with chronic medical conditions.

The impact of having a skin condition is often trivialised. Dealing with this patient group, however, taught me what a stigmatising experience living with a skin condition can be. Many clients told harrowing tales of being asked to leave public places such as gyms and swimming pools, people moving away from them on public transport to people staring or asking intrusive questions about their condition. Feelings of shame about their appearance caused many to avoid social interaction with others for fear of negative evaluation with detrimental consequences for their relationships, lives, and self-esteem. It quickly became apparent that having a visibly disfiguring skin condition was anything but a superficial, cosmetic issue, but rather one that could have an all-encompassing effect on sufferers' lives.

However, I also experienced that there was seemingly no direct connection between the severity of disease and the psychological distress experienced by clients. How severe or widespread the physical manifestations of disease was had little bearing on how the client coped with his or her condition. Some clients would be crippled by shame and anxiety about their appearance despite barely visible or

minimum disease activity. Others were covered from head to toe in angry, red plaques, but seemingly took it in their stride.

What I learnt was that how someone responded to having a medical condition had little to do with the illness and everything to do with the person behind the condition (Walker & Papadopoulos, 2005). The person's social context, what learnings or beliefs they had formed about themselves, others, and the world at large were paramount in understanding a person's illness-related distress. Consequently, psychological therapy would be most helpful when it centred not just on building adaptive coping responses, but on what lay behind that person's emotional, behavioural, and cognitive response to having the condition in question. And treating the person 'behind the condition' would, in some cases, translate into astonishing physical improvements whereby the condition would visibly shrink or disappear.

The specific research question of this study was the result of a meeting where consultant dermatologists and rheumatologists shared their observation that psoriasis patients, some with psoriatic arthritis, who had been offered a new and highly effective treatment drug called 'biologics' had mixed responses.

While some patients reported significant physical and psychological improvement following treatment, others, it seemed, did not manage to make real changes in their lives despite significant symptom improvement. Quoting from memory, these were patients who one consultant suspected 'might need rehabilitation or psychological help to move on with their lives'.

I immediately found this interesting as it tapped right into what I found fascinating; namely research showing that symptom severity is often not as important

as psychological factors in understanding coping and adjustment to chronic illness (Leventhal, Diefenbach, & Leventhal, 1992).

Furthermore, psoriatic arthritis patients were unique in that they suffered from both a skin and a joint condition. However, despite being affected by both psoriasis and arthritis, they had access to very little information about what it was like to have the condition and whether/how this was different from living with the well-established burden of psoriasis or arthritis alone.

Thus originating in a practice-based context, this thesis is the result of attempting to investigate further by attending to the experience of psoriatic arthritis patients treated with biologics.

Chapter I: Introduction

Chronic Illness

Recent years have seen an increased interest in the role of psychological factors in chronic illness management. A chronic illness can be defined as a disease that has a prolonged course, does not resolve spontaneously, and is rarely completely cured (WHO, 2005). Living with a chronic disease is therefore different from suffering from an acute condition, which, by definition, is characterised by a rapid onset, short duration, and, usually, identifiable and treatable origin of disease (Larsen, 2013).

Many chronic conditions are associated with physical symptoms that result in varying degrees of disability. Living with a chronic illness is therefore likely to introduce significant adaptive challenges and coping demands (Petrie & Reynolds, 2007). Indeed, data suggest that 20–25 % of patients with chronic medical conditions experience significant negative psychological symptoms (White, 2001) with depression being especially prevalent

Chronic Illness and the Biomedical and Biopsychosocial Model of Health

The current healthcare delivery system is founded on the biomedical model of illness; the focus is on disease and ameliorating the pathophysiology by medical procedures and interventions to restore health and functioning (Larsen, 2013). The inadequacy of the biomedical model in chronic illness management has been repeatedly highlighted (Waisbond, 2007). While clearly relevant for acute and episodic types of diseases, its ‘fix and cure’ model is ill-suited to meet the demands of patients with chronic illnesses, where recovery is incomplete and disease incurable per se (Larsen, 2013).

However, it is also the biomedical model's assumption of a linear correspondence between disease severity and degree of psychological distress that has been undermined. Whilst the prevalence of psychological disorders among people with chronic illness was initially assumed to be precipitated by the stress of having an incurable disease (Abram, Moore, & Westerfelt, 1971; Hong, Smith, Robson, & Wetzel, 1987), the correlation between disease severity and severity of psychosocial impact was found to be weak at best. Studies repeatedly found that the variability in coping, adjustment and psychological impact that came to the fore could not be explained by objective disease-specific factors alone (Rosenberg, Peterson, Hayes, Hatcher, & Headen, 1988; Hawley & Wolfe, 1988).

Instead, psychological factors have been shown to be crucial in explaining this variability (Leventhal et al., 1992; Lazarus & Folkman, 1984; Maes & Gebhardt, 2000; Devins, 2010). Indeed, a plethora of studies have demonstrated that it is how the individual perceives and experiences his or her illness and the meaning ascribed to having the specific illness that most significantly explain coping behaviours, psychological impact, and adherence to treatment across a wide range of medical conditions (Hagger & Orbell, 2003).

Such findings have spurred on a widening of the scope to include consideration of the role of psychological factors and social processes alongside the biomedical in health and illness. Such developments can be conceptualised as a shift from the biomedical model's focus on disease alone to a biopsychosocial model of health (Suls & Rothman, 2004), which holds that that biological, psychological, and social processes are integrally and interactively involved in health and illness (Engel, 1977).

The Relevance to Counselling Psychology

From a counselling psychology perspective, there appears to be a natural affinity between the biopsychosocial model and the values of counselling psychology. In a medical context, counselling psychology's holistic and humanistic emphasis thus places the individual, subjective illness experience at the centre of inquiry. The subjective illness experience will thus inadvertently contain within it the biological, psychological, and social *experience* of having and living with the disease in question.

For the counselling psychologist, it is the subjective, human experience of disease; how a disease is perceived, lived with, responded to and the meaning that is given to that experience that is in focus. This will mean paying attention to psychological factors that shape the individual response to disease, but also to the sociocultural context of that illness experience in recognition that "suffering, disease and illness are affected by multiple levels of organization, from the societal to the molecular" (Borrell-Carrio et al., 2004, p. 576).

A commitment to a scientific research base that guides practice is often heralded as the hallmark of counselling psychology (Lorrie & Callahan, 2000; BPS, 2005). Counselling psychology's historical emphasis on the personal, subjective experience and the use of phenomenological methods has led to a body of research seeking to promote understanding of and giving voice to those marginalised or overlooked by existing research (Strawbridge & Woolfe, 2010; Hoyt & Bhati, 2007; Ponterotto, 2005).

This has been reflected in the nascent body of research by counselling psychologists on the psychological impact of skin conditions like psoriasis (Papadopoulos & Bor, 1999; Papadopoulos, Borr & Legg, 1999a; Mizara,

Papadopoulos & McBride, 2012), which was previously seen as a primarily cosmetic issue with no significant implications for psychological and social well-being (Rumsey & Harcourt, 2005).

As no research to date has been conducted on PsA in which sufferers have both psoriasis and arthritis, it thus seems natural to extend the existing literature by widening the focus to PsA. It could furthermore be argued that this study's relevance to counselling psychology is augmented by counselling psychology's interest in what Davy (2000) terms *liminal experiences*. Defined as 'in-between' experiences, PsA sufferers can thus be understood to be positioned 'in between' the medical specialities of rheumatology and dermatology and possibly, therefore, as having received scant attention as a result (Gordon & Ruderman, 2005).

Giving voice to this population is therefore consistent with the values of counselling psychology as it aims to promote understanding of the experience of PsA sufferers undergoing biological treatment in order not only to raise awareness of what it is like, but also to potentially identify needs for and gaps in the provision of psychological support during their illness trajectory.

Such undertakings seem in line with recent UK government recommendations advocating an increased biopsychosocial approach in healthcare urging for the provision of 'integrated', 'holistic', and 'patient-centred' health care for people with long-term conditions (Department of Health 2012, 2013a, 2013b), just as the National Institute for Health and Clinical Excellence (NICE) has recommended that individuals with chronic medical conditions have access to psychological therapy (NICE, 2009).

Though it is unclear how many counselling psychologists work with clients suffering from physical health rather than mental health, data show that counselling

psychologists are increasingly employed within the NHS (Orlans & Van Scoyoc, 2009; James & Bellamy, 2010; Davies, 2016). Whilst understanding health and illness through a biopsychosocial lens is not the sole remit of counselling psychologists (Chwalisz & Obasi, 2008; Ogden, 2012), recent UK government recommendations on an increased biopsychosocial focus in healthcare thus gives the impression that counselling psychology is in a unique position to effect service provision by carrying out research on medical conditions or treatments that is consistent with counselling psychology's phenomenological and person-centred mode of enquiry (Ponterotto, 2005). Indeed, involvement in physical health has been argued to constitute an important future direction for the field (Karademas, 2009; Mrdjenovich & Moore, 2004).

It is therefore the contention of the researcher that phenomenological study with the aim of giving voice to subjective, first-person accounts of *what it is like* for PsA sufferers to receive biological therapy is both relevant to and consistent with the values of counselling psychology.

Chapter II: Literature Review

The following review of the literature will aim to provide an overview of what is currently known about the biological, psychological and social aspects of living with PsA.

Psoriatic Arthritis

Psoriatic arthritis (PsA) is a chronic autoimmune condition characterised by inflammatory arthritis that has been estimated to affect 10–30% of patients with psoriasis (Gladman & Chandran, 2009). PsA is currently incurable and typically develops sequentially to psoriasis with a typical onset of 10 years after the first psoriasis symptoms (Mease, 2009). PsA patients are therefore doubly afflicted; first by psoriasis, a visibly disfiguring skin condition, and subsequently by arthritis in the joints and connective tissues.

Psoriasis is a chronic, inflammatory skin condition characterised by the development of raised reddish lesions covered by a silvery build-up of scales on the skin surface. Symptoms include shedding or flaking of skin, debilitating itchiness (Globe, Bayliss & Harrison, 2009), bleeding, cracking, and dry skin and can range from mild to severe, the latter of which can lead to hospitalization.

The arthritis symptoms of PsA manifest as inflammation in the joints and connective tissue, which can lead to pain, stiffness, and swelling and, sometimes, permanent destruction of the joint structures. Disfigurement of fingers and toes, nail changes, and sausage-like swelling of fingers or toes are common, just as spine involvement occurs in up to 40% of patients (Gladman & Chandran, 2009).

The exact pathogenesis of PsA is unclear. The condition occurs equally among men and women with an average age of onset of 40 years. The condition is thought to

be triggered by an interplay between genetic and environmental factors, although evidence points to the primacy of genetic factors (Rahman & Gladman, 2005). Reports of prevalence vary, but the data that PsA affects 10–30% of psoriasis sufferers (Zachariae, 2003) suggests that less than 1% of the general population have PsA.¹

Like that of many other chronic conditions, the course of PsA is unpredictable and typically characterised by multiple periods of remission and relapse. This means that while sufferers are dually affected by both psoriasis and arthritis, symptoms may not manifest simultaneously. Sometimes symptoms of both psoriasis and arthritis develop in concert, other times only few or the symptoms of only one condition manifest (Mease, 2011).

Conventional Medical Treatment for PsA

Until recently, medical treatment for PsA was not particularly efficacious. Control of the inflammation and progression of disease was seldom adequate and treatment for the skin manifestations of the disease would involve a separate treatment altogether (Gladman & Chandran, 2009). The typical treatment for PsA patients would involve the dermatologist treating the skin and the rheumatologist treating the joints with each party prescribing a medical treatment according to their speciality that would have limited impact on the other condition. The result would therefore often be, not only a disconnect in the care of PsA patients, but also poly-pharmacy and a heightened risk of cumulative end organ toxicity (Gordon & Ruderman, 2005).²

¹ For further information about PsA, please refer to Appendix A.

² For an overview of treatment options for PsA, please refer to Appendix B.

The Emergence of Biological Treatments

However, the recent development of biological therapies ('biologics') has revolutionised the treatment prospects not only for PsA, but also for psoriasis and related rheumatologic conditions. It is now possible to simultaneously treat both the inflammation in the joints and skin by inhibiting specific components of the immune system that fuel inflammation (Wolfgang 2010).

Biologics are administered by injection or intravenous infusion (IV) and must be administered continuously to have an effect. Thus, patients either self-inject or receive IV at hospital on a fortnightly basis.

Adverse side-effects to treatment with biologics include injection-site and infusion reactions and the increased risk of infections (Gladman & Chadran, 2009). Being a relatively new drug, there is still uncertainty about the long-term effects of biologics. However, the majority of evidence suggests that approved biological agents are generally well tolerated and safe, when used according to guidelines in well-monitored patients (Soubrier et al., 2014; Basra & Hussain, 2012).

Biologics are, however, expensive at an estimated cost of £10,000 per annum per patient (NICE, 2012). Clinicians are therefore urged to follow a stepped-care model, where biologics are only offered to patients with moderate to severe disease impairment, who have not responded to or developed intolerance to conventional treatment with systemic agents. Alongside disease severity, a further eligibility criterion for biologics treatment is the demonstration of significant quality of life impairment (NICE, 2012). Thus, biologics tend only to be offered as a 'last resort' to

patients, who demonstrate moderate to severe impairment on both physical parameters as well as on domains relating to QoL.³

Quality of Life Measures

In the healthcare literature, QoL or HRQoL have emerged as broad terms to describe the personal and social context of patients. Such measures are now routinely included in randomized controlled trials (RCT) to supplement clinical measures of disease severity and clinical treatment effects. These work by generating a broad, overall numerical indicator of the impact a disease or treatment has on the physical, social and psychological well-being of an individual, which is thus seen as evidence of their effectiveness (Bowling, 2007).

The most widely used generic HRQoL measure is the SF-36 (Ware & Sherbourne, 1992). The advantages of its use are that the data generated can be used to systematically compare and contrast across different populations and conditions. The use of such measures can therefore yield highly valuable information of the extent to which QoL has been compromised by a disease (Rapp et al., 1999).

The Lack of Disease-specific Measures in PsA

The scant attention that has, historically, been paid to PsA has resulted in a situation in which there is currently no standardized and widely validated disease-specific measure available (Gladman et al., 2007; Mease, 2009). While attempts have been made to develop measures that assess both clinical and QoL domains in a manner that capture the patient's assessment of their impairment of both the skin and joint symptoms of the disease (McKenna et al., 2004), such efforts are still ongoing (Coates et al., 2014).

³ Please see Appendix C for details on biologics guidelines for psoriasis and PsA.

This has therefore resulted in a situation where researchers as well as clinicians have had to rely on either generic HRQoL measures, such as the SF-36, and/or instruments developed for related rheumatic conditions, such as the ‘Health Assessment Questionnaire’ (HAQ) (Bruce & Fries, 2003) for rheumatoid arthritis (RA), or the ‘Dermatology Life Quality Index’ DLQI (Finlay & Khan, 1994) for psoriasis⁴ (Mease, 2011).

Existing Research on HRQoL in PsA

When it comes to research into the psychosocial aspects of PsA, the majority of studies have been comparative quantitative studies that have employed generic QoL measures such as the SF-36.

One of the first studies investigating QoL in PsA patients was a Canadian study, which used the SF-36 and the HAQ to compare QoL data between 107 PsA patients and the 43 Rheumatoid Arthritis (RA) patients. The study found that even though joint damage and decline in physical functioning was more severe in RA, patients with PsA reported more limitations due to emotional problems and pain than in RA (Hufsted, Gladman, Farewell, & Cook, 2001).

Similar results were obtained in a Turkish study, which also compared QoL and life satisfaction in 40 patients with RA and 40 patients with PsA. It was likewise found that both patient groups demonstrated decreased QoL and life satisfaction compared to healthy controls, but even though joint damage and physical disability were greater in RA, the psychosocial impact was the same for both groups (Borman et al., 2007).

⁴ Please see Appendix D for more information and copies of these questionnaires.

In the same vein, HRQoL scores were compared among 469 patients with RA, 166 PsA patients, 164 patients with ankylosing spondylitis (AS) and 1579 healthy controls using the SF-36. Not surprisingly HRQoL scores were significantly lower compared to healthy controls for all the conditions. However, overall HRQoL was found to be the lowest in patients with RA, whereas the scores for the mental component were lowest in the PsA cohort (Salaffi, Carotti, Gasparini, Intorcchia, & Grassi, 2009).

A recent Greek study comparing psychological distress in PsA and RA found a high level of moderate to severe depression to be present among PsA, especially in those with polyarthritis (36.7%) (Kotsis et al., 2012).

A recent study comparing QoL between 201 patients with psoriasis and PsA found that PsA patients had poorer QoL compared with patients with psoriasis alone except for on DLQI, a questionnaire designed to measure skin-related QoL impairment (Rosen et al., 2012). These studies therefore suggest that QoL is lower for PsA patients than in patients with psoriasis and RA, but the studies are methodologically not able to investigate the reason for this.

The limitations of the SF-36, HAQ, and DLQI. Although validated for use in PsA (Husted, Gladman, Farewell, Long & Cook, 1997), the SF-36 has been associated with a range of shortcomings. While it has been shown to be valuable in capturing physical disability or impairment associated with joint damage in PsA, the SF-36 has been found to be limited in its ability to assess the disability associated with the skin or psoriasis component of PsA (Mease & Menter, 2006; Mease, 2009).

This is also a limitation that has been directed at the other instrument that has been used extensively in studies assessing impact of biologics treatment, namely the

HAQ. Originally developed to assess functional disability in RA, the HAQ has been widely used to assess disability in a variety of chronic conditions including PsA. However, given its explicit focus on disability resulting from the joint-related impairment, its utility is limited when assessing the disability associated with the skin component of PsA (Husted, Gladman, Long, & Farewell, 1995).

Both the SF-36 and HAQ have thus been criticized for falling short on capturing the skin-related aspects of PsA in terms of not only the physical discomfort or disability frequently experienced such as itching and bleeding, but also the psychosocial aspects, which have been shown to be an important aspect of having psoriasis (Mease, 2009).

The limitations associated with the SF-36 and HAQ have thus led many researchers to include the DLQI in clinical trials (Mease, 2011). However, as the DLQI was developed specifically to measure the impairment experienced by patients with dermatological conditions, it, therefore, does not contain any questions pertaining to the impairment that relates to the joint-related component of PsA.

The Turn to Qualitative

Not surprisingly, the reliance on measures in PsA research that are either generic or developed for other medical conditions have raised concerns as to whether these instruments reliably assess what is relevant to PsA sufferers' lives (Mease, 2009; McKenna et al., 2004).

This concern has prompted a turning to qualitative methodology to explore the patient experience of having PsA with the aim of finding out whether concepts important to PsA patients are covered by measures assessing functioning in two studies.

An Austrian study using thematic analysis interviewed 31 participants in 6 focus groups about their disease experience. The study found that 19 concepts identified as important to PsA patients, translating as 35%, were not captured by any of the 9 measures, which included the SF-36, HAQ and DLQI. The authors thus recommended further qualitative studies into patients' experience of disease when seeking to develop and refine outcome measures (Stamm et al., 2007).

An unpublished doctorate thesis utilised interpretative phenomenological analysis (IPA) to explore the disease experience of 10 PsA patients (Aitken, Anderson, Whyte, Adams, & Poole, 2007). The study's primary aim was to explore PsA patients' lived experience in order to cross-check fit between themes uncovered from the analysis with existing measures. This study likewise found that the use of existing outcome measures failed to take into account the psychosocial experience of having PsA, which were identified as depression, lack of social support, psychological impact of pain, fatigue, and concern about the long-term effects of drug treatment (Aitken, 2011).

From the analysis it emerged that having PsA was experienced as a series of losses related to what was now possible in life, in relation to goal-setting, self-identity and body image. Low mood and depressive symptoms were present in all participants, but were attributed mainly to the impact of the arthritic aspect of PsA. In fact, it was found that the impact of psoriasis on sufferers' lives was experienced as negligible compared to the pain and reduced mobility experienced as a result of the arthritic side of the condition. However, as noted by the author, it remained unclear whether this was because psoriasis at the time of the interviews had cleared following treatment as

opposed to participants' joint pain or because the pain and disability associated with arthritis was viewed as far more detrimental than those of psoriasis (Aitken, 2011).

Summary of Research Findings Into Psychosocial Aspects of PsA

The majority of studies on the psychosocial aspects of PsA have thus mainly employed generic QoL measures, which have been shown to be associated with a range of limitations and may not even measure the prevalent concerns of patients' experience of living with PsA. The only study that has attempted to provide an in-depth understanding of the experience, issues, and challenges associated with PsA could be argued to be limited by its aim of reducing these experiences to domains with which to check fit with measures used. Hence, research into sufferers' experience of having PsA is still in a 'fledgling state' (Mease, 2009, p. 320).

The Psychological Impact of Psoriasis and Rheumatoid Arthritis

Given the paucity of studies to inform our understanding of the experience of PsA, it is therefore helpful to briefly review what is known about the psychological impact of living with psoriasis and RA, with which PsA shares many clinical features.

Psoriasis. During the last few decades, a large body of research has shown that psoriasis is associated with significant psychological and psychiatric morbidity (Russo, Ilchef, & Cooper, 2004; Gupta & Gupta, 2003). Quantitative studies have shown that psoriasis is significantly correlated with depression and anxiety (Schmitt & Ford, 2007; Hayes & Koo, 2010), pathological worry (Fortune et al., 2000), suicidal ideation (Gupta & Gupta, 1998), and increased risk of suicide (Kurd et al., 2010).

Studies employing QoL measures among psoriasis patients have found that these were comparable to those seen in severe and life-threatening conditions such as

cancer, heart disease, and diabetes (Rapp et al., 1999). Indeed, it has recently been argued that the stigma associated with visible skin disease leads to a significant psychological burden that is cumulative over time to the extent that it can significantly affect the life course of people with psoriasis (Mattei, Corey & Kimball, 2013; Kimball et al., 2010; Pearce et al., 2006).

The high degree of psychological distress among psoriasis sufferers has been related to the wider social context of how others perceive and react to someone with a visible skin conditions. Experiences of stigmatisation are prevalent among psoriasis sufferers (Richards, Fortune, Griffiths, & Main, 2001; Ginsberg & Link, 1989), with many reporting experiences of rejection and negative judgements from others with devastating effect on sufferers' self-esteem (Holsinger, 2004; Jobling, 1976; Magin et al., 2009; Vardy et al., 2002; Wahl, Gjengedal, & Hanestad, 2002). Both quantitative and qualitative studies have found psoriasis to be linked with high degrees of social anxiety, embarrassment, shame, impaired self-image, low self-esteem, expectancy of stigmatisation among sufferers, and the frequent use of social withdrawal and avoidance-based coping strategies (Fortune, Richards, & Griffiths, 2005; Kimball, Jacobson, Weiss, Vreeland, & Wu, 2005).

Furthermore, a sociocultural perspective draws our attention to how powerful and pervasive sociocultural ideals of beauty are transmitted via a variety of channels, most notably the mass media (Tiggemann, 2011). A qualitative Australian study found that failure to live up to the media-generated ideal of flawless skin negatively impacted psoriasis sufferers' self-image and self-esteem, despite their recognising these representations of skin perfection to be artificial (Magin et al., 2009).

What these studies repeatedly highlight is that clinicians should not underestimate the often-significant psychosocial burden experienced by psoriasis sufferers, as this frequently does not correlate with clinical disease severity (Russo, Ilchef, & Cooper, 2004; Gupta & Gupta, 2003).

Rheumatoid arthritis. The impact of RA on sufferers' lives has likewise been shown to be considerable (Picavet & Hoeymans, 2004). Patients with RA have been shown to be more likely to suffer from anxiety (Van Dyke et al., 2004), depression (Dickens, Jackson, Tomenson, Hay, & Creed, 2003), low self-esteem, and poor body image (Macswen, Brydson, & Fox, 2004) as well as high levels of associated mortality and suicidal ideation (Timonen et al., 2003; Treharne, Lyons & Kitas, 2000). Especially pain and the loss of mobility resulting in work disability (Backman, 2004) and the inability to pursue valued activities have been associated with the onset of depressive symptoms (Dickens et al., 2003; Katz & Yelin, 2001).

Qualitative studies have identified fatigue as a major impediment to the sufferers' ability to carry out mundane everyday tasks, causing frustration and anger (Repping-Wuts, Uitterhoeve, van Riel, & van Achterberg, 2008). This finding was supported by a recent Swedish qualitative study that likewise identified feelings of loss, hopelessness, sadness, anger, and irritation when experiencing functional restrictions, but also shame and embarrassment pertaining to the visible manifestations of the disease, which resulted in avoidance behaviours (Ostlund et al., 2014).

Conclusion: Adverse Psychological Sequelae Associated With PsA

To sum up, compared to the extensive literature on the psychosocial aspects of living with psoriasis and rheumatoid arthritis respectively, scant attention has been

paid to PsA. This is surprising given that PsA sufferers are distinguished by having two diseases, each of which has been associated with substantial psychological and psychiatric morbidity on their own accord.

Taking into account the above evidence, may then suggest what is intuitively plausible; namely that it is the additional burden of a skin or joint condition that accounts for the lower QoL in PsA patients compared to patients who suffer from psoriasis or RA alone as demonstrated in the aforementioned studies (Husted et al., 2001; Rosen et al., 2012).

Though what it is like to have both a visibly disfiguring skin condition and a painful, mobility-reducing arthritis remains underresearched, given the above studies, it seems plausible to infer that the psychosocial burden associated with this condition is significant.

Clinical Trials Assessing the Effect of Biologics on Patient QoL

As mentioned earlier, biologics have been shown to significantly improve the physical symptoms of PsA. Indeed, a plethora of clinical trials assessing the impact of biologics on HRQoL have equivocally demonstrated improvements in physical and mental health aspects of HRQoL in PsA patients' lives (Strand et al., 2012; Saad et al., 2010; Papoutsaki et al., 2013; Gladman et al., 2006; Kaltwasser et al., 2004; Kavanaugh et al., 2005; Mease et al., 2005).

Whilst it is not possible to review all of these studies within the scope of this study, there is also evidence of inconsistencies. One example is a recent quantitative study that evaluated the impact of biologics (anti-TNF) therapies on QoL and functional status in 596 PsA patients using the HAQ and SF-36. The study found significant improvements in SF-36 subscales relating to physical components of

disease after 6 months (53.2%). However, improvements for the mental health scale were much lower at 16.9% (Saad et al., 2010). So although the study found significant improvements in HRQoL following biologics, closer scrutiny of scores show a significant difference between physical and mental health variables.

Similar findings have been reported in the literature on psoriasis. One study that differentiated between physical and psychological variables found that clearance of physical symptoms following a successful course of PUVA-therapy brought about immediate reductions in patients' psoriasis-related disability. However, symptom clearance did not bring about significant changes in the patient's psychological distress measured on scales for anxiety, depression, and worry. This was especially true for patients who had a longer history of psoriasis (Fortune et al., 2004).

Such findings were echoed in another study that likewise found that levels of distress remained the same or worsened at 3-month follow-up despite evidence of a reduction in disability in patients cleared of psoriasis symptoms following a course of UV-phototherapy treatment, (Gupta, Long, & Tillman, 1999).

Though reasons for this remain unclear, the authors suggest that patients with a longer history of disease may find it difficult to reappraise their changed disease-status just as fear of relapse and beliefs pertaining to the controllability of their condition are likely to impact psychological well-being despite successful symptom control (Fortune et al., 2004).

The Problem With Generic QoL Research

Furthermore, it is debatable how much quantitative studies employing QoL measures are able to uncover about how treatment with biologics is experienced in the lives of PsA sufferers.

Firstly, what constitutes QoL and whether it can be meaningfully measured is controversial (Finlay, 2005). While the term QoL is intuitively meaningful and understandable to most people, it is by its very nature highly idiosyncratic. The problem for QoL (or HRQoL) research is how to reach consensus in regard to what constitutes QoL and how to measure it (Ogden, 2012).

Whilst it lies beyond the scope of this study to review this debate (Koller & Lorenz, 2002; Testa & Simonson, 1996), suffice it to say that despite its extensive use, there is little consensus on how to both define and measure QoL within the value system of the individual being assessed, rather than the value system of others. Thus, the use of QoL measures is thus based on the assumption that it is possible to make objective and measure something that is, by nature, extremely subjective.

Secondly, it has been argued that HRQoL scores essentially require interpretation or unpacking (Marquis, Chassany & Abetz, 2004). Even when data are statistically significant, caution should be exercised in assuming that findings are causally related to biological disease variables or treatment effects. A difference in scores before and after intervention is often taken to represent the effects of treatment. However, making such inferences is built on a conception of causality, which many would regard as simplistic due to a limited ability to differentiate between psychological causal and indicator variables (Boehmer & Luszczynska, 2006). Thus, the issue is one of the degree to which one can assign qualitative meaning to quantitative scores (Lohr et al., 1996).

The Gap in Knowledge

The above examination of the literature shows that research on biologics treatment for PsA is dominated solely by quantitative studies. While the inclusion of

patient-based QoL questionnaires may provide some insight into how treatment is experienced in PsA sufferers' lives, these measures are associated with a range of limitations.

What can be known about the PsA patient's experience of receiving biological treatment may be limited in a double fashion. One limitation is that studies, to date, have all been situated within the parameters of a quantitative methodology, which means that what can be known about PsA sufferers' experiences has been restrained by pre-defined categories from the outset. Not only in regard to the illness experience of PsA, but the use of QoL measures as gateways into participants' experiences also taps into the controversial debate on how one can meaningfully measure and conceptualise a highly subjective construct such as QoL.

Another limitation pertains to the evidence that suggests that the QoL questionnaires used in the existing quantitative studies fail to capture the prevalent concerns of PsA sufferers (Aitken, 2011; Stamm et al., 2007; Coates et al., 2014).

Together these limitations therefore raise the question of how accurately studies based on theory-led quantitative methodologies reflect PsA sufferers' experiences of receiving biologics.

There is therefore a gap in the literature of studies that could further understanding of how treatment with biologics is experienced from the 'insider' perspective of PsA sufferers themselves.

Rationale, Aim and Research Question

Due to the novelty of biological treatment for PsA an in-depth exploration of the lived experience of PsA sufferers receiving biological therapy thus seems important to investigate for several reasons.

What initially prompted this study was anecdotal evidence from dermatologists that many PsA sufferers undergoing treatment with biologics still experienced psychological distress despite marked physical improvements. Whilst a review of the literature generally demonstrates unequivocal improvements in QoL following biologics, one study did however support the anecdotal evidence from clinical practice in finding that improvements relating to mental health was much lower than for physical health (Saad et al., 2010).

Hence, an in-depth exploration could be argued to be of relevance in terms of, potentially, elucidating these ambiguous findings. This could potentially provide counselling psychologists as well as other health care professionals working with this patient group with insights into how this client population experiences their illness and treatment with biologics, with potential implications for further research and practice.

As counselling psychologists are already working within health care settings such as psychodermatology, it is likely that they will encounter patients with PsA. As there is currently no counselling psychology research on what it is like to have both psoriasis and arthritis, this study could therefore extend understanding of the need for psychological counsel to those suffering from PsA.

In this respect, this study is in line with counselling psychology values of privileging the subjective experience and giving voice to those overlooked by existing research (Ponterotto, 2005; Strawbridge & Woolfe, 2010; Hoyt & Bhati, 2007) as well as being relevant to the increased emphasis on patient-focused and holistic medical care within the NHS in terms of its focus on the experience of the patient to potentially inform practice (Harper & Thompson, 2012).

The aim of this study is therefore to address this gap in the literature by giving voice to PsA sufferers by asking them what it has been like to receive biological therapy within a methodology that allows for in-depth exploration of this.

Given the above rationale, the central research question for this study is therefore;

How do patients with psoriatic arthritis experience receiving biological therapy?

Chapter III: Methodology

A qualitative methodology, more specifically interpretative phenomenological analysis (IPA) (Smith et al., 2009) was chosen as the most suitable method with which to answer the research question of this study. The rationale behind this choice will be accounted for in the following and reflexive consideration given to how this choice relates to the epistemological position of the researcher and the values of counselling psychology.⁵ Finally, the practicalities of how the research was carried out will be detailed along with a discussion of ethics and validity in the context of this study.

The Theoretical Underpinnings of IPA

IPA was developed in the mid-1990s by Jonathan Smith as a specific approach to qualitative research that was grounded in psychology. Concerned with detailed examination of individual lived experience and how individuals make sense of that experience, IPA has been used extensively in applied psychological research within health, clinical, counselling, and educational psychology (Smith, 2011a).

The conceptual underpinnings of IPA draw on concepts from phenomenology, hermeneutics, and idiography (Smith et al., 2009). IPA's phenomenological roots give emphasis to the detailed examination of what it is like to be experiencing a given phenomenon for a particular individual. As such IPA wishes to get as close as possible to that experience, but recognises the impossibility of gaining direct access to this experience.

Building on Heidegger's hermeneutic phenomenology means that a particular phenomenon can reveal itself only through interpretation. Any interpretative

⁵ The reflexivity sections are written in the first person in order to better communicate these experiences to the reader

endeavour will, however, be subjective and influenced by the researcher's own understandings and preconceptions (Smith & Osborn, 2003). Any analysis produced will always be an interpretation of the participant's experience, and in a sense, twice removed as captured by the term *double hermeneutic*: the participants trying to make sense of their world and the researcher trying to make sense of the participants trying to make sense of their world (Smith & Osborn, 2003).

Thus, holding that it is impossible to engage with something independently of our relationship to it means that it is paramount that the IPA researcher adopt a 'phenomenological attitude' (Finlay, 2011) – a careful balancing act between being reflexively aware of one's fore-understandings whilst trying to see or hear or remain open to what the participant or text is communicating. Such an approach gives the phenomenon under investigation the best possible chance of being seen, whilst acknowledging that an objective view is not possible.

The third pillar of IPA is an idiographic concern with the particular rather than the universal (Smith et al., 2009). Each individual experience is seen as a unit of analysis in its own right, which means that IPA, in contrast to the nomothetic principles underlying most psychological empirical work, is concerned with meaning, diversity, and the variability of human experience rather than establishing causal laws (Eatough & Smith, 2008). However, this does not hinder IPA from revealing 'something very tangible and very real about the constitution of the "object"' (Larkin et al., p. 110). Attending to the particular can reveal something about the universal in the sense that if an experience is possible, it can be subject to universalization (Willig, 2008).

The Choice of Interpretative Phenomenological Analysis

IPA has been extensively used in studies that explore the experience of illness and medical treatments from the perspective of the sufferer (Biggerstaff & Thompson, 2008; Dickson, Knussen, & Flowers, 2008; Bramley & Eatough, 2005; Smith, 2011a).

IPA's foregrounding of meanings and experience makes it a suitable choice when seeking to 'give voice' to experiences that are under researched and to broaden understanding of areas of study that have primarily been informed by a quantitative methodology such as the current study. IPA's focus on meanings also aligns well with findings suggesting that psychological impact of illness is informed primarily by the contextual and personal meaning the illness experience holds for that particular individual (Brocki & Wearden, 2006; Leventhal et al., 1992).

Other qualitative methods, such as discourse analysis (DA) (Potter, 1996) and grounded theory (GT) (Glaser & Strauss, 1967) were also considered.

DA has many similarities with IPA insofar as it is a qualitative approach that places emphasis on the importance of language and interpretation. However, DA rests upon a theoretical orientation that presupposes that discourse or language constructs reality rather than reflect it.

Drawing on Ricouer's distinction between suspicious and empathic readings, Willig (2012) argues that DA inhabits the 'suspicious' camp in the sense that language is analysed to reveal underlying discourses reflecting power structures in society that the participant may not be aware of. Decoding the data to draw out these discourses thus necessitates the application of a theory that 'provides us with concepts with which to interrogate the text' (Willig, 2013, p. 42). Thus, the application of DA can

itself be labelled an ‘act of interpretation’ which will generate a ‘theoretically-informed reading’ (Willig & Stainton-Rogers, 2008, p. 8).

While IPA also assumes that language does not simply mirror reality, it does however assume that what participants express is linked to their experiences of a particular phenomenon and thus offer insights into their psychological worlds and how they make sense of their life’s circumstances (Torodova, 2011).

Insofar as the aim of this research was to give voice to participants and allow for their own perspective and experience to be foregrounded, IPA was thus favoured because this would provide a means of getting as close to the participant experience as possible by attempting to understand it from ‘within’ (Willig, 2013) rather than through the lens of a specific theory, which provided a better fit with the research question of this study.

GT is a qualitative method that likewise shares many similarities with IPA in its inductive approach that aims to discover theory that is ‘grounded’ in data. However, it has been argued that GT is better suited to study social processes than psychological and experiential ones (Willig, 2013). This is because the aim of GT is the formulation of a theory that has explanatory value as to why or how something occurs within a specific social context. The use of strategies such as theoretical sampling, where data is collected until a point of saturation and no new concepts emerge, thus allows GT to build theory that is able to generalise and account for the phenomenon under investigation.

The choice of IPA was thus a reflection of this study’s aim. The aim was not to build a theory, but rather to give voice to a population and an experience. IPA was thus deemed a good place to start in that it allowed for the foregrounding and in-depth

exploration of the lived experiences and meanings given to the experience of receiving biologics for PsA in a manner that would allow for different and potentially idiosyncratic meanings to be explored rather than the generation of theory.

Epistemological Fit Between IPA and Researcher

Another reason IPA was an attractive option is because of its epistemological openness. On a continuum IPA can be argued be compatible with positions that span the spectrum across critical realism, contextual constructivism and the light end of the social constructionism (Eatough & Smith, 2008).

In assuming that what people say actually maps onto what they are experiencing, IPA adopts a broadly realist position to knowledge. IPA is therefore informed by an ‘empathic’ hermeneutic position that takes at face value what people are saying as opposed to a more ‘suspicious’ position, which sees the data as representative of something hidden (Willig, 2012). However, given IPA’s phenomenological underpinnings, it can also be positioned on a relativist continuum in so far as people are seen as active constructors of meaning in their lives. Thus, for IPA it is not a problem for the same event to be experienced in multiple and even opposing ways. Finally, IPA also leaves room for a contextual constructionist position in acknowledging that any construction of experience draws on existing social, cultural, and historical influences and as such is central to experience and to meaning-making (Eatough & Smith, 2008).

Given its relative epistemological openness, IPA thus provides a good fit with my own epistemological standpoint, which I have come to identify as a ‘common-sense’ position midway between a realist and a relativist position. I take the position that there is no single reality that can be revealed through the use of the correct

methodology. Rather, knowledge is always ‘local, provisional and situation dependent’ (Madill, Jordan, & Shirley, 2000). Human beings are constantly acting on the world around them and making sense of it, which means that meaning is constantly shifting and being created. Such a position therefore acknowledges that every encounter carries within it endless (?) potential readings as a necessary extension of the position that holds that what research is attempting to apprehend ‘can never be accessed directly or captured in its entirety’ (Willig, 2012, p. 162).

However, this does not mean that a critical realist position is discarded. Critical realism acknowledges that there are stable, enduring features of reality that exist independently of human conceptualisation. However, because of the inherent subjectivity within the knower, the experience of the world is different for each person. In this way an ontological realism and epistemological constructivism can be compatible.

In the context of research, a critical realist position therefore acknowledges that findings will be influenced by a multitude of factors: choice of methodology, method, the meeting of researcher and participant, the meaning systems of both the participant and the researcher, and their sociocultural backgrounds. However, there is also an assumption that research findings relate to some kind of reality about the experience being examined, albeit under no illusion that this is in any way exhaustive or that only one reading is possible.

Personal Epistemological Reflexivity

Reflexivity is derived from the Latin verb *reflecter*, which means turning back or bending back on oneself. For researchers the term therefore denotes the ability to

‘move fluidly back and forth between an inside and an outside perspective’ (Hunt & Sampson, 2006, p.4) by owning the assumptions that frame how they work.

The following is an attempt to inhabit a reflexive stance by critically reflecting on the ways I might have influenced the research process in regard to the choice of methodology.

Deciding to train as a counselling psychologist was a decision I made in my mid-thirties. My initial degree was in theology, which I have come to realise has profoundly shaped my epistemological position. Every day would involve exposure to many conflicting beliefs and positions, from those who espoused deeply personal religious convictions to those fond of espousing Freud’s view of religion being akin to a childhood neurosis and feeble attempt to explain the social world. Truth, it seemed, was an extremely subjective matter and in the realm of religion, one which lay beyond any scientific test or falsification principle (Flew, 1950). I therefore came to develop a decidedly social-constructive perspective on knowledge and truth, if not an extreme relativist position, where seemingly truth, most definitely, lay in the eye of the beholder.

When I first embarked on studying psychology, I was particularly drawn to the scientific aspect of the profession. The allure of science, rationality, logic, facts, hypothesis testing after years of engagement with theological and religious thought was irresistible. How I cherished being able to say ‘research shows...’ with reference to experimental studies that had compressed human experience and behaviour to a p-value. I relished the legitimacy, sense of certainty, and the air of ‘truth’ that the mention of the word science seemed to evoke (Chalmers, 1999).

However, this was short-lived due to my experience working with clients within a psychodermatological context. I was reminded of both the diversity and the subjectivity of human experience and of how messy and imperfect the real-world experience of practice was. The only thing that seemed certain was that how individuals coped with their condition had little to do with disease severity; it was how the individual experienced and gave meaning to their illness experience that mattered.

As a result I have been drawn towards phenomenological research methods that center on experience and meaning-making that, for me, provide a way of balancing research and practice or honouring counselling psychology's commitment to the scientist-practitioner model while anchoring this in the primacy of the client's subjective experience and context.

During the writing of this thesis, another layer of reflexivity emerged that I had first not been aware of. I became increasingly aware that I have deeply personal reasons for privileging first-person accounts rather than 'objective' medical representations of data.

My third pregnancy was complicated by my suffering from a life-threatening condition, which resulted in a close brush with death. The complex array of emotions that I felt in the aftermath of this ordeal; being told how 'lucky' I had been wanting to feel grateful to the medical establishment for saving my and the baby's life, but these feelings' somehow eluding me led me to realize that there can often be two very different, albeit co-existing and equally valid, narratives depending on whom you ask; one of a successful biomedical intervention and one of a trauma.

I must therefore acknowledge a position where I am critical of asking participants to give the briefest of answers and reduce their experience to tick off boxes, Likert-scales, or categories in preformulated questionnaires when it comes to the notoriously complex fields of health and illness. This is not to imply a position of disregard, which would be both haughty and akin to a reverse form of methodolatry (Curt, 1994), but rather that I am fine-tuned to the ‘loss’ of information that studies using numerical measures and attributing findings to statistical tables, averages, and the cut-off point of a p-value inevitably entail.

Given the above, it is clear to me that I may have chosen a phenomenological method such as IPA because of a deeply rooted personal assumption that a method that enables a researcher to come as close to the participant’s experience as possible is somehow something I regard as a more ‘trustworthy’ approach than quantitative, objective representations of the same data would entail.

Procedures

The following details the practical steps taken in order to address the research question of this study.

Ethics

Prior to recruitment, ethical approval for the research was sought and granted by London Metropolitan University ethics panel (Appendix E). Because the research involved recruiting participants receiving treatment from the NHS, ethical approval was subsequently sought from the Liverpool branch of the National Research Ethics Committee. A favourable opinion was granted on 17th of April 2014: REC reference number: 14/NW/0254 (Appendix F). Subsequently, approval was sought from the local R&D department and an SSI (Site-Specific-information) form was submitted

detailing the involvement of local collaborators. Permission to proceed was granted on the 28th of April 2014 (Appendix G).

Participants

In line with IPA principles, purposive sampling was employed to select a homogenous group of participants recruited for their ability to enhance understanding and hopefully yield rich data of the phenomenon under study (Smith et al., 2009).

Inclusion and exclusion criteria. Inclusion criteria were as follows:

1. Confirmed diagnosis of PsA with both skin and joint symptoms present;
and
2. Receiving biological therapy for PsA

Exclusion criteria included the following:

1. Co-existing medical conditions in order to avoid potential issues related to other conditions confounding the findings of this study; and
2. Due to IPA's general reliance on participants' ability to express and articulate their experiences, participants with reduced English language proficiency were excluded.

Recruitment

In accordance with the idiographic nature of IPA research, a sample size of six was deemed appropriate for a study of this size (Smith et al., 2009). Posters advertising the study were put on display in the dermatology and rheumatology departments at the NHS trust where the study was taking place (Appendix H).

Furthermore, A4 copies of the information sheet (Appendix I) were given to the specialised biologics nurses supervising PsA patients receiving biological treatment to hand out to potential participants. In an effort to circumvent potential

power issues that could lead to participants' feeling pressurised to take part, staff nurses informed only potential participants of the study taking place. If participants were interested in taking part, they were asked to contact the researcher directly using the email or telephone number provided on the information sheet. This, however, proved to be a somewhat unsuccessful recruitment technique, as only one participant contacted the researcher in the space of 3 months.

Subsequently, letters were sent out to 12 PsA patients identified by the biologics nurse through the biologics register informing them of the study (see Appendix J) along with the information sheet containing the contact details of the researcher. This generated a response from one additional participant. After 4 weeks, a second letter was sent out (see Appendix J), which led to the recruitment of three additional participants. The last participant was recruited after she was referred to the department's psychodermatology service from another NHS trust.

Informed Consent

A short telephone conversation was conducted with each interested participant as soon as the person contacted the researcher. This was done to give potential participants the opportunity to ask questions about the research and make sure that participants fit the criteria of the study. Subsequently, individual interviews were arranged to take place at the NHS dermatology department at a time and date suitable for the participant.

Before the interview commenced, the researcher went through the participant information sheet with the participant, detailing the research question, the voluntary nature of participation, options to opt out, the anonymising of data and limits to anonymity, as well as measures to ensure confidentiality of data (Appendix I).

All participants declared their willingness to participate in the study and a signed consent was obtained before the interview took place (Appendix K)

The six participants were aged between 45 and 67 years. Two were female and four were male. None of the participants dropped out after opting in.

Demographic data is provided in Table 1 using aliases.

Data Collection Method

The most frequent means of data collection in IPA is the semistructured interview based on a preformulated interview schedule (Smith et al., 2009). This approach allows for flexibility in making sure questions relevant to the study are covered, whilst allowing the researcher to probe emerging areas of interest or meanings important to the participant.

Table 1

Participant Demographic Data With Aliases

Name	Age	Ethnicity	Number of years with psoriasis	Number of years with PsA	Number of years on biologics
Matthew	45	White-British	25	20+	3
Hanif	55	White-other	20+	20+	6
Jack	60	White-British	10	5	3
Samuel	67	White-British	20+	5	1.5
Rebecca	52	White-British	30+	1	3
Alice	48	White-British	46	20+	10

The interview schedule was formulated using open-ended and nondirective questions in order to encourage participants to tell their story with limited imposition

of meaning (Smith & Eatough, 2007). Probes were used to get participants to detail their experiences and any unanticipated themes that emerged. The interview schedule was developed with the help of supervision (Appendix L)

A pilot interview was conducted to test the interview schedule. This interview was subsequently included as part of the data.

At the beginning of each interview, the researcher stressed that the interview was intended as a ‘conversation with a purpose’ (Smith et al., 2009 p. 59) rather than a closed yes/no interview. The researcher emphasized that the purpose of the interview was to learn as much about that participants’ experience and that there were no right or wrong answers. The interviews ranged from 45 minutes to 75 minutes and were audio-recorded.

Debriefing

Following the interview, participants were given the opportunity to discuss their experience and any concerns or feelings evoked. The researcher made sure that participants were in possession of the contact details of the researcher and her supervisor, and it was stressed that participants could contact the researcher post-interview if the need arose. A debrief sheet was given to each participant that detailed relevant sources of psychological support (see Appendix M).

Analysis

The interviews were audio-recorded and transcribed verbatim for analysis. Following a step-by-step approach to the analytic process (Smith et al., 2009; Smith & Osborn, 2008), several hundred themes were initially identified, which were then organised under broad thematic groups and subsequently subsumed under three master themes and inherent sub-themes.

Firstly, each individual transcript was read repeatedly and initial thoughts, associations, and comments were recorded in the right-hand margin of the transcripts. Once such initial observations ‘dried up’, an attempt was made to identify and label salient themes in each of the transcripts. These were recorded in the left-hand margin of the text in different-coloured ink (see Appendix N for an example of an annotated transcript).

At this stage the researcher employed a deliberate noncritical attitude, noting down everything that came up resulting in more than 100 themes per transcript, most of which were purely descriptive. These ‘themes’ were then written down and ordered under preliminary sub-headings (see Appendix N). At this stage, the researcher put the transcripts aside and repeatedly read and re-read the lists of preliminary themes in order to cluster similar ones together, resulting in +50 preliminary themes per transcript.

In order to facilitate the conceptualization of ‘cluster-themes’, themes were repeatedly re-named, re-arranged, and re-named again, whilst the researcher thought about how themes related to and differed from one another both within and across transcripts (Appendix O).

During this process, hunches and notes were made regarding links to tentative master and sub-themes. These were written down in a notebook and checked against the transcript data. This process was then repeated for each transcript, whilst emergent themes were gradually filtered down in a cyclical process.

In an attempt really ‘hear’ what participants were saying and embody the ‘phenomenological attitude’, the researcher revisited the material after putting it aside for a while. As a result, themes and clusters were continually re-arranged and re-

named as the researcher ‘saw’ new meanings and links emerge in a recursive process of interpretation and re-interpretation.

Finding this process both frustrating and confusing, and at one point fearing that the process might be endless led the researcher to further consultation of the IPA literature. Here, the researcher found comfort in learning that it was not uncommon for interpretations to shift and gradually unfold and be allocated varying degrees of significance with each reading as captured by the concept of the ‘hermeneutic spiral’ (Smith et al., 2009).

The challenges encountered by the researcher involved how to separate inter-linked themes and choose which themes to discard. Gradually, more abstract themes were developed, which were subsumed as appropriate and finally turned into three super-ordinate themes with three sub-themes each.

However, the researcher found it was difficult to close the door on the interpretative process, and hence, themes continued to be re-arranged and re-named on both a master and a sub-level even as the results section was written up, thus illustrating not only the iterative, cyclical approach of IPA, but also how open-ended it is.

Quality and Validity in Qualitative Research

What constitutes good qualitative research has been debated at length (Chamberlain, 2000; Madill et al., 2000; Forshaw, 2007). One of the problems has been the application of quantitative criteria to evaluate qualitative research, but also that there has been a tendency to treat qualitative research as a unified field (Dixon-Woods, Shaw, Agarwal, & Smith, 2012). It is therefore crucial to consider the

epistemological underpinnings i.e. what kind of knowledge the research is attempting to generate, before any evaluative criteria can be meaningfully applied.

The researcher has endeavoured to meet the four principles suggested by Yardley (2008) to evaluate qualitative research.

The first criterion is sensitivity to context. This has been attempted by a detailed examination of the existing literature conducted to demonstrate the gap and hence the rationale behind the research question. Hence, a methodology that allowed the participants' experiences to be foregrounded was chosen, and the interview schedule was constructed to allow for this exploration. Sensitivity to data was also strived for throughout the analysis by grounding interpretations in the data and carefully considering what participants were conveying.

The second criterion is that of commitment and rigour. Whilst the depth and insight in terms of analysis are ultimately for the reader to decide upon, I have endeavoured to make sure that participants in this study were appropriate by the use of purposive sampling. Furthermore, an independent person was shown an anonymised transcript for a validity check.

The third criterion relates to coherence and transparency. Epistemological coherence was aimed for by considering the fit between the aim of the study, research method, and how the analysis of disconfirming data was presented. Transparency was aimed for by being explicit about how methodological processes were carried out. To this end, a paper trail is provided in the appendices to show how the analytical process of turning raw data into the final analysis unfolded. I have also attempted to engage in a process of reflexivity throughout the study, addressing this in the preamble as well as in the methodology and discussion sections.

The final criterion relates to impact and importance. My hope is that as a result of ‘giving voice’ to the participants in this study, clinicians involved with PsA sufferers will have a better understanding of what it is like to receive biologics for PsA, which might have implications for the type of care this population receives at different points in their illness trajectory. This will be further elaborated on in the discussion section of this study.

Chapter IV: Analysis

The following presents the results of the analysis utilising IPA to learn about PsA patients' experience of biological therapy as interpreted by the researcher. The researcher arrived at the three master-themes and inherent sub-themes presented in Table 2.

Table 2

Master Themes and Inherent Sub-themes

Master Themes	Sub-themes
New lease of life	Embodying a miracle Being able to do normal things again Freedom from stigma and shame
Living with the fear of the unknown	It's a firewall not a cure Embodying an experiment The role of information in facilitating agency and choice Coping with the fear of tomorrow
The importance of seeing the person and the disease	I am a person not a petri-dish Not knowing the disease Mobilising the self to help the body

These master-themes will be accounted for in the following, and interpretations will be grounded in the data through verbatim extracts to illustrate and support these.

Master Theme I. New Lease of Life

The first master-theme that I arrived at through the analytic process was one of participants experiencing a new *lease* of life, with biologics constituting the

demarcation point between life as it is now and life as it used to be. A key element of participants' experience was one of disbelief that biologics had reversed the path of steady degeneration. Biologics was experienced as affording participants a chance to re-enter life, which they embraced with a fervour and appreciation that is the provenance of people who have lived on 'the night-side of life' (Sontag, 1988, p. 3).

Sub-theme 1: Embodying the miracle of biologics. Treatment with biologics was described as defying what participants thought could be possible. To their amazement, their psoriasis suddenly vanished.

It was like magic after a few weeks – gone! (Hanif, 116–117)

The bafflement and incredulity experienced by participants is given even more poignancy in the light of their previous experiences of spending years at the receiving end of increasingly toxic, time-consuming medical treatments that, at best, maintained a status quo.

Several participants had experienced severe side effects as a result of previous treatments. Hanif experienced liver failure following an alternative treatment, Matthew's skin burnt during PUVA-treatment, leaving him looking as if he'd been in a fire. Rebecca experienced a systemic allergic reaction that left her unable to move, Matthew's legs turned black as a result of a sudden allergic reaction to penicillin, leaving him unable to be touched due to pain, whilst Alice suffered anaphylactic shock. Still, the various, increasingly toxic treatments had little long-lasting effect on their condition, which continued to deteriorate.

Physically my whole body was getting worse, pain-wise and skin [-wise]; I was steadily going downhill. (Matthew, 777–779)

The thing is...⁶you know, constantly taking a medication which really has no effect is very depressing. (Jack, 184–186)

Faced with the prospect steady degeneration, participants understandably experienced an increasing sense of despair as to what this would mean for their lives, compounded by feelings of utter helplessness at not being able to do anything to change this.

It is with this context in mind that the accolades bestowed on biologics must be understood. Matthew calls biologics a ‘*miracle*’, Samuel ‘*unbelievable*’ (142), Rebecca ‘*brilliant*’ (213), and Jack ‘*a huge success story*’ (157), while Hanif, as seen earlier, likens biologics to a vanishing act.

You don't imagine you'll ever get that (...) I didn't have a single plaque on my body for the first time in so many years. It was, 'Hold on, this is not right, you know?' I remember the feeling, it was so fantastic (...) the elation...it was from the pit of my stomach and it went upwards and up. I know, this is how I got it, the feeling went from the pit of my stomach up, and then I got a tingling on my hair like Goosebumps, and then I could feel it – look, I'm getting it again now a bit... Because I know, I remember it so vividly. What a feeling. (Matthew, 515, 1052–53, 1034–1040)

For participants, their now blemish- and psoriasis-free bodies embody and make palpable this miracle. Their bodies bear witness to a miraculous transformation having taken place, which is accompanied by a sense of disbelief and strong, positive psychological states, along with otherworldly physical sensations befitting when witnessing a miracle.

⁶ ...indicates omission of words such as erm, uh, to improve fluency for reader.

Likewise, Hanif remembers how he sang joyfully in the shower.

I do remember the time, when my skin was clear, one day when I brought myself under the shower; I was singing for the first time, and I was so happy because I couldn't take a shower easily, because when water brought to my skin, the pain was terrible and my skin came, became like a baby, very soft.

(Hanif, 671–678)

Biologics transforming Hanif's '*itchy, broken skin*' (106) to the softness of a baby's is again indicative of biologics being perceived along the lines of a miracle. Biologics, it appears, is experienced as an event or point in time which not only demarcates between life as it was before and now, but is infused with hope at the new life that has suddenly been made possible.

The miracle of biologics not only heralded a new beginning, but also enabled participants to travel back in time to before their lives were changed by disease. For Jack, biologics enabled him '*to go back to before I ever had any manifestations of the, of the symptoms*' (157–159).

For Matthew, biologics transported him back to a time just before his PsA became severe.

I'm back to how I was when I was 18. You know? (445)

Thus, being afforded a second chance and how this is experienced is explored in the next sub-theme.

Sub-theme 2: Being able to do normal things again. A prominent theme characterising participants' lived experience after commencing on biologics was one of life opening up again and being able to do things they had not done for years.

Again, there is a powerful discourse of ‘then’ and ‘now’ with participants experiencing varying degrees of liberation from what had hitherto restricted them.

For Rebecca, biologics enabled her to feel normal.

I could get up in the morning, I didn't have to start having a bath with oil, sit in it for an hour, then put on cream, and then... I, I used to have a bath, like sometimes three, four times a day, 'cause I couldn't cope with my skin. And everything used to be oily, you know? (...) And here, I just felt like a normal person. I could get up in the morning, and get dressed, and go out, and you know, like – I just, yeah, I felt normal (...) I felt like everyone else does, you know? It was really, really – I really felt good, I really, really did (pause). Like my whole mood was good, you know, 'cause like I didn't have to think about it the whole time. (241–257)

For Rebecca, normality is thus the ability to smoothly carry out small, everyday, routine tasks such as getting up in the morning, getting dressed, and going out. The inability to carry out what for many people are taken-for-granted and ordinary tasks thus shows the extent of the disruption wrought by PsA. Being able to carry out these tasks again was now experienced in a new light, as in the aforementioned example of Hanif’s happiness at being able to take a shower without pain.

The ordinary becomes extraordinary when it becomes possible again, which reflects back on biologics’ being experienced as an existential turning point or life-changing miracle as participants leave behind a period of debilitating dysfunction.

The theme of life opening up was also emphasised by Samuel, who described life after biologics thus:

You haven't got any of those restrictions. You do what you want to do, as you want to do it, not because you're being restricted. So you've got a freedom.

(845–852)

Likewise, Hanif said that he, after biologics, began '*to go out and started seeing people again*' (693–694), thereby revealing that this was something he had refrained from doing.

There is thus a prominent theme of restrictions and chains being lifted. It seems that treatment with biologics is experienced as presenting participants with a, now, perceived luxury of freedom and choice; doing things when and because they want or wish to do them – in stark contrast to before, when they seem not to have felt they had that choice.

In fact, Hanif described his life before biologics as being in prison.

I was like a person who is in a prison. My office is in my home, just upstairs, actually (...) I was in a prison in my home, 24 hours a day, just I visited my client, doing the web design, and searching the internet and that's it, and go to sleep, shower, work, eat (...) And out? No. Visiting people? No. Going on holiday? No. (417–437)

Being a prisoner in one's home designates a paradox. Prison usually connotes a nonvoluntary confinement, where the incarcerated is robbed of choice. Home, however, is usually a place imbued with a sense of belonging, where we can be ourselves and exercise a degree of autonomy, choice, and freedom that is denied us outside the home.

Questions that readily arise are therefore: What imprisoned Hanif? What restricted Samuel? What changed to make Rebecca feel like a 'normal person'?

From all participants' accounts, it is evident that a major restrictive factor is that of the arthritic symptoms of joint pain and stiffness. Participants experienced this as the body gradually closing down, evoking images of old age.

Because it's like, 'Is my body breaking down?' (...) And suddenly, erm, it's something that you think, 'Well, I'm old now, because this is something which, generally speaking in, erm, in, the, the body breaking down. It's something which I associate with a, a, with a (...) a later stage, a, a later or even a sort of proto-final phase of life' ... You, you think, 'Well, it's going to go, it's all going to be degenerative from now on.' (Jack, 350–361)

For Rebecca, her body was completely taken over by her arthritic pain in a manner more akin to paralysis. When Rebecca described her pain as 'stopping' her life, she meant it in the most literal sense of the word. Any attempt at movement and trying to will life into her frozen form was punished by more pain. Mundane, everyday tasks such as walking and going to the toilet thus become acts of bravery and defiance against the disease that was stopping her from living.

It had stopped my life, literally. My life stopped for months (...) I wasn't able to do anything, I couldn't hardly go up and down the stairs. Every time I went to the toilet it was like, nightmare. Because I couldn't walk to the toilet, I couldn't, I, I'm so embarrassed to say this, but I couldn't even wipe myself after I'd been, do you know what I mean? It was, everything was hurting me. (Rebecca, 1592)

With biologics reversing this slow bodily demise, pain, and impairment that can be construed as a slow death, it is hardly surprising that participants experience

intense joy at being able to partake of ordinary, everyday tasks, which for them have become symbols of living and life itself.

Sub-theme 3: Freedom from stigma and shame. Participants, however, seemed also to have experienced freedom from another kind of prison, which will be explored in the following.

The shedding of dry skin was an aspect of psoriasis that all participants found hard to deal with.

I used to leave trails of, you know, like scales the whole time (...) Even when I went shopping and I tried on a skirt, I was so embarrassed, you know, 'cause like all the scales used to come off on the skirt, if I didn't buy it. And you know, like, it wasn't... It was, you know, it wasn't, it wasn't nice to live with it.

(Rebecca, 199–213)

Many participants commented on the constant self-awareness that would accompany them everywhere, as demonstrated by Jack below.

It's the fact that you're shedding skin...and you, you, you, you get into habits like, you know, surreptitiously checking a chair where you've been sitting... Because it, you think, 'Well, I wouldn't want to go and sit in a chair that was covered with... You know, with, er, with skin particles,' so, you know, you, you, you're just feeling psychologically, I think, on the back foot all the time. (284–295)

For Jack, the mere act of sitting in a chair was experienced as exposure. He was on the 'back foot', vigilant that he should not cause offence and his shame be exposed to others. He readily identified with 'the other', imagining how they would feel sitting in

his chair. Seeing himself through the eyes of others, it seemed he felt guilt and condoned the behaviour of anyone who shunned him.

Jack went on to describe how

shedding skin at a, at a kind of mega-dandruff level 'absolutely' destroyed my 'self-image', 'because it's, erm, and, and that may be, that may be very harsh (...) But the fact is it's an unattractive condition (...) it just does make you, it, it made me feel, you know, ugly and, er, and, er, it's like having a deformation.

(Jack, 231–236)

By passing judgement on psoriasis as an '*unattractive condition*', Jack was passing judgement on himself. Rooted in a body and in a skin that has altered and de-formed him, Jack had become a '*deformation*' and had become unacceptable to himself. Yet, he could not escape or distance himself from this ugliness, as he inhabited it. Thus, his feeling merged with a body he wanted to distance himself from is perhaps why he experienced his self-image as destroyed.

Jack relates this to dandruff being a "socially frowned-upon thing (...) one of those things where it kind of shows that somebody isn't looking after themselves well" (Jack, 222–229).

Suffering from psoriasis therefore appears to be an experience that moves beyond the confines of the physical symptoms. It spreads to connote something about the sufferer to others, which goes far beyond suffering from dry skin but carries with it connotations of bad hygiene.

Lack of self-care therefore implies that sufferers are *choosing* to not take care of themselves. It is perhaps this perceived chosen departure from collective or societal grooming norms bound up with a fear of contagion that leads to experiences of social

rejection, intrusive questions, and comments from others, which are the norm rather than the exception for all participants.

Strangers would comment on it, and say, 'What's that? Can I catch it?' Can they catch it off me, you know? It wasn't easy, so I tried avoiding a lot of social – the social side of anything, I tried to avoid it, you know? (Matthew, 327–342)

Suffering from psoriasis therefore becomes a very public illness experience in which it seems to be legitimate that sufferers are not accorded the regard and respect for social conventions normally in place.

I was on the Tube on the London Underground and a gypsy came over begging with her daughter. She was going through the train begging, and she got to me and she was like, she physically screamed. She got down and she was grabbing her daughter, 'Get off, get off. You'll catch it. Don't go near him.' In front of the whole train, so in one sense she didn't beg off of me, but she made me – and there was nowhere to go. Once you're on a Tube train and you're going through the tunnel, there's nowhere to go. So for the rest of the time to the next stop, everyone was just looking at me. It was, you know, people's perceptions. (Matthew, 540–550)

My psoriasis is bad on my hands and people treat you like a leper or they step back and they go, 'Oh,' or they stare or, you know, shops are an awful thing when they slam the change on the counter, they won't put it in my hand, 'cause I got psoriasis on my hand. I've come out with many – I, I build all my confidence, I pluck up the courage to go shopping and, and again. (Alice, 1370–1376)

Alice and Matthew's accounts are similar in describing the different ways in which public disapproval is communicated to them. One is overt, e.g. the gypsy screaming and running away from Matthew and shopkeepers recoiling from Alice and the shopkeeper slamming down the change.

The other, whilst more subtle, may be more damning, namely the harsh, scrutinising gaze of the other. It has been argued that we assume coherence in relation to the gaze of 'the other' in the sense that to see ourselves we must be seen (Lacan, 1977). The other's gaze is therefore instrumental in how we come to define and see ourselves.

This may account for Samuel's feeling unclean although he knows he is clean, coupled with a societal idea that having blemished and flaking skin is associated with impurity and poor hygiene.

I never felt clean. I never felt clean, and I was always very conscious of the flaking skin and so on. (333–334)

For participants in this study, it seems the repeated encounters with 'the other' eventually come to define and defeat them. Jack feels ugly. Samuel feels dirty. What ultimately comes to determine their worth and sense of self lies outside the self in the gaze of 'the other' (Lemma, 2010). In this way, 'the other's' gaze has become theirs.

The taken-for-granted world of everyday life, such as Alice going to the shop to buy something, becomes an act of immense bravery that requires careful contemplation before being carried out.

It is thus not surprising that participants' ensuing experiences of public rejection become immensely painful, to the extent that participants eventually retreat

to places where they are likely to be protected from the gaze of others and possibly themselves.

Actually, one of the reasons, yes, because when I was out everyone was just showing me to each other, you know? (...) Yes, yes, it was terrible, and (...) No, strangers (They would point?) Yes. Everywhere, because yes, it was all over the skin. I tried to be relaxed, even with shorter sleeves, even out, in shorts as well but people just pointing me to each other and yes (...) Actually when you feel this way, you don't feel good when – on the other hand, I had pain as well. Then I didn't go out, because of the people first, and the pain as well. (Hanif, 700–718)

A similar trajectory is exemplified by Matthew, who described not being too bothered about his psoriasis when he first developed it, because he had grown up with a friend with it and had never ‘*taken a second look*’ (320). However, over time he described coping by avoiding social gatherings or by covering up.

I just used to cover myself up all the time and try and avoid situations. I didn't have a girlfriend for 10 years because I was too ashamed of how I looked. (Matthew, 327–328)

Psoriasis, it seems, can therefore be construed as a form of social death. Hence, participants' skin suddenly clearing after biologics opens up the possibility of a life free from self-consciousness, stigmatisation, and shame.

One example is Matthew's joy at being able to join the ranks of the untarnished he had envied for so many years by having a picnic with his friends, wearing shorts and a t-shirt. Again, the ordinary became extraordinary and a source of intense appreciation as Matthew revelled in the freedom of having cast off his stigma.

I mean, straight away I could wear shorts, and t-shirts or a vest, you know? I could do that, but I'd have to walk around and all my friends might be in shorts and I'm in jeans and I'm sweating. Oh, just that. I mean, I still have the joint pain so it's not like I can go back to playing football again or that sort of thing, but as regards, I can go out and not feel – I'd be jealous. Friends of mine would say, 'Oh, we went down to the boating lake. We sat there, we had a picnic.' Things like that. I could actually go and do that without being self-conscious. It was superb. I could sit in shorts, without looking out of place because I'd normally have to wear a long-sleeved top and jeans, and everyone else is in t-shirts and shorts. You feel very, very different then, so that only adds to the self-consciousness. (Matthew, 441–460)

It is therefore the interpretation of the researcher that Hanif's previous prison metaphor is to be understood as a dual imprisonment brought about by the experience of having a condition Jack calls '*an evil combination of opposites*' (747). One is visible and leads to a social death. The other is invisible and leads to the death of the body.

Such was the extent of the pain and imprisonment wrought by PsA that Hanif was consumed by hate and wanted to end it all.

At the time, I didn't know what is love. I hated everyone (...) I can describe in one word. I coming close to suicide. I was suicidal, and it was terrible. It was terrible, and I couldn't sleep. I had pain all the time. I hated people. I didn't want to talk to someone. I didn't want to see someone. Just a terrible situation. (Hanif, 128–133)

Treatment with biologics saved Hanif's life and enabled him to transition from death to life, from hate to love, from imprisonment to freedom.

Yes, I'm very well now and I can love, and I couldn't love at all. No. (Hanif, 251–252)

Master Theme II. Living With Fear of the Unknown

Despite participants' experience of biologics affording them a new lease of life, it was called a *lease* to invoke the temporary quality of this experience.

Participants experienced a pervasive sense of uncertainty in terms of both the future effectiveness and long-term side effects of biologics. It is this experience and the different ways participants made sense and coped with this that is explored in the following.

Sub-theme 1: Biologics is a firewall not a cure. There is an awareness among participants that biologics is only a means of gaining temporary control over their condition. Jack's use of the term 'firewall' captures the experience of biologics not being a cure, but rather a treatment that demands continuous upkeep to keep PsA at bay.

Going through that self-injecting process is very much a reminder, erm, that, you know, I'm, it, I've, I've got a, I've a firewall against something which if I stopped doing that would probably return with a vengeance very quickly.

(Jack, 730–733)

For the majority of participants, the regularity and means with which biologics must be administered, usually by self-injection, is experienced as manageable and as freeing up time compared to previous treatments.

The biologics, you don't need to go the whole time [to hospital] you just have to go for your injection, and that's it. So for me, it was amazing (...) amazing, amazing, it was brilliant, 'cause all I had to do was inject myself. I didn't have to take four tablets a day...It was like so easy...It was ever so good, it was really, really good. (Rebecca, 172–197)

But for Alice, the participant who has been on biologics for the longest, the duration and repetition of treatment on both a micro- and macro-level has become almost unbearable.

It's every single week. It has been for the last 5 years. I've had other biologics previous to that... Erm and very often they work for the first sort of three months on me then they stop working. (Alice, 19–26)

Alice's current treatment consists of a combination of biologics and Methotrexate, the latter of which requires administration every Monday at hospital. Due to the side effects Alice suffers as a result, there is thus a fixed pattern to Alice's week.

Erm, I feel terribly sick after the tablets... and I'd come back after I'd taken them, I'd lie on the settee, blanket over me, and the rest of that day or the next day I'd feel sick. (200–204)

...and then I just start to feel better Thursday and Friday and then there's never a break, and then it's gosh, you know, it's the weekend...time again. So it's, you know, if it was every month or 2 months, it wouldn't be so bad, but I just start to feel better and I feel better in my head... and then, wham, it's back again. (410–418)

The use of the expression ‘*wham, it’s back again*’ indicates that Alice experienced treatment as akin to being hit or punched on a continual basis. Treatment knocked the life out of her and she was incapacitated to the extent that she had to lie down for the next 2 days. As soon as Alice regained her footing, she had to repeat the cycle all over again. There was thus an almost nightmarish Sisyphean quality to how she experienced treatment; it was endless and she was condemned to repeat it every week.

Sometimes Alice did not turn up for treatment.

I was supposed to have had it yesterday, but I didn’t have it ‘cause I’ve had it absolutely up to here with it all and every so often I just can’t stand it. And yet I know I need it because about 2 years ago, erm, I’d had enough of it, the side effects and, erm, I didn’t, I missed four injections and I was bedridden with my psoriasis and my arthritis. I was that bad. So I know I need it. (Alice, 37–42)

When Alice stopped her treatment, it was not because she was under the illusion that this was a viable option. In fact, when Alice missed her injections, her life took a turn for the worse.

I was just in a mess. I couldn’t sleep, I couldn’t get dressed, I couldn’t wash.

The cream was having no effect at all... I’d be crying all the time... I literally wanted to die because I had no quality of life. (Alice, 331–334)

In Alice’s words, when she stopped treatment, it was rather because;

I just want a breather. I just want time out. (1082–1087)

The constancy with which the ‘firewall’ needed to be maintained was experienced as suffocating Alice; she was unable to breathe. Taking ‘time out’ was therefore enacting the illusion of a choice she knew she doesn’t have, if only for a moment. The paradox for Alice was thus that the treatment she knew she needed in order to live was

experienced as relentless in its cyclic, repetitive manner to the extent that Alice simultaneously experienced it as killing her.

Alice was thus faced with the choice of enduring a partial death that lasted 2 days or being engulfed to an extent that it was as close to death as one can come, whilst still living; in bed, unable to move. Choosing the former, Alice experienced dying and revivification every week. Such was the relentlessness of the cycle of repeated deaths that Alice voiced this desperate plea:

I want to, I want it to stop, I want an end to it all. (1066)

It with this in mind that one must understand Alice's partly self-censored remark, that she finds herself envying her friend with breast cancer. However harrowing both the disease and treatment for cancer may be, it was attractive to Alice, because it has an end.

This sounds awful, but I had a friend with breast cancer, absolutely awful, she had treatment. She was lucky, she got over it. Her treatment has stopped now eventually and I know you can't compare it, but five years, every week and I'm sick of it. (Alice, 47–51)

In sharp contrast to Alice's experience is that of Matthew. Also recognising that biologics is essentially no more than a 'firewall', Matthew, on the other hand, felt both hopeful and positive in regard to the future.

I can only assume it's going to get better and better, because my treatment has got better and better over the last 3 or 4 years. It's been fantastic so to me, even if I'm on the same dose of Humira for the next however long, 5 months, 5 years, whatever it may be, I know my condition will only get better. I'm positive about that. (810–816)

At first glance, it is plausible to surmise that it is the nature of the side effects and the accompanying intrusion on Alice's time that made her experience so different to the other participants' experience. Albeit important, it is however the interpretation of the researcher that what makes their experiences so different is far more wide reaching, which will be accounted for in the following.

Sub-theme 2: Embodying an experiment. Alongside the awareness of biologics not being a cure, participants shared a concern about the long-term implications of treatment. Given that biologics work by suppressing the immune system, concerns about side-effects have crossed the minds of all participants.

If you're reducing...your efficacy of your immune system, what are the other ailments are you leaving yourself open to?... That was never really explained.

(Jack, 382)

There was a sense that beating or rather halting the spread of PsA came at a price; namely the stripping of one's defences. Paradoxically, getting better therefore entailed getting weaker by running the risk of leaving oneself open and vulnerable to other infections and diseases.

For Jack, this led to the immediate comparison to the human immunodeficiency virus (HIV).

A terrible part of that disease, of that virus – is...the depression of the immune system and leaving individuals open to other sorts of...viruses which...can

become a serious condition in its own right. (Jack, 391–406)

The analogy with HIV is thus that beating PsA comes with the risk of paying the price of dying of from something else tomorrow.

The fear, uncertainty, and anxiety that can ensue from the immensity of such a predicament is in stark contrast to how participants experienced the efforts of medical professionals to explain this. In fact, as Jack says above, it was never really addressed.

Not having been offered an explanation is, as far as Jack is aware, to do with medical research not having been able to fully understand *why* biologics work on PsA.

*You're using something which has an effect, but you don't understand
(laughter) why it has an effect... It's just, it is effective. Well, that's is, is not
best medicine, in my view. (Jack, 423–434)*

For Jack, certainty and predictability as the antithesis to not knowing comes from *understanding* why something works. Wishing he had been afforded an explanation is therefore wishing for a degree of control, certainty, and knowing what's to come.

Faced with the limits of medical knowledge and realising that treatment is based on trial and error, there was a sense among the participants of being the flesh and blood at the experimental frontlines of the battle against PsA. Their lives, their bodies are thus an embodied experiment in the sense that no one knows what will happen or if there will be a price to pay tomorrow.

*What it's doing to my body, nobody knows the, the long term side effects
because they're relatively new treatments, so what damage is it doing. (Alice,
543–545)*

Enhancing Alice's dread was her past experience of having '*more than a lifetime's worth of treatment*' of PUVA that was promoted as safe, but since recognised as linked to skin cancer;

I know three people who've had skin cancer who had PUVA at the same time as me. So I, I'm very fearful. (Alice, 295–296)

Not surprisingly, Alice's trust in the medical profession has been destroyed. Any assurance or information provided by her care team has been rendered meaningless.

Just how broken Alice's relationship is to the medical profession was evidenced by Alice's perceiving the profession as dishonest and operating with a hidden agenda, where they would only reluctantly admit to the real risks of treatment.

They...kept a lot back from me on, on the side effects of these things. They, they don't tell you and then it's only after you've been on it for a while that... things come to light, 'Oh yes it does do that, oh yes.' (Alice, 1124–1137)

Alice's experience of being experimented on was accentuated by her experience of objectification. Alice described being '*prodded and poked*' (123), which reveals not only how invasively she experienced treatment, but conveys an insensitive, callous jabbing of her and a sense of being cruelly goaded to see what her reaction will be.

The extent of the rupture and distrust was revealed when Alice perceived the profession as having immoral, almost criminal motives, where they would happily administer her toxic drugs to see what happened. This led Alice to wonder '*whether it's, it's a benefit to them to push the drug or they're, they're getting, erm, you know, money for it, I don't know*' (Alice, 278–282).

The heart of Alice's conflict becomes painfully clear. It was an almost irresolvable conflict of knowing that she had no choice but to put her life in the hands of a profession she so fundamentally distrusted, and knowing she needed a treatment that she at the same time believed was destroying her.

Sub-theme 3: The role of information in facilitating agency and choice.

Surrounded by unknowns, participants seemed to attempt to create a level of control or predictability by looking to information to install this.

Many participants talked about their illness trajectory, wishing that they had been forewarned about the possibility of developing the arthritic side of the condition.

Nobody ever mentioned to me that one of the things that you might have to face in future years, X percentage of people who have psoriasis will also have psoriatic arthritis. It never was discussed. (Samuel, 662–665)

However, on reflection, Samuel was more hesitant as to whether he would have welcomed such information at the early stages of disease, seemingly indicating that it in some instances might be better not to know.

Maybe not. Maybe not, because you don't want to be told when you're going to die. You know you're going to die but you don't really want to know when you're going to die because you'll spend your whole life focused on the wrong thing. But it was never mentioned at any stage (...) it was never mentioned, so when I first got my pains and so on, we didn't know what it was. (Samuel, 662–677)

Samuel voiced an existential predicament here. He was conflicted between wanting to know and not wanting to know. Seeking information seemed to represent to Samuel a fixture or a point of certainty from which to negotiate the all-pervasive terrain or experience of the unknown. However, Samuel also seemed to imply that too much information can tip the scales, not towards certainty and control, but towards more uncertainty and anxiety that can detract from living and overpower life.

The fine balance was succinctly expressed by Jack, who like Samuel wished that more information had been made available about his condition, but emphasised that it *'has to be handled sensitively, because you don't want to start a fire where ... there isn't one'* (1197–1198).

Jack and Samuel's use of analogies of death, dying, and starting a fire conveys that participants felt as if they were living in most treacherous and dangerous waters. In this sense, not knowing could protect them and constitute a protective or defensive action, which serves to minimise threat to the self.

This stance was exemplified by Rebecca, who experienced that the information provided to her on the potential side effects of biologics provoked her anxiety to the extent that she considered not going ahead with treatment.

So even when they gave me things, leaflets to read and everything, I said, 'I'm not reading it, because then I'm not gonna take the tablets.' (Rebecca, 168–170)

Perhaps reflecting that Rebecca, like Alice, knew that opting out of treatment was not a choice she could reasonably make, she instead came up with a relatively simple solution to her predicament. Namely to read the information on potential side effects only after treatment had commenced and started to work. Though this path was thus different from that of many of the other participants, the shared motivation lay in self-protection.

A crucial difference, however, was that providing Rebecca with information placed the choice of what to do with it with her. So even if there fundamentally really is no choice, information becomes linked to a *degree* of choice, which might instil in

participants a degree of agency and control that makes their utter powerlessness in the face of not having a choice more tolerable.

That information seems to be linked to participants' perception of having a choice is illustrated by Alice's account of when she was first put on biologics.

The very first time I went on a biologic, I was sort of forced into it. I wasn't given lots of information about it... I was told...basically 'Well, if you don't have this treatment, 'cause I said I'm a bit worried about the side effects, well, if you don't have this treatment, if, if the treatment doesn't kill you, the disease will.' So virtually you got no option but to go on it. (Alice, 343–350)

Thus being denied both a choice and information about the treatment she was about to receive, explains a lot about the fear and powerlessness that underpinned Alice's experience. Alice was angry that she was never given a choice, and this contributes to the resentment she felt towards the medical profession, as those who were in power to make choices that related to her body but never bothered consulting her.

Well to me the patient has the right to know, I have the right to know... I'd rather, it's my body, it's not their body... I'd rather, I'd like to know everything...and then and then weigh up the pros and cons...and then it's my... (Alice, 1180–1194)

It is quite possible that Alice, had she been given a choice, would have a different perception of her treatment. By not providing her with information, and thereby choice, Alice was made powerless and her sense of agency and ownership of her body were taken from her.

So, while the participants in this study may have known that they did in fact not have a choice, the sharing of information may have served to re-install agency and ownership in their lives.

Sub-theme 4: Coping with the fear of tomorrow. With the many unknowns all around them, participants were forced to negotiate different ways of making sense and coping with their predicament.

Several participants coped by making their predicament more tolerable by comparing their situation to that of other people perceived to be less fortunate. One aspect regards treatment itself, such as Matthew comparing his own situation to that of his grandfather, who also had psoriasis.

Back then when he was a young man, there was nothing. There was nothing. You might get a load of coal tar and that was it. Smother yourself in that or put petroleum jelly. That was it. (398–400)

Reminding himself that he was lucky and that there is always someone worse off became a sort of coping mantra for Matthew.

No, you're lucky you've got some treatment (...) And there's always someone worse off than you.' You know, so you can keep on thinking that every day of the week, every day of the week. It's what might get you up. You know, it probably got me up out of bed a few times, you know? (Matthew, 647–651)

Having to constantly remind himself that he was lucky thus seemed to be a way of taking the potency out of a predicament that otherwise threatened to overwhelm Matthew. It needed to be said 'every day of the week', thus indicating that it might be a form of psychological survival without which Matthew would 'go and lie down, curl in a ball and cry' (747).

It seems that the drive to construct an image of oneself as fortunate by comparing oneself to others perceived less fortunate is mainly something that happens under threat. This can therefore be seen as a coping mechanism against which Matthew and Rebecca defended themselves against the threat of destruction and therefore a form of survival.

Throughout their accounts Matthew and Rebecca make a series of comparisons to people with serious medical conditions, such as Rebecca describing coming out of a doctor's waiting room thinking,

Thank God I have my psoriasis, because other people had so much worse.

(Rebecca, 897)

There is, however, also a social facet to this downward comparison, which taps into making participants feel that they are not alone in their suffering, which can become a source of inspiration and strength. One example is Rebecca reading about a paralysed lady who was '*so positive, and so, erm, like smiles, and, and, and you know*' (1111) and another, Matthew, comparing himself to terminal cancer.

I think to myself, 'Well, look at them. They're getting up and going.' You know? (Matthew, 747–753)

Another way of coping with the unknown was represented by Samuel and Hanif and summed up in the following;

I don't concern myself about the future. I've learnt to live for today and not in excess, but to take each day as it comes. (710–712)

Samuel did, however, concede that this stance was not so much a development that had emerged out of having PsA, but had always been part of his general

philosophy of life. Rather, Samuel attributed this life lesson to his having lived in Israel when he was younger.

I would have been like that if I hadn't had the illness. I learnt very early on when we went to live in Israel, Israel is a troubled place at the moment... But one of the things we learnt because of that stressful type of society that Israel is, because of what goes on there, was that you need to live for today because you don't know what tomorrow will bring and I think that most of us in England don't have that attitude, purely and simply because our lives are, well, we don't expect to be living in a warzone. (Samuel, 736–748)

That the closest analogy Samuel employed was that of living in a warzone seems poignant as it may denote something about the terror and extent of helplessness that is perhaps experienced by participants, not knowing what tomorrow brings, indeed, if tomorrow brings death or mutilation.

Likewise, it could be argued that Samuel used the people living in England as an analogy for people who have not experienced the powerlessness that comes with having a chronic illness like PsA and who still live with the illusion of control. The implication therefore seems to be truly fathoming that the only certainty in life is the 'now' is a perspective that can emerge out only of suffering.

Living and breathing the unknowns of tomorrow has perhaps made Hanif and Matthew more attuned to a paradox influencing a society that places great value on predictability and control, namely how much effort goes into eliminating uncertainty, undertaking actions that foster an illusion of certainty, control and predictability, which was never possible in the first place.

An example is Hanif relating what he found himself thinking when listening to a programme on the future mortgage interest-rates

Oh, it's going to be blah-blah-blah in this country, the most part of your earning goes for the mortgage and I said to myself, 'How about now? If it's going to be in a few years' time, in 6 months' time, I will think about it then, not now.' (Hanif, 801–807)

Hanif drove home his point of how there are no certainties in life by relating what a man suffering from a terminal illness had said to an interviewer, asking him how he felt knowing he only had a few more years to live.

Is there any guarantee that you [will] live more than me? (789)

Hanif seems to be making the point that feigning that anyone can know anything about what tomorrow brings is an illusion. Having to deal with not knowing what tomorrow brings is not only a predicament that the participants of this study have to negotiate. Rather, it is a condition shared by all humanity. Thus, Hanif's predicament is normalised. By normalising it, Hanif became just like everyone else, which perhaps made his predicament more tolerable.

Whilst one is trying to live in the present, the past is however lurking just around the corner. Maintaining a focus on the now thus implies not letting your mind drift to past or future, which is sometimes difficult. Hanif described not wanting to think about the possibility of his condition coming back, but also noted that he is sometimes overwhelmed when he remembered how it was.

I do remember before the biologic medication, even after that for a few years, I couldn't talk to any doctors and medical team, and when I remembered the pain I had, I cried. I couldn't stop myself (...) I didn't want to go back, and I

didn't want to think about it, and even a few days ago I found one of my images taken from my body, naked body and oh my god... Yes, for a second, and I tried to just forget the past. (Hanif, 737–752)

For Hanif, the memory of the years living with PsA were still very raw and traumatic. The horror of what it was like seemed to lurk just beneath the surface and if triggered, was threatening enough to engulf the now.

For Alice there was no respite. She was deeply conflicted – trapped in an irresolvable predicament of loathing what she needed to stay alive.

I knew then that I needed it, that it was keeping me well and yet I still hate it. I don't understand, 'cause it's doing me good but I hate it. (Alice, 336–338)

Alice experienced high anxiety on the days leading up to her treatment, and the only way she coped on the morning of treatment was by pretending she was not going to go, only to go at the last minute.

So the weekend, I spend all weekend worrying and my stomach's churning because I'm dreading going to the hospital on Monday. So then my appointment's Monday morning right at the last minute I'm thinking I won't go, I won't go and that's how I get myself through the morning 'cause I think I'm not going. Erm, then I always do go, very often I go. (Alice, 365–377)

Despite her dread, Alice's rational self won over her emotional self, thereby locking her in an exhausting and continuous cycle of emotional distress.

As this master-theme has hopefully demonstrated, living with the fear of the unknown is an existential predicament that accompanies participants' experience of receiving biologics. It is the contention of the researcher that this can only be made

tolerable when trust in and support from the medical health provider are present, which will be explored in the final master-theme.

Master Theme III. The Importance of Seeing the Person and the Disease

As was seen from the two previous master-themes, negotiating the balance between the ‘new lease of life’ and a future full of unknowns is a taxing experience. This master-theme is about the importance of recognising and attending participants’ illness experience as a whole rather than just the disease.

Sub-theme 1: I am a person, not a petri-dish. Like treatment with biologics, there is no shortage of accolades bestowed on the medical care participants in this study are receiving. Matthew called it ‘*out of this world*’, ‘*superb*’, and credited it with just making him ‘*feel so much better*’ (956). Jack stated he felt ‘*very positive to this hospital*’ (701) and Rebecca said she has ‘*really been happy, and everyone's been really nice (...) They really, really care. I can't get over it*’ (731), before adding;

Like, if I ever complain about the NHS, I don't complain any more (laughs).

(1917)

It may not be a coincidence that Alice – the only participant being treated at another hospital – was the only participant who did not join in the chorus of accolades bestowed on biologics. Whilst certainly deeply conflicted, beneath all the layers of her despair Alice actually stated that she was ‘*quite happy*’ with her current biologics, which she credited as ‘*helping me*’.

Thus, it is the researcher’s interpretation that a main reason Alice felt destabilised by receiving biologics is inextricably connected to her experience of the medical care she was receiving.

They just, I don't know, the medical profession, they, I feel they really don't give a damn. It's not their bodies, it's me. They don't care, we're just a number and they'll just treat us, you know, they wanna get the, their numbers of patients out, and they don't care. (Alice, 562-566)

Alice's repeated emphasis on the medical profession not caring conveyed how she felt that she was someone no one wanted to see, hear or listen to. When Alice attempted to tell medical staff about the side-effects she was experiencing, she reported,

It's like no one wants to know. They, they ask me when I have my Methotrexate, 'Oh how are you?' And I'd tell them, but it's all like [lip] service. They don't really take note, they make light of everything. (Alice, 1094-1098)

When the depth of Alice's pain and her cries for help were not acknowledged, but instead made 'light of' it was as if her whole existence was negated. She didn't matter to those who were supposed to care for her. It wasn't about her; it was about getting through a certain number of patients per day. Alice was a 'number' in a factory's assembly line – she was not a person, she was dehumanised.

The disparity between the existential angst and torment Alice was feeling and how this was met with superficial chitchat that characterises the kind of service one would encounter in a shop only amplified her loneliness, suffering, and psychological torment and added another layer of understanding to why treatment with biologics was almost impossible for her to bear.

There are strong parallels between Alice's account and the way Jack and Matthew experienced the treatment they received at their previous hospital.

You know, when I noticed the two different sides to the treatment, it was like, 'Wow.' All I've been doing at [previous hospital] was, I was just going through the motions: 'Turn up, take them, go away. Turn up, take them, go away' and I did that for so many years. (Matthew, 973–979)

The image of a mechanical treatment that Matthew robotically complied with is accentuated by 'turn up, take them, go away. Turn up, take them, go away', where one can almost hear the sounds of this patient's assembly line. Matthew then went on to qualify wherein the difference between his previous treatment and his current one lay.

Everyone I see [now], all of it, is based on you as a person, not just you as a patient. (591)

What Matthew meant by his distinction between being seen as a person and patient becomes clearer when he described his relationship to his previous doctor.

It was terrible because not once, I saw him for about 4 or 5 years and not once did he look me in the eyes in all those times. He was always staring at his paperwork. He'd look at my skin, but not once in my eyes, and then say, 'Right, those tablets and that cream aren't working. Here's another set' and that's all I ever got for 4 or 5 years from the one doctor. (Matthew, 350–365)

It seems clear that Matthew, for this doctor, represented a disease alone. For Matthew, being a patient thus seemed to denote that he was objectified, scrutinised, and studied. To look Mathew in the eyes would mean to recognise, to see the person behind the disease and engage with what it is like to for him to live with this disease. When this doctor turned his gaze away from Matthew, Matthew was, like Alice, dehumanised, disregarded, and reduced to a bunch of cells gone awry.

Yes. He might as well have been looking in a petri dish. Yes, he might as well have just been looking in that, because that's all he saw the skin as. He never... You know? (Matthew, 374–377)

Jack described a similar experience with the medical care he received at a previous hospital, which he found was not ‘*particularly sympathetic*’ (55). Though Jack was the only participant to reference it, what eventually made him reach the end of his tether, stop taking his medication because he was so ‘*fed up with it all*’ (118), was the disconnect in his medical care.

I'd be going regularly for blood monitoring and monitoring things for the psoriasis and a separate se-, a completely separate series of appointments for rheumatology. And it seemed to be they, it was just stuck in a ridiculous loop where each department had an idea about what Methotrexate dosage there, there should be, which varied, but they didn't seem to speak to each other, erm, it, meanwhile, both conditions were worsening. (Jack, 68–80)

Seeing Jack as a patient thus meant subsuming him under a system in which increased sub-specialisation results in an absence of a coordinated effort to treat PsA as *one* disease. And it was the person, Jack, who paid the price of this disconnect with his condition, paradoxically, worsening as a result.

Sub-theme 2: Not knowing the disease. Most participants in this study went through a long process and several misdiagnoses before their joint pains were linked to PsA. The most extreme example of this is Matthew, who went for 20 years without medical professionals linking his psoriasis with the pain he was feeling in his joints.

Before I came here, there was no link. Even though I was in pain and it all coincided at the same time, there was no actual link. They said, ‘You haven't

got rheumatoid arthritis. 'I said, 'Right, fine, but I've got pains.' No, that's it, you haven't got rheumatoid [arthritis]. They didn't link it with the psoriasis, you know? (31–35)

Likewise, Alice described an incident at A&E, where a nurse and a doctor told her that the pain due to arthritis in her rib cage was not possible.

'You don't get arthritis there.' And this was a doctor, and the nurse laughed at me, 'You don't get arthritis there,' and I was saying, 'Well actually I do, I get it in my rib cage, I get it here.' And they just laugh at me, 'You don't get arthritis there.' Even the medical profession aren't aware of it. (Alice, 724–735)

Both Alice and Matthew found it difficult to describe what it was like not to be believed. Matthew thought he was *'losing it'* (48), as he was beginning to question whether he could be imagining his pain, since doctors were so adamant that there was nothing wrong with him.

For Alice, not being believed, having her pain denied as real, and being ridiculed by professionals she came to for help, was like being invalidated at the most fundamental level of her existence. It had such a devastating effect on her, to the extent that she couldn't find the words.

I can't even, I can't even put it into words. It, it, it just, I, I can't explain it. It affected me that badly I can't even find words to, you know, again it's not being believed. (Alice, 737–739)

But even after diagnosis, there appeared to be minimal support for patients with PsA. Several participants noticed the disparity between the support offered and information being made available to patients with other rheumatoid conditions, and wondered why there was never anything for PsA.

There's all these posters all around the, the clinics and the wards, you know [for] rheumatoid arthritis, lupus, osteoarthritis, it's all these leaflets for arthritis, there's never anything for psoriatic arthritis. There's, there's nothing. There must be other people with it. (Alice, 695–701)

Alice tried to communicate her struggles and repeatedly asked for support to help her 'to cope with, with my treatment (...) and to try and help me accept my condition', but no resources were made available to her.

Oh no, there's nothing like this. You, you could go somewhere privately, you could do this, do that. (Alice, 1207–1211)

It is clear that medical professionals' turning a deaf ear to her struggle and distress only amplified her loneliness and isolation. Owing to her own research and ingenuity, Alice went to her GP, who referred her to a London hospital, 6 hours away, for psychological support.

I've got this [condition] but I'm having to fight all the time. Why should I fight, why isn't stuff offered to, for treatments for things. So again skin rheumatology, just wash their hands. (Alice, 1222–1226)

For Alice, her struggles were thus exacerbated by what she perceived as the complete lack of support and of recognition of PsA as a serious disease.

It is a serious illness and it just gets you down, makes you feel run down.

There should be things to help along the way. (Alice, 1306–1312)

This was echoed by Samuel and Jack, who also found that there was a lack of recognition of the psychological toll PsA can have.

They usually give you a leaflet, and I find that the leaflets are oversimplistic in some respects, and they don't do anything about conveying emotion. They only just talk about hard facts. (Samuel, 577–589)

The already substantial existential and psychological pain of living with PsA is thus amplified by medical professionals, who seem unaware of the existence of the condition, and of the devastating impact living with and being treated for PsA can have.

The last sub-theme explores the importance of recognising PsA sufferers' experience and what happens when this does not take place.

Sub-theme 3: Mobilising the self to help the body. Attesting to the all-encompassing influence that medical care of his PsA has had on his life, Matthew said that changing hospitals was:

The best decision, other than marrying my wife, it's probably the best decision I've ever made in my life. Honestly. (920–922)

Further qualifying this, Matthew said;

I know everything that gets done here is totally proactive and it's for my own good, you know? I know it's all for me. You know, that's how I get made to feel here. It's proactive for me (...) It's all for me and to feel like that, it does, I'm sure it must have something to do with the fact that my skin is so good anyway, now it has to have, you know? Because if you get – the feeling that it's all for you, it puts a positive spin on everything because you're thinking, 'Oh yes, it's because they're focused on me. I'm going to focus on me. I'm going to beat this.' (1013–1022)

Evident in the repeated use of ‘*me*’, it is clear that Matthew now feels that he constitutes the epicentre of medical care as opposed to before. He is no longer a patient, disease or petri dish, but his persona is at the centre of everything. Crucially, Matthew also seems to imply that being treated as a person has improved his psoriasis, which deteriorated during the years when he was neither seen nor heard.

I’ve probably gone maybe a whole year at one stage where I had about 95% of my skin covered and everything. But I’m positive that had something to do with it. The fact that they wouldn’t recognise the pain I was in. I’m sure that made the skin flare up. (Matthew, 90–96)

The implication of Matthew’s account seems to be twofold. Being treated as a person made Matthew stronger and gave him the confidence that he, now, with his new ally at his side, can defeat his condition. Being treated not only as a disease, but as a person, as a self (with a disease) united the former divide, strengthened him, and made him whole.

When the pain of their illness experience is not recognised, participants are also denied the opportunity to integrate or come to terms with the loss and pain connected with having PsA. By blocking out, ignoring, not hearing what it is like to both have PsA and be treated with biologics, the existential pain that these participants feel is deemed unacceptable. However, the irony is that the sole focus on disease in chronic illnesses like PsA does not help the suffering go away, but rather amplifies it to make an already difficult situation almost intolerable to bear.

This connects to the other implication of Matthew’s account, where he links mind (psychological state) to body (psoriasis severity). Matthews seems to imply that

turning a blind eye to the suffering of participants in the service of curing or fixing the disease paradoxically seems to worsen the disease it is attempting to cure.

Thus, the traditional biomedical model's sole focus on disease pathology aimed at alleviating the suffering of those afflicted with diseases like PsA paradoxically ends up weakening sufferers by insisting on a divide between mind and body. In this manner, the biomedical model actually enhances the suffering of people with chronic illnesses like PsA by amplifying their psychological suffering and thereby physical suffering.

As the following excerpt illustrates, the connection between mind and body is complex and intricate. Forcing herself to have a treatment she at the same time perceived as destroying her caused Alice's body to rebel.

The tablets, they'd make my mouth blister... I'd put it in my mouth and if I couldn't swallow it straightaway where the tablet had been I'd get blisters in my mouth. I could feel it stick all the way down (Alice, 179–186)

I've never had a problem with, with having my blood taken or cannulas, but I think it's my, my veins have, have, when they're overused, if they sunk or something or they, they're scarred so the cannula pops out and I dread having that done, 'cause it's three or four attempts now having that in. (110–114)

It is clear that Alice's body is acting out and voicing the fear Alice feels. In a protective gesture her veins curl up, her throat dries up, thus trying to save Alice by making both the infusion and tablets almost impossible to be administered. However, whilst defending her, her body could also be construed as betraying her, because Alice needed this treatment to live. Her body's actions can thus be seen as a somatic

representation of the heart of her conflict – namely, being unable to resolve whether treatment with biologics was killing or saving her.

I keep writing lists of pros and cons every week...shall I have, shan't I...I've got this constant battle going on in my head. I don't know whether to go ahead with it or not. But then when I didn't have it, I was in a real mess and I couldn't cope anyway. (Alice, 306–312)

Thus guilty of not seeing or hearing Alice's cries for help and focusing solely on the remediation of disease, Alice's medical caregivers can be seen as responsible for underpinning and fuelling this conflict. Not surprisingly, the lack of being seen or heard has meant that Alice is on the verge of giving up – just as Jack was at his former hospital.

I'm exhausted. I'm exhausted with it all. Every so often I think I've had enough, I've had enough of everything, there's no escape from it and I just think I've had enough. (Alice, 481–487)

I'd got to the point where I came in here for a meeting...for a, consultation and I, I burst into tears (Laughter) because I, I was just so frustrated and, and the fact that really what was the point? (Jack, 429–439)

The importance of seeing, hearing, and recognising the pain of what the person is going through beyond a sole focus on disease pathology is illustrated by the contrast between Hanif's and Jack's accounts.

Like Alice, Jack remembered asking for help at his former hospital when he was struggling to cope with his pain.

I was absolutely exhausted and worn out by pain. I was on quite strong pain killers and there seemed to be, I don't know, maybe a, maybe a (pause)

complete insensitivity that it was because I – maybe if you're in that kind of department, all your patients are going to suffer from pain (...) But I remember saying, you know, 'I really need some help for managing pain.' And getting really nothing (...) But, yes, it was really, when I think about it, it was, I was, it was really painful. Getting to sleep was really difficult. Waking up and then you were incredibly stiff. And try, and getting out of bed in the morning and standing up and getting dressed were painful processes... And there was no help for it. And I was thinking, well, I was aware of the concept of pain management yet it wasn't offered. (Jack, 1371)

Reflecting on this experience Jack said the following:

Well, it makes you angry... And then ultimately, I think it does make you depressed... Because, because, you know – if you could, if you could maybe, or for me, if, if, if one could pinpoint the origin of depression (...) it originates out of an area of...frustration of not being able to be in synch with...how maybe you would like things to be (...) and not having a successful mental stratagem for dealing with how they are (...) And that divergence spirals into depression (...) Because it's, it, it's like an inability to cope. (1262–1278)

Evident in Jack's account is the utter powerlessness he felt being at the mercy of a pain could not get rid of and did not know how to cope with. Not being heard when he cried out only cemented his feeling of powerlessness and, like Alice, brought him to the verge of giving up.

In contrast, Hanif, likewise in excruciating pain, was offered to participate in a pain-management programme offered by his care team, which he credits as being transformative in his life.

I don't know how to explain, it's nothing changed, but the way I think about the pain is totally different (...) If I have pain now, I don't go to my cupboard and take the medication straight away. I try to think about the pain first, try to be relaxed, try to be calm and breathing helped me a lot, deep breathing.

Breathing in and exhaling, and going out, even for 5 or 10 minutes of walking.

(Hanif, 1024)

Hanif seemed to indicate that reliance on painkillers promotes a form of helplessness that gradually overpowers the self as a locus of choice and control. By learning new ways to cope with the pain, he becomes empowered and installed with a sense of agency that counters helplessness. Hanif learnt how to live with his pain, not by getting rid of it, but by transforming his relationship to it and learning new ways to respond to his pain.

For instance, last night, I had pain. I had pain on my ribcage. The pain was under the rib and I had this pain with each breath in and out, one deep pain in and one deep pain out, in time, and I could see it, and with breathing, I could manage to stop the pain. (Hanif, 531–536)

It is perhaps this sense of agency that has been put back into his former helpless self, knowing that he is now able to cope with the pain that explains why Hanif says he is '*fine*' despite still describing his pain as '*unbearable*' (443–451).

I can't walk very fast, with the walking stick, even 100 metres, 200 metres can help you to ease your pain, or cope with your pain, and socialising with people helps as well. I was not able to smile, and all the time I was sad, and tired because I couldn't sleep. Actually, even now, I can't sleep because of the

pain I have in my chest. My maximum time of sleep is two and a half hours, three hours but I'm fine. (Hanif, 443–451)

Hanif's account is therefore interesting because it indicates that there are other ways, when the traditional biomedical path fails. However, it would be a mistake to think that the provision of psychological therapy or programmes aimed at promoting adaptive coping can stand alone.

Though Hanif expressed a belief that he would have '*suffered less*' if he had had access to a '*good psychologist*' who could have taught him to '*manage [himself] psychologically*', he had second doubts, upon reflection, as to whether it would have helped due to the extent of his physical pain and disability at the time (329–334).

Actually, on the other hand, I just went back to 15, 16 years ago, at a time when psoriasis was all over my body, even if a good psychologist advised me something, did I listen to him or her, or not? (Hanif, 989–993)

What Hanif seemed to imply is that it is not a question of juxtaposing psychological and medical treatment. When it comes to the experience of participants with PsA, both treatments have limitations on their own and both are needed.

In the words of Hanif, with the help of both, he's found a way.

Yes, I've found a way (...) I found a way and now I can cope with it. (Hanif, 543–545)

Chapter 5: Discussion

Man is said to be composed of soul and body. However proper this language may be in religion, it is not so in medicine. He is, in the eye of the physician, a single and indivisible being, for so intimately united are his soul and body, that one cannot be moved, without the other.

—Benjamin Rush, *Sixteen Introductory Lectures*, 1811

The aim of this study was to gain an in-depth understanding of participants' experience of receiving biologics for PsA. The idiographic focus of IPA meant that this study was able to offer a richer, more complex, and nuanced 'insider' account of this experience.

The following will consider the three main themes that emerged from the researcher's interpretative engagement with the data in the light of existing research and consider the clinical implications of these findings. The limitations of this study will also be discussed along with considerations of methodological and personal reflexivity.

First Master Theme: New Lease of Life

Bury (1982) compared developing a chronic illness to a biographical disruption. The ability to carry out routine behaviours is disrupted and taken-for-granted assumptions are challenged. In the words of Bury (1982), living with a chronic illness 'involves a recognition of the worlds of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others' (p. 169).

The first-master theme showed how the improvements pertaining to both the skin and joint symptoms of PsA following biologics were life-changing for

participants. Participants' experience of treatment with biologics can thus be seen as an undoing of this disruption. Participants are given a second chance and experience euphoria and elation at being able to re-enter life and do things again as their psoriasis disappears, their mobility improves, and pain lessens. This finding therefore supports the plethora of quantitative studies that demonstrate significant improvements pertaining to QoL after commencing treatment with biologics (Strand et al., 2012; Saad et al., 2010; Papoutsaki et al., 2013).

In this respect, participants' description of their lives before biologics shows the devastating impact that having PsA can have. Participants' lives were dually impacted by pain and reduced mobility that restricted functioning and participation in even the most everyday tasks. Alongside this, participants also suffered from psoriasis, which put them at the receiving end of deeply rooted stigmas surrounding fear of contagion and what it means to have blemished skin (Goffman, 1963).

Whilst the illness experience of PsA sufferers was not the explicit research question of this study, but was relevant in terms of informing the context in which participants' experiences of biologics had to be understood, "sometimes reading destabilises purposes" (Davy, 2010, p.79). In other words, the immensity of the participants' suffering and their experience of the lack of awareness surrounding PsA was so pervasive that not to highlight this would border on being unethical in the sense that a key aim of this study was to give this population a voice.

The devastating impact that PsA can have on participants' lives was summed up by Jack's stating that living with PsA was a 'double whammy' consisting of an incredibly 'evil combination of opposites'.

Making sense of participants experience of living with PsA can be partly illuminated by research findings of what a stigmatising experience having psoriasis can be (Richards, Fortune, Main & Griffiths, 2003; Schmid-Ott et al., 2005; Vardy et al., 2002). All participants related experiences of stigmatisation and rejection that they experienced as having a devastating effect on their self-concept and body image (Khoury, Danielsen, & Skiverin, 2014). Indeed, the participants in this study seemed to have formed negative beliefs about themselves such as feeling unclean, unattractive, and almost guilty at giving offense (Jobling & Naldi, 2006).

Indeed participants in this study increasingly withdrew in order to avoid negative reactions from others (Richards, Fortune, Griffiths, & Main, 2001); supporting findings that show that concealment and avoidance of social interaction are common coping strategies employed by psoriasis sufferers (Fortune, Richards & Griffiths, 2005; Magin et al., 2009), though acceptance, active coping and positive re-interpretation are also frequently used (Fortune, Richards, Main, & Griffiths, 2002).

This suggests that it would be misguided to locate the source of psychological distress only within the individual. Clearly people's lives and self-concept are affected by how others judge and treat them (Thompson & Kent, 2001). Goffman (1963) used the idea of social identity to identify stigma as something that disqualifies an individual from full societal acceptance. When an individual departs from the norm and does not meet societal expectations, that person is devalued, discounted, and disqualified.

Studies show that people hold negative attitudes towards people with skin conditions, suggesting that automatic negative stereotypes appear to be activated (Grandfield, Thompson, & Turpin, 2005), and that they even consider the sufferer as

responsible for their condition due to beliefs that the person must have done something to deserve this (Shaw, 1981; Novak & Lerner, 1968).

Furthermore, the influence of mass media's constant barrage of messages about beauty ideals which promote flawless skin as desirable for success and happiness should also be considered (Orbach, 2009). Though the extent to which these media-perpetuated societal ideals contribute to psychological distress in people with visible skin conditions requires more research, the current epidemic of appearance-related concerns among the general population suggests that the communication of, mostly, unattainable ideals confers a powerful point of social comparison for people both with and without visible differences, with implications for psychological well-being and social functioning (Rumsey & Harcourt, 2005, 2012).

Insofar as PsA results in visible differences in relation to not only the skin, but also the joint aspects of the disease, it seems that it is important to consider the challenge of living within the wider sociocultural context of an 'appearance-obsessed society' (Rumsey & Harcourt, 2012, p. 680) with an appearance that is different from the norm.

Because there is a dearth of studies on the experience of pain in PsA, it is necessary to look to studies on chronic pain and pain in RA. One of the most consistent findings emerging from the literature on pain is that avoidance behaviours, where one actively seeks to avoid activities that cause pain, are linked to higher levels of disability and psychological distress (Burns, Mullen, Higdon, Wei, & Lansky, 2000). This is thought to initiate a vicious cycle whereby the fear of pain is maintained and possibly intensified, which exacerbates negative appraisals of pain

and its consequences, leading to a decline in physical activity and to increased emotional distress and pain related-disability as a result (Roditi & Robinson, 2011).

Participants in this study thus seemed to be affected by both psoriasis and arthritic pain in equal measure, albeit not always simultaneously. Interestingly, this does not support the findings of the only other study that has explored the lived experience of PsA sufferers, which found that participants had little to say about what it was like to live with psoriasis (Aitken, 2011). Indeed, several participants commented that the impact of psoriasis was more difficult to deal with because of the stigma associated with it compared to the more acceptable societal attribution to walking with a limp.

It might, however, be argued that what is relevant in this context is to recognize the devastating impact that PsA can have on sufferers' lives. The suffering and distress experienced as a result of PsA is evident in participants' accounts. One participant even described himself as feeling suicidal before being put on biologics.

Whilst biologics may have been able to significantly improve the lives of participants, it is important to bear in mind that this treatment is expensive and is offered to sufferers only as a last resort in accord with the stepped care model (NICE, 2012). This invariably poses the question of how many other PsA sufferers are experiencing a similar illness trajectory to that described by the participants in this study.

Given the substantial impact that suffering from both a skin and a joint condition was found to have on participants' lives, it is extraordinary that this phenomenon, to a large extent, remains unrecognised. Though biologics is experienced as life-changing, this master-theme also attests to how vulnerable PsA

sufferers are and suggests this population would benefit from additional awareness and support throughout their illness trajectory.

Second Master Theme: Living With the Fear of the Unknown

Despite distinct physical improvements, uncertainty regarding what to expect both in terms of the future efficacy of biologics and potential side effects pervaded participants' experiences.

Uncertainty can be understood as the 'cognitive state created when the person cannot adequately structure or categorise an event because of the lack of sufficient cues' (Mishel, 1990, p. 225). In this way, the dearth of information surrounding biologics can be seen as fanning the flames of uncertainty with participants experiencing their bodies forming the front lines of dangerous, experimental treatments.

However, it was also clear that participants appraised and gave different meanings to uncertainty, with only Alice being destabilised by it. This fits with theorists concurring that uncertainty is neither good nor bad, but can be appraised along a continuum of threat (fear) to opportunity (Mishel, 1999).

As was seen from the analysis participants managed uncertainty and the emotions associated with it in different ways. Alice was at one end of the spectrum appraising the uncertainty as a threat. Alice's psychological state thus fit with threat-related attribution being associated with poor adjustment, maladaptive coping, higher psychological distress, anxiety, and depression (Mishel et al., 1991; McCormick, 2002).

Though the other participants also lived with the uncertainty surrounding biologics treatment, most managed to find adaptive ways of coping with this

uncertainty. This echoes the literature that living with uncertainty is the hallmark of living with a chronic disease (Mishel, 1990, 1999), but it needs to be appraised as a threat to have a detrimental effect (Johnson, Afari, Zautra, 2009).

Indeed, uncertainty can also be appraised as an opportunity for re-evaluation that can herald new ways of being in the world. Hanif, Samuel, and Rebecca all described experiencing an increased appreciation for life, a greater focus, and meaning being attributed the present and day-to-day activities, which have often been reported in the literature as ‘benefit-finding’ (Carver & Antoni, 2004; Sodergren, Hyland, Crawford, & Partridge, 2004) and post-traumatic growth (Hefferon, Grealy, & Murie, 2009).

Seeking out information also emerged as a prominent way of managing the uncertainty experienced by participants. This is supported by research showing that that information-seeking is a common way of trying to manage illness uncertainty and uncertainty-related anxiety (Hogan & Brashers, 2009; Mishel, 1990; Brashers, 2007).

There thus seems to be a link between information and uncertainty insofar as a lack of information denies the person the opportunity to form a frame of reference (Mishel, 1988). Participants’ wish that their health care provider had made more information available to them thus contrasts with the reality of having a chronic illness, where the ability to provide accurate information is usually compromised. When the availability of information was scarce, participants often resorted to finding their own information on the internet. In this way, seeking information may be linked to participants’ efforts to gain a measure of control over their uncertainty by forming a representation of what’s going on that they can give meaning to.

A notable exception was Rebecca, who appeared to want less information. This suggests that patients will differ in their preferences. Some patients may actually prefer to have their health care professional make the decisions and not wish to be more involved.

Indeed, some studies have found that increased involvement actually worsens outcomes for some patients (Savage & Armstrong, 1990). This therefore again suggests that one of the key aspects of medical care is the ability of the professional to act sensitively and to recognise the patient's desired level of involvement in decision-making (Guadagnoli & Ward, 1998).

Another prominent way that participants attempted to cope with an uncertainty that perhaps threatened to overwhelm them was by downward social comparison. This is also supported by the literature showing that comparisons with others perceived as being less fortunate is frequently employed to promote positive affect and well-being (Buunk & Ybema, 2003; Festinger, 1954). By construing themselves as fortunate, participants in this study may thus have been actively trying to reduce the adverse impact of PsA on their lives.

It was thus found that uncertainty, albeit appraised and given meaning to in different ways, was a key aspect of participants' experience of receiving biologics. It is thus possible that it is the appraisal of biologics as a threat that accounts for the discrepancy in findings in quantitative studies, where participants score significantly lower on psychological than physical QoL dimensions after the administration of biologics (Saad et al., 2010).

Third Master Theme: The Importance of Seeing the Person Behind the Disease

It was the similarities between Alice's experience of her medical care and how Matthew and Jack described their medical care at a previous hospital that led the researcher to infer that participants' relationship to their health care provider was crucial in shaping their experience of biologics.

From participants' description of the two different types of care, it seemed that this difference could be conceptualised as a difference between a biomedical and a biopsychosocial model of health care.

The following experiences can thus be seen as representative of a biomedical model of care with a sole focus on the remediation of disease. The clear signs that Alice was in severe emotional distress and was struggling to cope were ignored just as her direct cry for psychological help was overheard. Jack's asking for psychological help to manage the pain that he experienced as overwhelming was likewise ignored. Despite being treated for psoriasis, which is widely recognised to have a significant impact on sufferers' lives, Matthew's doctor never asked him how he was – in fact he never even looked him in the eye. The lived experience of illness and the psychological burden associated with this is, it seems, considered outside the remit of this type of medical care.

Whilst research on PsA is still in its infancy, the literature on psoriasis has repeatedly advocated a patient-centred approach, which in the current context will be considered synonymous with a biopsychosocial approach (Feldman, Behnam, Behnam, & Koo, 2005; Kimball et al., 2005; Moon et al., 2013). Given that psoriasis is associated with high levels of psychological distress that is related to adverse

clinical outcomes (Moon et al., 2013), it is surprising that so few dermatology units have access to specialist psychological care (Psychodermatology UK, 2012).

Though there is a dearth of studies investigating pain in PsA, research on other medical conditions that involve chronic pain attests to the limitations of a biomedical view of pain. Viewing the intensity of pain as proportionate to or in linear correspondence to the degree of tissue damage has not been supported by research. Instead, findings suggest that pain must be understood from a biopsychosocial perspective that views pain as a ‘complex and multifaceted experience emerging from the dynamic interplay of a patient’s psychological state, thoughts, emotions, behaviours as well as socio-cultural influences’ (Roditi & Robinson, 2011, p. 42).

Whilst it is not possible to review the literature on pain in RA within the scope of this study, suffice it to state that these studies support the biopsychosocial view on pain as complex and multidimensional. Psychological factors such as perception of control and helplessness have been found to be the strongest predictors of depression and pain among RA sufferers (Covic, Adamson, Spencer, & Howe, 2003).

The experiences of Jack, Matthew, and Alice therefore suggest the continued stronghold of biomedical assumptions such as the clear divide between physical and psychological within the health care delivery system, despite policy level calls for a biopsychosocial care model that integrates physical and psychological aspects of chronic disease (‘Better Integrated Care Could Save the NHS Millions,’ Department of Health, 2012).

The findings of this study also suggest that there is a lack of awareness and knowledge about PsA, even among medical professionals. All participants, except Samuel, described going for many years before their joint pains were linked with

psoriasis. The worst case was that of Matthew, whose symptoms of joint pain were dismissed for over 20 years. This is supported by research finding that patients with PsA often take long to be correctly diagnosed (Kane & Pathare, 2005, suggesting that clinicians should be urged to be attentive to signs of arthritis among psoriasis sufferers (Mease et al., 2014).

It thus seems that the physical and psychological suffering incurred by PsA is amplified by a lack of awareness and recognition of the severity of disease, and not only in terms of the psychological impact that not being believed had on Alice and Matthew, who both struggled to find words to describe this. But Matthew suffered severe consequences from the failure to identify his joint pains as PsA as his joints were permanently damaged, rendering him unable to work. Likewise, Jack's experience of PsA being treated by separate medical departments is also supported by the literature, where this disconnect in patient care is attributed to the historical neglect of PsA (Gordon & Ruderman, 2005).

Furthermore, there is also evidence to suggest that paying attention to the illness experience and psychological distress of PsA sufferers has direct clinical relevance. A growing body of evidence shows that negative views of illness held by patients are associated with poorer health outcomes (Petrie & Weinman, 2006; Hagger & Orbell, 2003). As mentioned in the literature review, disease severity has been found to have little bearing on how individuals cope and adjust to having a chronic illness. Instead, it has been found that it is patients' beliefs or representations of illness that most significantly explain coping behaviours, psychological impact, and adherence to treatment (Leventhal et al., 1992).

There is preliminary evidence that patients' beliefs or illness cognitions predict level of disability and HRQoL in PsA sufferers (Kotsis et al., 2012) echoing findings in RA (Graves, Scott, Lempp & Weinman, 2009; Os, Norton, Hughes, & Chilcot, 2012). Likewise, studies on psoriasis demonstrate that patients' illness representations predicted levels of disability that could not be explained by disease severity (Fortune, Richards, Main, & Griffiths, 2000; Scharloo et al., 2000). This therefore suggests that a focus on the illness experience and the specific representations of illness could serve to identify vulnerable patients who may go undetected if the focus is on severity of disease alone.

For example, despite Alice's recognising that treatment with biologics has significantly improved her PsA symptoms, her representation of treatment as unsafe can thus account for her psychological distress and resentment of biologics. In line with research linking psychological distress with poor treatment adherence (Katon, 2002), this manifested in Alice's reluctantly turning up for treatment that she paradoxically also recognised as making her better. Likewise, Matthew's belief in the controllability of his PsA symptoms following biologics can also explain Matthew's positive psychological state despite his still being quite impaired by pain.

What is, however, perhaps more relevant in the current context, is that if illness representations form the basis of emotional responses and coping, a focus on these can inform interventions within the context of cognitive-behavioural psychological therapies. As such there is evidence to suggest that psychological intervention targeting maladaptive illness cognitions can both improve psychological distress and reduce disease severity in psoriasis (Fortune et al., 2002b; Fortune et al., 2004; Zachariae, Oster, Bjerring, & Kragballe, 1996; Lavda, Webb, & Thompson,

2012). Likewise, psychological intervention based on a cognitive-behavioural perspective has been successful in helping patients to manage pain in arthritic conditions such as RA (Sharpe et al., 2001; Turk & Monarch, 2002).

Though no studies, to date, have investigated whether psychological interventions are effective in managing the distress associated with PsA, this topic may warrant further exploration.

Hanif's experience of participating in a pain-management programme, which he credited with transforming the way he dealt with his arthritic pain, is particularly significant. This supports findings showing that there are other pathways to manage pain when the biomedical model's attempt to eliminate or manage the physical cause of pain through, for example, medication fails. Hanif's experience is therefore illustrative of the evidence supporting psychological approaches to pain management and thus suggest that this could be a fruitful avenue of intervention for PsA sufferers (Kerns, Sellinger & Goodin, 2010; Veehof, Oskam, Schreurs, & Bohlmeijer, 2011).

Another facet of Hanif's experience may be related to his self-efficacy in the sense of feeling more in control of his pain. Research suggests that self-efficacy is enhanced when patients succeed in solving a problem, which they can be taught to do through the use of self-management skills (Roditi & Robinson, 2011). Hanif's description of how he was able to manage his pain through breathing rather than relying on medication for relief could thus be seen as enhancing his sense of self-efficacy and belief in his ability to deal with the psychological demands of his pain.

Furthermore, evidence supporting the use of psychological intervention to improve physical health outcomes is emerging from the hard sciences themselves.

The emerging field of psychoneuroimmunology is increasingly able to show that negative emotions and stressful experiences can lead to immune modulation (Carver, Scheier & Segerstrom, 2010; Harter, Conway & Merikangas, 2003; Kendall-Tackett, 2010). This link between mind and body, the so-called ‘brain-skin access’ is often emphasised within dermatology, with several studies suggesting that psychological factors play a role in triggering and exacerbating psoriasis (Chapman & Moynihan, 2009; Fortune et al., 2003; Hunter, Griffiths & Kleyn, 2013).

This was supported by several participants in this study, who experienced their skin flaring up during periods of increased psychological distress, with Matthew’s experience of his skin being 95% covered by psoriasis during the time his joint pains went unrecognised being exemplary in this regard.

This theme therefore highlights the need for a biopsychosocial approach to management of PsA, which considers the individual illness experience of sufferers as they go through their different stages of their illness trajectory in line with the emphasis on person-centred care in the context of chronic illnesses such as PsA (Naylor et al., 2012).

Implications of Findings for Counselling Psychology in Health Care Settings

The findings of this study suggest that living with PsA is associated with considerable psychological distress and life impact that is not yet widely recognised. There is therefore little doubt that there is room for improvement to address the significant psychological and social challenges PsA sufferers are likely to experience at different stages of their illness trajectory. Further research into how psychological interventions can be employed as an adjunct to conventional medical management to improve the lives of PsA sufferers is therefore needed.

For the practitioner psychologist working with clients with visible differences such as PsA, it is natural to focus on psychological aspects implicated in the aetiology and maintenance of distress. However, counselling psychology's explicit concern with the unique experience of the individual also means attending to the biological, psychological and social aspects of the PsA sufferer's illness experience. It is therefore imperative to resist being drawn into locating or explaining the source of psychological distress solely within the individual, but rather to "remember the social (...) within a truly biopsychosocial model of understanding and practice" (Strawbridge, 2008, cited in Douglas, 2016, p. 161).

As counselling psychologists we are reminded to recognise the powerful sociocultural factors surrounding what it means to live with a visible difference – both on the level of what appears to be deeply rooted stigmatizing attitudes to blemished skin, and in terms of critically engaging with how ideals of perfection are fuelled by the mass media and a global beauty industry with a vested interest in having consumers strive towards, often unattainable, ideals of beauty (Orbach, 2009; Rumsey & Harcourt, 2012).

In order to engage with actions that reflect or 'talk the talk' (Rafalin, 2010, p. 51) counselling psychologists are therefore urged to venture beyond the therapy room to engage with sociocultural issues to effect change in wider society as well (Milton, 2010; Vera & Speight, 2003).

There is therefore also a pressing need for involvement in public health campaigns and organisations, such as Changing Faces, that aim to educate the public, to promote acceptance and diversity of appearance, to view people with disfigurement

as ‘just that. People first, who happen to have a disfigurement rather than a population apart’ (Rumsey & Harcourt, 2012, p. 681).

Whilst there is undoubtedly a gap between the need for and provision of psychological support in physical health, increasing budgetary restrictions within the NHS mean that the provision of psychological services within units such as dermatology may not be prioritised. Counselling psychologists are therefore called to disseminate research findings beyond academic journals to demonstrate at policy level the need for the provision of specialist psychological care (Corrie & Callahan, 2000).

Reflexivity on Methodology and Process

On reflection, there were pros and cons associated with the choice of IPA for this study. On one hand, this methodology provided rich data anchored in the subjective life-world of participants with which to answer the research question of this study. On the other hand, a challenge I persistently grappled with was how to balance IPA’s focus on “the person-in-context and their subjective experiences” (Torodova, 2011, p. 35) with the sociocultural context in which participants’ experiences were embedded.

During my analysis I kept finding that participants’ experience of biologics could not be understood in isolation from, for example, their experiences of previous medical treatments, the social meaning that having a skin condition seems to be imbued with and their experience of the medical care in which it was received.

It was only when I read Torodova’s (2011) commentary that I was able to explicate the nature of my challenge, namely how to maintain coherence – a synchrony of epistemology, methodology, and methods – whilst allowing for a

deepening contextualisation. The last master-theme could thus be argued to straddle a fine line between invoking a higher-order category to explain participants' experience rather than capturing their experience.

However, it has also been argued that IPA offers a position of epistemological flexibility (Smith et al. 2009), and it is important that IPA should expand its interpretative and contextualising potential (Larkin et al., 2006). Hence, I can only admit awareness of what Torodova (2011) terms pushing the 'envelope of what coherence means' (p. 37) by perhaps venturing into an epistemological perspective that borders on explanation rather than interpretation. But at the same time, I hope this has been done in the spirit of avoiding methodolatry (Chamberlain, 2000), understood here as the strict adherence to method with an ensuing 'sacrifice of content and substance' (Torodova, 2011, p. 37).

On reflection, therefore, in light of how salient the last master-theme was deemed to be, grounded theory may also have been a suitable alternative mode of enquiry. However, at the outset of the study, the main aim was to access participants' experiences and therefore IPA was chosen.

Although I, on a personal level, have long been sceptical of any claims toward objective knowledge in research, this process affirmed the epistemological position adopted for this research. I feel I have been instrumental in the creation of this account, from the wording of the interview questions to analysing to the best of my abilities what I thought participants were conveying.

Two reflections arose from this. Participants were invited to participate on headed paper bearing the name of the NHS department responsible for their medical care, and most interviews took place there. I therefore wondered about whether

recruitment was influenced by participants' seeing me as a representative of that department too. The five participants who agreed to participate all felt very positive towards their care. Perhaps participants with negative experiences did not want to participate because they saw me as a representative? Perhaps it was no coincidence that the only person with a predominantly negative experience received her medical treatment elsewhere?

Another cause for reflection was that the importance of personalised medical care of which I am an avid proponent seemed to have been affirmed by this study. Thus, I did wonder about the extent to which I influenced these findings in terms of the questions I asked participants, the prompts I used, and how I responded to what participants were saying as well as of course the process of analysis and interpretation itself.

The themes that emerged from the analytic process were a result of bringing the double hermeneutic to life (Smith et al., 2009) in the sense that interpretation of the wealth of data in the interview transcripts involved both selection of what to focus on as well as my filling in gaps, making meaning out of ambiguities and what I thought participants were saying to allow a coherent narrative to emerge.

During the analytic process I realised that I found this power unsettling. I realised that I was initially uncomfortable with making interpretations that went beyond what I was sure participants were saying and that I would rather err on the side of caution than to risk interpretations that might conflict with participants' self-understanding. What if they didn't agree with my interpretations of their experience? What if I was 'forcing' my assumptions onto participants' accounts in an attempt to create a coherent and convincing account?

Willig (2012) argued that putting ethics at the heart of interpretative research is essential. For me, this research process has highlighted that interpretative methods such as IPA open up fundamental ethical issues of ownership and power that become necessary to engage with.

Thus finding the responsibility of interpretation enormous, I feel a sense of humility and responsibility to the participants in this study who put their story in my hands. I was struck by the immensity of participants' suffering and, during the interviews, I strongly felt and still feel that this is a much-neglected client population in need of much more support. Thus, I must acknowledge becoming emotionally invested with the plight of the participants in this study. Yet I have tried to 'tread carefully' and to achieve a balance between interpretative depth and staying close to the data. I hope I have done participants justice in interpreting the meaning of their experience.

Limitation of Study and Direction for Further Research

This study presented an in-depth understanding of participants' experience of receiving biologics for PsA. A limitation of this study was that participants had all been on different types of biologics for varying lengths of time. Thus, it is unclear whether the length of time each participant had received biologics for had affected their experience. It is possible that participants who had been on biologics the shortest length of time were still in a 'honeymoon period' compared to those participants who had been on biologics the longest and may have wearied of treatment.

It is also possible that the recruitment of five out of six participants were from a dermatology unit that practices person-centred care may have had a bearing on the overall positive experience of treatment, as indeed was the contention of this study.

Recruitment from this unit may have skewed the experience of biologics in a positive direction, as it is possible the sample in this study may not be particularly representative of PsA sufferers receiving biologics.

Further qualitative research conducted in different healthcare settings and more longitudinal qualitative examination of the same participants' experience of biologics at different stages of treatment might yield interesting data relating to how the experience of receiving biologics may change over time and how medical care potentially affects this experience.

Conclusion

Whilst it is not possible to generalise on the basis of the methodology used in this study, the findings of this study highlighted that treatment with biologics was experienced as complex. While biologics significantly improved sufferers' lives, treatment brought with it challenges of its own such as worries and uncertainty about what to expect both in terms of the future efficacy of biologics and potential side effects. This suggests that a biopsychosocial approach that attends to the psychological and social aspects of the PsA sufferers' illness experience in adjunct to the biomedical aspects of disease management is warranted even when positive changes in health status are experienced, such as those following treatment with biologics.

This study highlighted the discrepancy between the considerable impact that having PsA can have on sufferers' lives and the level of support offered to this patient population. Despite wide consensus that a biomedical approach is inadequate when it comes to caring for individuals with chronic dermatological and rheumatoid conditions (Psychodermatology UK, 2012; Roditi & Robinson, 2011) the experiences

of participants in this study suggest that the implementation of a biopsychosocial model on the level of practice leaves much to be desired.

PsA patients suffer from the dual impact of skin and joint conditions, both of which are associated with considerable psychological distress and life impact. Given that psychological distress is related to adverse clinical outcomes (Moon et al., 2013) and significant financial burden on the healthcare system (Naylor et al., 2012), it is surprising that PsA sufferers going through the different stages of their illness trajectory have little access to specialist psychological care.

However, what was perhaps even more striking was the lack of awareness and knowledge about the condition, even among dermatologists and rheumatologists treating the condition. This suggests a pressing need for further research and education about PsA so that this condition can be identified and managed appropriately.

Given the paucity of studies on PsA, there is little doubt that there is considerable room for improvement in the way the care for patients suffering from this condition is managed. This study therefore calls for a multidisciplinary collaboration among psychologists, dermatologists, and rheumatologists on both research and practice levels to further develop, implement, and demonstrate the need for psychological counsel for PsA sufferers as they pass through various stages of their illness trajectory. It is thus hoped that insights from this study can be a stepping-stone to improve the support for this population.

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Appendix A

Further Information on Psoriatic Arthritis

What is psoriatic arthritis?

Psoriatic arthritis (PsA) is a form of arthritis affecting the joints in around one in five people with psoriasis. PsA often affects the hands and feet causing swelling, stiffness, pain and problems moving the joints. Once it develops, is a long-term condition.

The pain and swelling of PsA are caused by an overactive immune system, which inflames the tissues around the joint. Typically, symptoms will flare-up and recede periodically.

Psoriasis preceding the arthritis symptoms of the disease is estimated to occur in about 70-80% of cases. It is, however, possible for the manifestations of arthritis to precede the onset of psoriasis, just as a simultaneous sudden onset of both skin and joint symptoms has also been seen.

Psoriasis can develop at any age, but PsA usually happens later, often between the ages of 25 and 50 years. About two to three per cent of the population, have psoriasis. Of these, about 20 per cent will develop PsA.

There are five different kinds of psoriatic arthritis.

- *Asymmetric arthritis* makes up about 70% of all cases of psoriatic arthritis. It often involves one or a few joints, like the knee, hip or fingers. Although it's frequently mild, it can sometimes be debilitating. The inflamed joints may be red and hands and feet may be swollen.
- *Symmetric arthritis* is the second most common form of psoriatic arthritis. It often causes symptoms in the same joints on both sides of the body.

Symptoms are similar to rheumatoid arthritis and symmetric arthritis can cause permanent damage.

- *Distal interphalangeal predominant (DIP)*, a less common form of psoriatic arthritis, affects the joints close to the fingernails and toenails. The nails are often affected too.
- *Spondylitis* can make movement painful, especially in the neck and back. It can also cause inflammation of the spinal column.
- *Arthritis mutilans* is a rare and often debilitating and destructive form of psoriatic arthritis. It often affects the hands and feet and sometimes the back and neck, and it can result in permanent deformity.

What are the symptoms of psoriatic arthritis?

The symptoms of psoriatic arthritis are similar to those of other kinds of arthritis. They include:

- Stiffness in the joints
- Pain or swelling in the joints
- The presence of psoriasis will make diagnosis of psoriatic arthritis easier

How is psoriatic arthritis diagnosed?

PsA can be diagnosed through blood tests, joint fluid tests and X-rays in order to examine the affected areas and rule out other diseases.

What is psoriasis?

Psoriasis is a chronic inflammatory skin disorder. The underlying cause is not known, but the immediate cause of psoriasis is the rate of growth and differentiation of the epidermis (the outer layer of the skin). In unaffected skin, the epidermis is renewed approximately every 28 days. With psoriasis, however, the epidermis is

renewed every four days, a process referred to as hyper-proliferation. The effects of hyper-proliferation result in psoriatic plaques from the thickening and reddening of the skin; the sloughing of silvery scales; pruritus (severe itching) of the affected areas; and thickening and yellowing of the fingernails and toenails. The surface area of the body affected varies from small patches to total skin coverage.

Psoriasis also affects the nails by causing discolouration, pitting and loosening of the nail from its bed (onycholysis) and abnormal growth of the nail bed (hyperkeratosis)

Two-thirds of people have type 1, which typically presents before the age of 30. It has a strong hereditary component. Type 2 occurs after the age of 30. Men and women are equally affected, but there is a large variation between ethnic groups. Psoriasis is most common in white skin.

Psoriasis may present in one of 5 forms, though approximately 80% present with *plaque psoriasis* or psoriasis vulgaris. This is characterized by raised, inflamed, red lesions covered by a silvery scale, typically found on the elbows, knees and scalp, lower back.

Inverse psoriasis are red, shiny lesions, located in the armpits, groin and skinfolds. It is brought on by irritation from rubbing and sweating and tends to be more troublesome in overweight people with deep skin folds.

- *Erythrodermic psoriasis* is a form of psoriasis that affects most of the body surface and is characterized by periodic, widespread, fiery redness of the skin often accompanied by severe itching and pain. This form can lead to severe illness as infection, pneumonia and congestive heart failure brought on by erythrodermic psoriasis can be life-threatening.

- *Guttate psoriasis* is a form of psoriasis that often starts in childhood or young adulthood and usually appear on the trunk or limbs. This form often has a sudden onset and can be brought on by respiratory infections, tonsillitis, stress, injury to skin and administration of certain drugs.
- *Pustular psoriasis* is primarily seen in adults. It is characterized by white pustules surrounded by red skin. It is cyclical in nature, often starting with reddening of the skin followed by formation of pustules and scaling. This form may be triggered by internal medications, overexposure to UV light, pregnancy, systemic steroids, emotional stress.

Appendix B

Overview of Treatment Options for Psoriatic Arthritis

Drugs for the treatment of PsA can be divided into several categories:

- *Nonsteroidal anti-inflammatory drugs (NSAIDs)*. These drugs decrease inflammation, pain and stiffness and include over-the counter medication such as aspirin and ibuprofen.
- *Disease-modifying anti-rheumatic drugs (DMARDs)*. These are immunosuppressants, which reduce the activity of the immune system. They work by slowing disease progress and can therefore reduce the amount of tissue damage making it an effective treatment for more severe symptoms of psoriasis and PsA. Examples include methotrexate (Maxtrex), sulfasalazine (Salazopyrin) and leflunomide (Arava). Most are taken in tablet form, but may sometimes also be administered by injection. They can have serious side effects, so you will be carefully monitored.
- *Oral steroids*. These can be used to treat acute joint pain, but cannot be used safely for long periods of time. Stopping treatment with steroids suddenly can also cause a flare-up of symptoms.
- *Biologics*. These are the newest class of drugs and are genetically engineered proteins derived from human genes. They are designed to inhibit specific components of the immune system that play pivotal roles in fueling inflammation, which is a central feature of rheumatoid and psoriatic arthritis.

Biologics are used to treat moderate to severe psoriatic arthritis that has not responded adequately to other treatments. They differ significantly from traditional

drugs used to treat arthritis in that they target specific components of the immune system instead of broadly affecting many areas of the immune system.

The most common side effect seen with biologics is pain and rash at the injection site. This occurs in less than 30% of patients. Since biologics given by infusion (in the vein) have the potential to cause an allergic infusion reaction, patients are monitored during infusions. Symptoms of infusion reactions include flu-like illness, fever, chills, nausea, and headache.

As with any drugs that suppress the immune system, biologic therapy poses some increased to infections and other diseases. Biologics may also cause some chronic diseases that are dormant (such as tuberculosis) to flare, and they are not recommended for people with multiple sclerosis and other conditions such as severe congestive heart failure. All patients should be skin tested for tuberculosis prior to starting biologics, and many are also tested for chronic hepatitis.

There are a number of different biologics licensed for use in the treatment of PsA in the UK. These include targeted therapies (alefacept) and anti-cytokine therapies (anti-tumor necrosis factor (TNF) therapies such as adalimumab, etanercept, infliximab and a monoclonal antibody against interleukin (ustekinumab).

Appendix C

Guidelines for Biologics for Psoriatic Arthritis

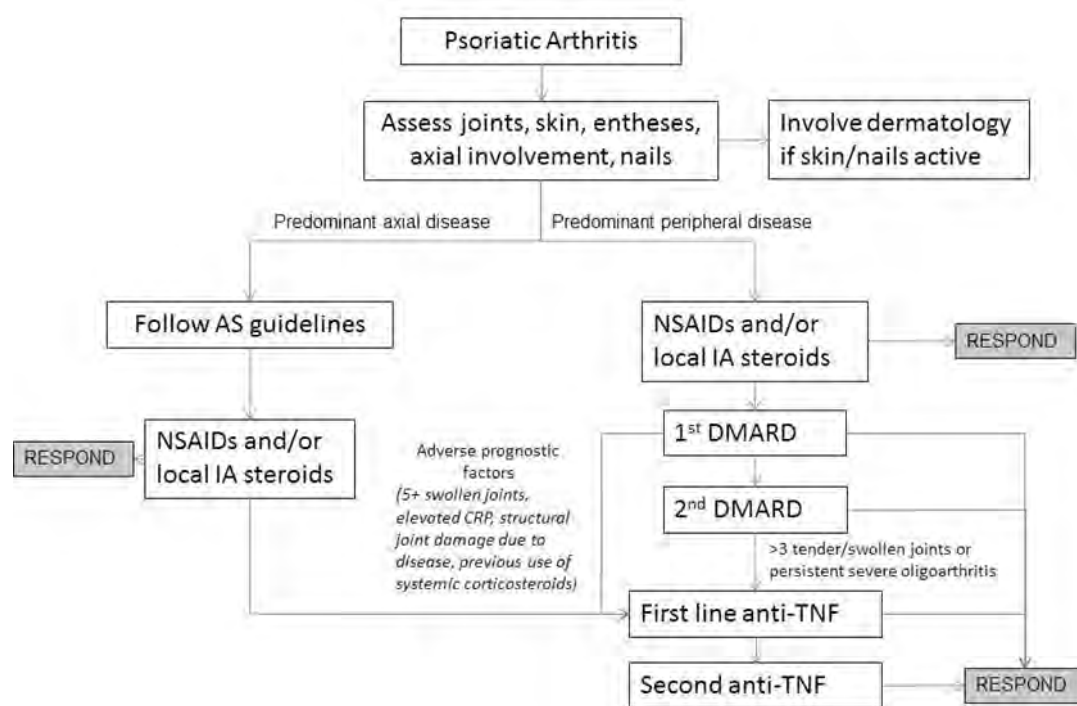


Figure 1. Recommended treatment algorithm for psoriatic arthritis. (Retrieved from http://www.rheumatology.org.uk/includes/documents/cm_docs/2012/b/bsr_guidelines_2012_treatment_of_psoriatic_arthritis_with_biologics.pdf, p. 5)

Appendix D

Examples of Quality of Life Questionnaires (DLQI, SF-36 & HAQ)

DLQI: The Dermatology Life Quality Index (Finlay & Khan, 1994) is a dermatology-specific QoL measure that has been developed specifically to capture the impact of skin disease on patient's quality of life. Developed on the basis of 120 dermatology patients with a variety of skin conditions responses to the impact of their skin condition on their lives.

It is a short, self-administered questionnaire that consists of 10 questions with each question having four possible responses: not at all, a little, a lot, and very much. A total score can range from 0-30, with a higher score indicating greater QoL impairment.

HAQ: The 'Health Assessment Questionnaire ' was originally developed in 1980 by Fries et al. (1980) to assess physical function in rheumatoid arthritis and was one of the first measures to assess outcomes from the patient perspective. Because the HAQ emanated from rheumatology, it has sometimes been characterized as a disease-specific instrument, but should be seen as a generic measure because the dimensions assessed are widely applicable across many different diseases.

The HAQ consists of 20-items divided into 8 domains: dressing and grooming, arising, eating, walking, hygiene, reach, grip and common daily activities. Respondents rate the degree of difficulty they have had in the past week on a 4-point scale, ranging from 0 (no difficulty) to 3 (unable to do), The highest scores in each category are summed (0-24) and divided by the number of categories scored to yield a summary score of 0-3.

SF-36: The Short Form-36 (SF-36) is a 36-item questionnaire developed by Ware & Sherbourne (1992). It has been widely used to assess quality of life across a range of medical conditions.

The SF-36 measures health across 8 domains; 4 domains of physical health (physical functioning, bodily pain, role limitations due to physical problems and general health perceptions) and 4 domains of mental health (social functioning, role limitations due to emotional problems, psychological functioning and vitality/fatigue). The responses to items within each dimension are summed to produce a health profile consisting of 8 scores, which can be subdivided into 2 summary scores – a physical and mental component score. These scores are then transformed into standard scores ranging from 0 (lowest health status) to 100 (highest health status).

DERMATOLOGY LIFE QUALITY INDEX

DLQI

Hospital No:

Date:

Name:

Score:

Address:

Diagnosis:

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick ☐ one box for each question.

- | | | | | | | |
|-----|--|------------------------------------|-----------------------------------|-------------------------------------|-------------------------------------|---------------------------------------|
| 1. | Over the last week, how itchy, sore, painful or stinging has your skin been? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | |
| 2. | Over the last week, how embarrassed or self conscious have you been because of your skin? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | |
| 3. | Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> |
| 4. | Over the last week, how much has your skin influenced the clothes you wear? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> |
| 5. | Over the last week, how much has your skin affected any social or leisure activities? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> |
| 6. | Over the last week, how much has your skin made it difficult for you to do any sport? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> |
| 7. | Over the last week, has your skin prevented you from working or studying? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | | | Not relevant <input type="checkbox"/> |
| | If "No", over the last week how much has your skin been a problem at work or studying? | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | | |
| 8. | Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> |
| 9. | Over the last week, how much has your skin caused any sexual difficulties? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> |
| 10. | Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time? | Very much <input type="checkbox"/> | A lot <input type="checkbox"/> | A little <input type="checkbox"/> | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> |

Please check you have answered EVERY question. Thank you.

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HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)Date: Patient Name:

Please tick the one response which best describes your usual abilities over the past week

	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do	
1. DRESSING and GROOMING					
Are you able to:					
a. Dress yourself, including tying shoelaces and doing buttons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
b. Shampoo your hair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
2. RISING					
Are you able to:					
a. Stand up from an armless straight chair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
b. Get in and out of bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
3. EATING					
Are you able to:					
a. Cut your meat?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
b. Lift a full cup or glass to your mouth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
c. Open a new carton of milk (or soap powder)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
4. WALKING					
Are you able to:					
a. Walk outdoors on flat ground?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
b. Climb up five steps?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
PLEASE TICK ANY AIDS OR DEVICES THAT YOU USUALLY USE FOR ANY OF THESE ACTIVITIES:					
Cane (W) <input type="checkbox"/>	Walking frame(W) <input type="checkbox"/>	Built-up or special utensils (E) <input type="checkbox"/>			
Crutches (W) <input type="checkbox"/>	Wheelchair (W) <input type="checkbox"/>	Special or built-up chair (A) <input type="checkbox"/>			
Devices used for dressing (button hooks, zipper pull, shoe horn) <input type="checkbox"/>					
Other (specify).....					
PLEASE TICK ANY CATEGORIES FOR WHICH YOU USUALLY NEED HELP FROM ANOTHER PERSON:					
Dressing and Grooming <input type="checkbox"/>	Eating <input type="checkbox"/>				
Rising <input type="checkbox"/>	Walking <input type="checkbox"/>				

SF-36 QUESTIONNAIRE

Name: _____

Ref. Dr: _____

Date: _____

ID#: _____

Age: _____

Gender: M / F

Please answer the 36 questions of the Health Survey completely, honestly, and without interruptions.

GENERAL HEALTH:

In general, would you say your health is:

☐ Excellent☐ Very Good☐ Good☐ Fair☐ Poor

Compared to one year ago, how would you rate your health in general now?

☐ Much better now than one year ago☐ Somewhat better now than one year ago☐ About the same☐ Somewhat worse now than one year ago☐ Much worse now than one year ago**LIMITATIONS OF ACTIVITIES:**

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.

☐ Yes, Limited a lot☐ Yes, Limited a Little☐ No, Not Limited at all

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all

Lifting or carrying groceries

☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all

Climbing several flights of stairs

☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all

Climbing one flight of stairs

☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all

Bending, kneeling, or stooping

☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all

Walking more than a mile

☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all

Walking several blocks

☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all

Walking one block

☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all

Appendix E

Ethical Approval From London Metropolitan University



London Metropolitan University,
School of Psychology,
Research Ethics Review Panel

I can confirm that the following project has received ethical approval to proceed:

Title: Psoriatic arthritis patients' experience of receiving biological treatment: An interpretative phenomenological analysis
Student: Eva Schepeleem
Supervisor: Dr Philip Hayton

Ethical clearance to proceed has been granted providing that the study follows the ethical guidelines used by the School of Psychology and British Psychological Society, and incorporates any relevant changes required by the Research Ethics Review Panel. All participating organisations should provide formal consent allowing the student to collect data from their staff.

The researcher is also responsible for conducting the research in an ethically acceptable way, and should inform the ethics panel if there are any substantive changes to the project that could affect its ethical dimensions, and re-submit the proposal if it is deemed necessary.

Signed:

A handwritten signature in blue ink, appearing to read "Chris Chandler".

Date: 31/01/2014

Dr Chris Chandler
(Chair - School of Psychology Research Ethics Review Panel)
chandler@staff.londonmet.ac.uk

Appendix F

Ethical Approval From National Research Ethics Committee

1



NRES Committee North West - Liverpool Central

HRA NRES Centre - Manchester
3rd Floor
Barlow House
4 Marshall Street
Manchester
M1 3DZ

Telephone: 0161 625 7818
Facsimile: 0161 625 7299

17 April 2014

Ms Eva Schepeleern
Doctoral Student in Counselling Psychology
3 Connaught Mews
Pond Street
London
NW3 2NW

Dear Ms Schepeleern

Study title:	The experiences of psoriatic arthritis patients receiving biological treatment: A qualitative study.
REC reference:	14/NW/0254
Protocol number:	n/a
IRAS project ID:	139657

Thank you for your email of 15 April, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Carol Ebenezer, nrescommittee.northwest-liverpoolcentral@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Appendix G

Site-Specific Information (SSI) Approval



Joint Research Office

Office Location:
R&D Office
Admin Corridor Room G848
Medical School Building

Postal Address:
Royal Free Hospital
Pond Street
London NW3 2QG

Email: rfurandi@nhs.net; Tel: 020 7754 0500 ext: 33211 Fax: 020 7451 8209
Website: www.royalfree.nhs.uk, www.ucl.ac.uk/rfo

Ms Eva Schepelern,
Royal Free London NHS Foundation Trust
Pond Street
Hampstead
NW3 2QG

25/04/2014

Dear Ms Schepelern,

Project ID: 6858 (Please quote in all correspondence)
REC Ref: 14/NW0254
Title: The experiences of psoriatic arthritis patients receiving biological treatment: A qualitative study

Thank you for registering the above study with the Joint Research Office (Royal Free site). I am pleased to inform you that your study now has local R&D approval (NHS permission) to proceed and recruit participants at Royal Free London NHS Foundation Trust subject to Sponsor confirmation.

Please note that all documents received have been reviewed and this approval is granted on the basis that the key documents provided have been approved by the Research Ethics Committee.

Document	Date
RFC approval and REC approved documents	17 April 2014
MHRA Approval (if applicable)	Not applicable
Agreement between sponsor and Royal Free (if applicable)	Not applicable
ARSAC licence (if applicable)	Not applicable

As Principal Investigator you are required to ensure that your study is conducted in accordance with the requirements on the attached sheet. These include the conditions of your NHS permission.

Do not hesitate to contact a member of the team should you have any queries.

Yours sincerely

Dr Adole K. Fielding
Director of Research and Development
Royal Free London NHS Foundation Trust

Appendix H**Recruitment Poster****PARTICIPANTS NEEDED FOR
RESEARCH STUDY**

Do you have psoriatic arthritis?

Have you received treatment with biological agents?

My name is Eva Schepelern and I am a doctoral trainee on the counselling psychology programme at London Metropolitan University. I am looking for participants to take part in a study on psoriatic arthritis and how treatment with biological therapy has affected their lives.

You would have to be willing to share your personal experience of what having psoriatic arthritis has been like for you and how you feel now after biological treatment.

Taking part in this study involves taking part in an interview about your experience for approximately 60-90 minutes at a location here at the Royal Free Hospital.

The interview will be audiotaped and transcribed for analysis purposes, but any information you provide will be anonymised to protect your confidentiality.

To receive an information pack with further details, please contact Eva Schepelern on e.schepelern@nhs.net or ask reception here at the Dermatology/ Rheumatology clinic for one.

Thank you for your time.

This study has been reviewed by, and received ethics clearance through the NHS research committee and the Office of Research Ethics, London Metropolitan University.

Appendix I

Participant Information Sheet



INFORMATION SHEET FOR PARTICIPANTS

You are being invited to take part in a research study that investigates the experience of having psoriatic arthritis and how the treatment with biologics has affected your life. Before you decide whether you would like to participate, please take the time to read the following information to help you understand why the research is being carried out and what it will involve for you.

Who is the researcher?

My name is Eva Schepelern. I am a Trainee Counselling Psychologist and I am carrying out this study as part of a Doctorate qualification in Counselling Psychology at London Metropolitan University in collaboration with the Dermatology and Rheumatology Departments at the Royal Free Hospital.

What is the purpose of this study?

The purpose of this study is to gain an in-depth understanding of how treatment with biological therapy for your psoriatic arthritis has affected your life. There has been very little research done on what it is like to have psoriatic arthritis, and what the psychological impact of living with this condition may be and no research has yet investigated how treatment with biological agents impacts on psoriatic arthritis patients' quality of life.

What will taking part in this study involve?

Taking part in the research will involve taking part in a 60-90 minute interview with. The interview will not follow a set of pre-set questions, but be more of a conversation that evolves between you and me about what your experience of having psoriatic arthritis has been, what it has been like to receive biological therapy and what impact the treatment has had on your life and how you feel now.

Do I have to take part?

You are under no obligation to take part. Participation in this study is entirely voluntary and your decision will not affect the standard of care you receive in any way either now or in the future.

What should I do if I want to take part?

If you have decided to take part in this study, please contact me using the contact details below. We will then either arrange to meet in person or have a conversation by phone where you get the opportunity to ask any questions you may have about the research. If you decide you want to take part, you will be asked to sign a consent form and given a copy to keep and we will arrange for the interview to take place.

What if I change my mind?

Should you at one point change your mind about taking part in this study, you are free to withdraw from this study within *three* weeks of the interview taking place without having to explain your reasons. You are merely asked to do this for practical reasons *before* the data is analysed and written up. You do not have to give a reason for leaving the study and this will not affect the care or treatment you are receiving in any way.

What will happen to the information I give during my interview?

The interview will be audio-taped and transcribed for the purpose of analysis. A professional transcription service may be used which would mean that the person transcribing will listen to the interview. In this case, potential transcribers will not have access to your identity and confidentiality agreements will be signed. This means that transcribers will be legally bound to maintain full confidentiality in regard to any information revealed during the interview.

The audio-recordings and the typed out interviews will be anonymised and kept in a secure facility. The anonymised transcripts will be used for data analysis. The only people, apart from me, who will have access to the anonymised interview data are academic supervisors and representatives from assessment bodies that assess the quality of the research. Following transcription, the audio-recordings of interviews will be destroyed.

The results of this research be written up and submitted in the form of a Doctorate thesis, which will be deposited in the University Library. However, it is also intended that the results of the research will be disseminated in the form of one or more articles in scholarly journals.

It is therefore important that you are aware that it is highly likely that you will be quoted in the write-up of this study. However, any information which might contribute to identify you and other participants in this study (names, references to places, of work, study, schools etc.) will be changed, and the original names only be known by me.

What are the risks of taking part?

You will be asked to discuss your experiences of having psoriatic arthritis and how the medical treatment you have received has impacted on your life. This may or may not be distressing to you. If during the interview you are asked a

question you do not wish to answer, you may skip it. Likewise, should you experience distress, you will be given the option of taking a break or stopping the interview all together. Following the interview, I will be available for you to contact if you need to talk or reflect on some of the issues raised. I will also provide you with details of where you can receive counselling, if you should find that you need additional support.

What are the potential benefits of taking part?

Though I cannot promise that there will be benefits involved from taking part in the study, the information you have provided may help to improve understanding of what it is like to be treated with biologics for psoriatic arthritis, which may improve treatment for others in the future. You may also appreciate having the opportunity to talk openly about your experiences.

What if I have concerns about the study?

If you have concerns about any aspect of this study, you can contact me at any time and I shall do my best to answer your queries. In the event that you wish to speak to someone else, you can contact my academic supervisor Dr. Philip Hayton at London Metropolitan University. You may also contact the Patient Advice and Liaison Service at the Royal Free Hospital (please see contact details below).

Will my taking part in this study be kept confidential?

The material collected during the course of the research will be treated with utmost confidentiality in accordance with the data protection act. No other person, besides me, will have access to the raw interview material. You will not be identified by your real name, but by a study number, and nothing that identifies you will be made available to others.

However, it is important to make you aware that in the event that you disclose any information, which suggests that either you or someone else is at risk of harm, I am obliged to breach confidentiality and inform someone. However, this will not be done without your knowledge and I will do my best to discuss this with you first.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced in connection with your participation in the research, National Health Service complaints mechanisms are available to you. Please ask me or your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available to you. If you suspect that the harm is the result of the Sponsor (London Metropolitan University) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Eva Schepelern,

who is the Chief Investigator for the research and is based at Dermatology, clinic 6, 1st floor at the Royal Free Hospital. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and it is recommended that you consult a lawyer about this.

If you have any questions regarding the nature of this study, please do not hesitate to contact me at e.schepelern@nhs.net or 0798 4289 774, and I shall do my best to answer your questions.

Thank you for your time!

Contact details

Eva Schepelern (Chief Investigator)
Dermatology Clinic 6, 1st floor
The Royal Free London NHS Foundation Trust
Pond Street
London NW3 2QG
Email: e.schepelern@nhs.net
Mobile: 0798 4289 774

Academic supervisor

Dr Philip Hayton
Counselling Psychology Programme
London Metropolitan University
Room T6-20
Tower Building
166-220 Holloway Road
London N7 8DB
Email: p.hayton@londonmet.ac.uk
Tel: 0207 1332 667

Patient Advice & Liason Service

The Royal Free London NHS Foundation Trust
Pond Street
London NW3 2QG
Telephone: 020 7472 6446 / 6447
(020 7472 6445 – 24 hour answer phone)
Fax: 020 7472 6463
SMS/Text number: 447860023323 (for use by D/deaf, hard of hearing and hearing impaired patients only)

Appendix J**Letters Sent out to Participants**

Royal Free Hospital
Dermatology Clinic 6
Pond Street
London NW3 2QG
Email: e.schepelern@nhs.net
Mobile: 0798 4289 774

May 2nd 2014

Dear xxx,

My name is Eva Schepelern and I am a counselling psychologist working at the psychodermatology clinic at the Royal Free hospital, where I have a particular interest in medical conditions such as psoriatic arthritis.

I am writing to invite you to participate in my study, which looks at how people with psoriatic arthritis experience receiving biological therapy. This is a very underresearched area. Understanding more about how treatment with biologics affects people's lives is therefore important in order to identify how to better help people with psoriatic arthritis.

Participating in this study would involve for us to meet at a location that is convenient for you and for you to tell me about your personal experience. Our conversation will be audio-recorded and transcribed for analysis. It is anticipated that it will last about an hour.

I am including an information sheet that includes further details about the study.

If you are interested in participating, please contact me either on my mobile 0798 4289 774 or by email e.schepelern@nhs.net.

I will of course be happy to answer any questions you may have, so please do not hesitate to contact me if there is something you would like to clarify.

I would be extremely grateful for your help and will of course compensate you for both your time and any travel expenses you may have.

Many thanks for your time.

Hope to hear from you.

Kind regards,

Eva Schepeleern



Royal Free Hospital
Dermatology Clinic 6
Pond Street
London NW3 2QG
Email: e.schepeleern@nhs.net
Mobile: 0798 4289 774

July 22nd, 2014

Dear xxx,

My name is Eva Schepeleern and I am a counselling psychologist working at the psychodermatology clinic at the Royal Free hospital.

I hope you received my previous letter inviting you to participate in my research study. The study is looking at how people with psoriatic arthritis feel after receiving biological therapy. This is a very underresearched area. Understanding more about how treatment with biologics affects people's lives is therefore important in order to identify how to better help people with psoriatic arthritis.

I am sorry to send out a second letter to you, but unfortunately not many people have contacted me about participating. So this is just a further invitation to participate and a friendly reminder to contact me at the earliest possible convenience if you would consider telling me about your experience. It is anticipated that it will last about an hour.

You can contact me on my mobile 0798 4289 774 or by email e.schepeleern@nhs.net and I will be happy to answer any questions you may have.

I would be extremely grateful for your help and will of course compensate you for both your time and any travel expenses you may have.

Many thanks for your time.

Hope to hear from you.

Kind regards,

Eva Schepeleern

Appendix K

Participant Consent Form

**CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES**

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

REC REF: 14/NW/0254

Title: The experience of psoriatic arthritis patients receiving biological treatment: A qualitative study

Please initial
all boxes

- I confirm that I have read and understand the information sheet, version 4 issued 14.04.2014 for the above study and have had the opportunity to ask questions which have been answered fully. ☐
- I agree to the interview being audio recorded and transcribed for further analysis. ☐
- I agree to the use of anonymised direct quotes in the writing up of the study. ☐
- I understand that my participation in this study is voluntary and that I am free to withdraw within 3 weeks of the interview taking place, without giving any reason and that this will not affect the medical care I am receiving. ☐
- I understand that data from the study may be looked at by regulatory authorities or by persons from the Trust where it is relevant to my taking part in this study. I agree to these persons having access to this information. ☐

By signing this consent form, I agree to having understood the above and agree to take part in this study

Participant: Printed Name

Date and Signature

Person taking consent: Printed Name

Date and Signature

I would like to be informed of the outcome and results of this study.

☐

Appendix L

Semi-Structured Interview Schedule

- Looking back can you tell me about when you were first diagnosed with psoriatic arthritis and the treatment you received until you were offered biologics?
- Can you tell me about your experience of receiving biological therapy for your psoriatic arthritis?
- How has having psoriatic arthritis affected your life? (physically, emotionally, socially, work-life)?
Prompt: what has been the most difficult part to cope with?
- How has treatment with biologics affected your life? (physically, emotionally, socially, work-life)?
Prompt: What has changed? What are you able to do now that you couldn't before?
- Can you tell me about how you feel now both emotionally and physically compared to before?
- Considering the impact biologics has had on your life, are there any aspects of your life that you are struggling with and that you would like to receive help with/ has not changed as a result of treatment?
- Looking back what do you think you would have liked to have been made available to you, which might help others with psoriatic arthritis receiving biologics?
- What has it been like to talk about your experience? Is there anything you would like to add that we have not talked about?
- *Prompts:* Can you give me an example of that? Could you tell me a little bit more about that? What do you mean when you say...?

Appendix M

Debrief Participant Sheet



REC REF: 14/NW/0254

Study title: The experience of psoriatic arthritis patients receiving biological treatment: A qualitative study

Debriefing information sheet

Thank you very much for taking part in this study.

The study aimed to explore how the lives of people with psoriatic arthritis are affected by treatment with biologics. I was interested in:

- How psoriatic arthritis has impacted on your life
- How having psoriatic arthritis has affected you emotionally
- How treatment with biologics has impacted your life and how you feel now

Existing studies show that there can often be a significant psychological burden associated with having a chronic illness. However, what the experience of psoriatic arthritis is like is a very under-researched area and there is an almost complete lack of research investigating the psychological impact of this condition on people's lives. Furthermore, there is a widespread assumption that people will start to feel better psychologically, once their symptoms improve. But the literature shows that this does not necessarily always happen. The aim of this study was therefore to find out more about why this might be, so that the challenges facing people with psoriatic arthritis may be better understood.

This study is, to the best of my knowledge, the first of its kind, so this is what your participation has helped towards. So thank you again for taking part and making this possible.

Sources of support

Sometimes talking about difficult experiences can leave us feeling low or upset. This is quite normal and should pass within a few days. However, if you find that these feelings persist and you think you might require additional support, here is a list of counselling organisations that you may consider contacting.

- **The Samaritans** (tel. 0845 90 90 90; www.samaritans.org). The Samaritans is a national helpline, which is open 24 hours a day for anyone in need.
- **Mind** (0300 123 3393; www.mind.org). Mind is a national organisation with local branches in boroughs all over the UK. Mind provides individual counselling sessions for a small fee. Mind also has helplines that are open Monday to Friday 9 am – 6 pm.

You are of course welcome to contact me at any point to discuss any aspect of your participation in this study, to share any concerns you might have or to ask questions.

Contact details

Eva Schepelern
Royal Free Hospital
Dermatology Clinic 6
Pond Street
London NW3 2QG
Email: e.schepelern@nhs.net
Mobile: 0798 4289 774

If you have any concerns that you would like to raise with London Metropolitan University, you can contact my academic supervisor:

Dr Philip Hayton
Doctorate in Counselling Psychology Programme
London Metropolitan University
Faculty Of Life Sciences and Computing
Room T6-20
Tower Building
166-220 Holloway Road
London N7 8DB
Email: p.hayton@londonmet.ac.uk
Tel: 0207 133 2685

Appendix N

Example of Annotated Transcript and Subsequent Identification of Themes

Alice

1 I: ...to have psoriatic arthritis...

2 R: Yeah.

3 I: ...and to receive biological therapy for it.

4 R: Yeah.

5 I: So if we, erm, just, erm, to begin with I was wondering what's
6 your experience been with having psoriatic arthritis and
7 receiving biological therapy for it.

limp: ? / always
left hand of
what?
What it means to see

8 R: Erm, it's very hard with this arthritis 'cause people can't always
9 see, like I don't walk with an obvious limp, erm, so people can't
10 see. I get a lot in my rib cage and around my heart and the
11 pain's horrendous. Nobody can see it.

invisible - no
obvious/visible
manipulation
when people see -
they believe.
what happens when
people see?
Pain invisible
response of the other
→ normalise pain
→ old age
loneliness
don't understand
→ the usual -
normalisation
→ can't see
→ "normal"
expectation towards?
A. → feels funny?

12 Erm, if I do say, "Oh you know I'm struggling today I've got
13 arthritis." "Well, erm, you're just getting old like me, ooh my
14 knee aches," they'll say to me and I'm thinking but it's not it's,
15 it's not that I want it to look like I've got anything wrong with me,
16 but people don't understand, and, "Oh it's just Amanda with her
17 aches and pains again," you know. Erm, and they still expect
18 me to just carry on as normal.

19 Erm, and the, the treatment, erm, all the treatments I've
20 received I, I shouldn't detest them so much because it's there to
21 help me but I hate it, because it's every single week. It has
22 been for the last five years. I've had other biologics previous to
23 that.

24 I: Hmm.

25 R: Erm and very often they work for the first sort of three months
26 on me then they stop working. Erm, so the current lot I'm on
27 now I've been on for about five years.

28 I: Yeah.

detest
hate
→ strong words
self-censorship
(don't mean it
said ungrateful)
[help/hate]
time consuming -
paradox
how an animal
hate/help
never-ending
→ cyclical.
→ improvement →
relapse

- 29 R: And, erm, it's the Methotrexate every week. I have to traipse up to the hospital for the injection because now I've developed, which I've never had before, a needle phobia and it's from all the injections and having my bloods taken all the time.
- 30 I: Yes. Hmmhmm.
- 34 R: Erm, so there's that side of it. Then there's the way it makes me feel afterwards.
- 36 I: Hmmhmm.
- 37 R: Erm, and I actually, I was supposed to have had it yesterday, but I didn't have it 'cause I've had it absolutely up to here with it all and every so often I just can't stand it. And yet I know I need it because about two years ago, erm, I'd had enough of it, the side effects and, erm, I didn't, I missed four injections and I was bedridden with my psoriasis and my arthritis. I was that bad. So I know I need it. So, and people say to me, erm, "Well you know you need it. It's for your benefit so you should." And I still can't accept it. It's, there's no end to it.
- 46 I: Hmmhmm.
- 47 R: And, and this sounds awful, but I had a friend with breast cancer, absolutely awful, she had treatment. She was lucky, she got over it. Her treatment has stopped now eventually and I know you can't compare it but five years, every week and I'm sick of it.
- 52 I: Yes.
- 53 R: I'm [ground down 0:02:58] and worn out and then I have all the worries of the side effects. Erm, and you can't get any independent advice from anyone as to the side effects 'cause the people who give it you if, like I was treated for a blood clot on my lung, now I'm having heart problems, and so you can't get any independent information. So I look on the internet and

Phobia:

Impact:

needle phobia
social phobia(Intrusion/
violation that
body responds to.)Fed up
Conflict
want/needOther people
say / conflict.Comparison
with other
conditions

Lack of trust

worry/
concern about
side-effectsLack of
independent
advicecan't get
an honest
answer

something new

fear: new

what's behind
needle phobia?psychodynamic
reading of phobia as
self-protection?

: aftermath.

Real conflict.

can't stand it, oh
hysteria to
herself
↓
bedridden.
needs:what does that
mean.Benefit →
lack of acceptance
never-ending.it's not socially acceptable
companionShame: watching
enjoying her friend
with breast
cancer →
end to it
the implication
being a grueling
treatment: but
it ends.

Side-effects.

What does this
mean? Independent
everyone is vested
in itcan't trust.
thinks treat-
ment has
brought it
on.

worry (not bring leads to) Internet: listened to → not read?

15/12/2014

→ information seeking

Internet: information seeking

Sh, don't like

physical proof body

Medical profession

Fight/ignore

Ownership: It's my body

Toxicity poison in my body

Fear

Internet: uncontrolled → strategy born of real concern? not feeling safe!

message: don't do it → limbo of worry → compelled to help

→ worrying signals (and interpretation of cause-effect) → not being seen heard:

fight "hidden secret" ownership: whose body is it anyway? → normal self

Toxic body poison

Fear/frightened

59 hear all this worrying, er, all this worrying information, you
60 know, this treatment can cause this, this, this. And then I
61 suggest it to the hospital, "Oh don't take any notice of that, don't
62 look on there, oh you're alright." I mean for the last, I don't know
63 how many months, my liver count's been rising and rising which
64 I think is to do with the Methotrexate. So they keep their eye on
65 it...

66 I: Hmmhmm.
67 R: "...but they don't do anything. Finally now I'm going for a liver
68 scan but they don't, they, they don't willingly do anything. It's
69 just swept under the carpet and, and they just, it's not their
70 body, it's my body and I resent it every week. If I have a
71 headache I don't even like taking a Paracetamol...

72 I: Yeah.

73 R: ...and I resent having a highly toxic drug...

74 I: Yeah

75 R: ...into my body. I hate it.

76 I: Yes, yes. So what you're saying is that you have this quite
77 ambivalent relationship, knowing you need it-

78 R: Yes.

79 I: ...because you tried it out two years ago...

80 R: Yes.

81 I: ...and yet really coming to resent it.

82 R: Yeah, yeah.

83 I: Yeah.

84 R: And, and fear, I'm frightened.

85 I: Yeah, yeah.

86 R: When I have my infusions, erm, I'm quite happy with the

87 infusion I'm on at the moment...

88 I: Right.

89 R: ...which is every six to eight weeks, because I don't tend to

90 have many side effects. Everything else, all the other biologics I

91 have horrible side effects. Now Infliximab, I'm pretty okay with.

92 I: Okay.

93 R: But in the five, six years I've had it I've only ever had two or

94 three very, very scary reactions.

95 I: Okay.

96 R: One I went into anaphylactic shock, another one, erm, I started

97 to feel sick and just a funny sensation while I was having it.

98 I: While you were having the infusion?

99 R: I was actually having the infusion I got a funny feeling and they

100 stopped the infusion temporarily and I, I vomited and then they

101 started it again, I felt better. And there's always the scare before

102 I go for my Infliximab. I've seen one person having it and they,

103 er, had some problem with their heart and they were rushed,

104 they went into cardiac arrest, they were rushed over to, you

105 know, the, the A&E. And I always have a, a fear before I go.

106 I: Yes.

107 R: So I spend all weekend worrying about it. Erm, the other thing I

108 can't stand, it might only be a minor thing but the cannula.

109 Because I've had it, I've never had a problem with, with having

110 my blood taken or cannulas, but I think it's my, my veins have,

111 have, when they're overused, if they sunk or something or they,

112 they're scarred so the cannula pops out and I dread having that

happy with
biologics
not many
side effects

history of
horrible
side effects

Experience of
bodily
shock/reaction

Fear of body
what she feels?

Body
as spasms
→ rejection

Worry:
problem
popping

veins
disappeared
and made
it physically
impossible to have
infusion

biologics

working on
now.

seven
Side-effects
scary

meaning of
feeling sick -
body rejecting
it.
What's going to
happen?

Is my body going
to reject?
Is it going to
reject what I
will feel - that
it's enough?

Weekend?
(leisure)
the implication
that time off
is not available
to her.

: Body takes
veins disap-
pearing
↓ retreated
into
protection
saying what
mind?

damaged

113 done, 'cause it's three or four attempts now having that in. Erm,
114 and I hate it. *no chore*

*overriding:
keep going
despite
protest.*

115 I: So every time they two or three, three or four times because...

116 R: Only recently, the last probably six infusions it doesn't go in
117 easily.

*not putting
it in is
not an option*

118 I: Yeah. Yeah.

*alive
worm-
snake-like*

119 R: The one time it went in, they wiggle it about and then it pops out
120 or, then they try and put it somewhere else, so that's a massive
121 thing. I have fear of needles.

*experiment
fun quality
let's see what
happens?
objectified*

122 I: Yes.

123 R: And I just feel like I'm being prodded and poked. And that can
124 be like Monday I have my Methotrexate injection, erm, then
125 Friday I have my infusion, then I have to have my bloods done
126 every two weeks, and, and I'm just, I hate it.

*Continuous
injection
infusion
taken as:
blood*

127 I: Yeah.

128 R: And then it's the, erm, it's, it's other people's react-, "Oh just a
129 mat-," they never ask anymore how I've got on at the hospital or
130 how my day, and, you know, if I mention it I've been the ho-,
131 "Oh you're always at the hospital or, or didn't ask 'cause you're
132 used do it now." No, I'm not. I'm not.

*lack of under-
standing
compassion
fatigue*

133 I: So it hasn't, it hasn't gotten any easier for you.

*that's
normal -
not unusual
~ used to
no*

134 R: It's got harder rather than, than easier.

135 I: Yeah.

136 R: And...

137 I: Could you say a little bit more about that, how it's gotten
138 harder?

139 R: Erm.

*Normally things
are supposed to get
easier - adjustment -
but this has gotten
harder.*

140 I: Psychologically, emotionally?

141 R: Oh I think psychologically, it's like next week I've got - it's time
142 consuming, it's draining, it's tiring. Erm, next week I'm at the
143 hospital every day apart from Wednesday, and it's, it's
144 exhausting and I don't, I feel I never have one day at home to
145 myself.

146 Erm, I have my Methotrexate Monday, Tuesday I feel ill all day,
147 so I can't do anything. I'm tired and I feel ill, so I can't really do
148 much. Erm, and the other thing are the side effects of that.

149 When I first started it I kept saying, "No, I'm having
150 ____ [0:07:40]," and they'd look it up ____, "Oh this isn't, erm, this
151 isn't a side effect, it's probably not from your Methotrexate.
152 Have a word with your doctor." And I knew it was because I'd
153 get it every, erm, a few hours after my Methotrexate and it
154 would last all day Tuesday and then other times for any reason
155 I haven't had my Methotrexate I don't get those feelings.

156 I: Yeah.

157 R: And I've been telling them for years this is what I get. Suddenly
158 now they recognise it.

159 I: Yeah.

160 R: And I was on a high dose of Methotrexate, now I'm on the
161 lowest possible one now.

162 I: Hmmhmm.

163 R: And when I have been particularly bad with my arthritis, I'll
164 sometimes say, "Should I increase it?" "No, no, because of your
165 side effects." So now they finally believe me but they didn't
166 believe me. The doctors and the nurses they wouldn't believe,
167 erm.

168 I: So what was it like not to be believed?

fatigue:
hospital wants
swallows up
your time!

never alone -
safe -> by myself
-> not interfered

stick regime:
Rigid
mand. - tres.

Expert-role:
no you can't
feel like this:

expert / me
conflict
not being
heard.

not recognised

why?

: listened to
her and
lowered dose

this experience!

"not believe
me"
pathologist:
obsessed:
prodded / poked

Is there anything
more soul-destroying
than having this
happen?

169 R: Erm, oh, I'd, I'd get, I'd get angry and upset and, and tearful. It
 170 was just not being believed. I knew, apart from you know your
 171 own body, I knew that the times I haven't had the injection I
 172 don't get those side effects, so I knew. And it took them two
 173 years until they finally believed me.

174 I: Okay. What kind of side effects were they?

175 R: Erm, before you're allowed to have the injections they always
 176 try you with the tablets first.

177 I: Hmmhmm.

178 R: And maybe that's because it's cheaper, because it's a cheaper
 179 option. Erm, with the tablets, they'd make my mouth blister as,
 180 and you read the instructions and it says, "Highly toxic, do not
 181 handle," and yet I'm putting, so that's another thing that builds it
 182 into me, I'm putting this toxic drug into me.

183 I: Yeah.

184 R: Erm, and then I'd put it in my mouth and if I couldn't swallow it
 185 straightaway where the tablet had been I'd get blisters in my
 186 mouth. I could feel it stick all the way down...

187 I: Yeah.

188

189 R: ...er, my chest and, and it would stick. Erm, I'd get very tired, I'd
 190 feel sick with the tablets. My hair actually went, it started to fall
 191 out, not big clumps but it was coming out and it went brittle and
 192 like straw.

193 I: Hmmhmm.

194 R: And whatever conditioner I put on, it just wouldn't work and my
 195 hairdresser said, "It's obviously affecting your body from the
 196 inside so all the conditioning won't do anything."

I know
no, you don't
whose body is
it anyway?
couldn't

illustrates well: vulnerability

body reacting
forming a
protective layer!

toxic/
don't handle
into me:
vulnerability

open, vulnerable

violator
swallow
something
you react

hair: body
dying from
toxin
→ sick/
dying

inside →
out

no camouflage
will help

197 I: Hmmhmm.

helplessness

Helplessness

198 R: So I couldn't do anything with my hair and I knew it looked a
199 mess. I was very self-conscious about that, but I couldn't do
200 anything about it. Erm, I feel terribly sick after the tables...

appearance
like anxiety
→ powder

201 I: Hmmhmm.

slow death
poison
effect

202 R: ...and I'd come back after I'd taken them, I'd lie on the settee,
203 blanket over me, and the rest of that day or the next day I'd feel
204 sick.

defeat: blanket
surrender
dying a
lost: life out
of me
wear
rejection
recuperate

205 I: Hmmhmm.

206 R: Erm, because that was so troublesome eventually they put me
207 on the injections. (methotrexate or B?)

208 I: Yeah.

→ inside
change

Taste
changes
(for senses)

209 R: With the injections I get tired. Erm, also things like, erm, coffee,
210 it must affect my taste...

fatigue
→ senses
(taste)

211 I: Okay.

212 R: ...because erm, I love coffee and I, and I drink it and I think,
213 "Oh there's something wrong with this," and I make myself
214 another cup or...

taste

215 I: Hmmhmm.

love
away: taken

216 R: ...I say to my partner, "Does the coffee taste funny?"

217 I: Yeah.

stop:
end to

218 R: But it's always after Methotrexate but that wares off after two
219 days.

ware

220 I: That wares off.

Head
and
thoughts
so funny

221 R: But the worst possible side effect for me, which they didn't
222 believe me is what it does to my head and my thought. It's not

Head thought
location of
me?

223 pain, it's not a headache, I get a muddled head. It's like sofas,
 224 you're full of cotton wool, I can't understand simple instructions,
 225 I can't carry out tasks. My head is just...

226 I: Hmmhmm.

227 R: ...it's, it, I can't, it's difficult to explain it. It's just a fuzzy head...

228 I: Yeah.

229 R: ...and I can't understand things. Erm, and then I get tearful and
 230 upset because...

231 I: Hmmhmm.

232 R: ...I ca-, I'm getting frustrated with myself.

233 I: Hmmhmm.

234 R: Erm, and...

235 I: So it's kind of double aspect, you know it's not you but you just
 236 feel completely, something in you, in your body...

237 R: Yeah, yeah, yeah.

238 I: ...a cotton wool feeling.

239 R: A fuzzy cotton wool, confusion...

240 I: Hmmhmm.

241 R: ...erm in my head, yeah.

242 I: Hmmhmm, and you say they finally recognise that there...

243 R: Finally, I've been telling them for...

244 I: Yeah.

245 R: ...two years, you know...

246 I: Yeah.

fuzzy

→ cotton wool?
 eye?
 → without life/
 action
 → comprehension

someone
 looking in /
 judging

knowing this
 normally not like
 this,

What does this
 mean? Why extra
 cotton wool?

Every head.
 Muddled:
 cotton wool.

Outside
 coming in

247 R: ...I always, erm, my head I get a cotton wool, I get confused, I
248 get upset, and they say, well it's not a pain in my head, it's a
249 funny feeling in my head.

250 I: Hmmhmm.

251 R: And, and I, I, can't explain but finally after me telling them, and
252 they say, "well that's not, we haven't had any reports, like that's
253 not a side effect." Whether they have had other people finally
254 tell them now, but now they, they understand that.

255 I: Yeah. Yes, and so has anything changed after they've
256 acknowledged that that's a side effect?

257 R: Just that they've put me on a lower dose instead of being on the
258 high dose...

259 I: Yeah.

260 R: ...I'm on the 7.5 milligrams.

261 I: Yes. So this feeling of telling someone this is happening and
262 not being believed and saying, "Oh but this is not..."

263 R: Hmm.

264 I: ...you know, we know that you somehow don't know have been
265 discredited.

266 R: Hmm.

267 I: But how does that impact you emotionally?

268 R: Erm, at first I'd get annoyed, I'd get angry and I'd get annoyed
269 with them, and, erm, then it has a longer lasting effect that I
270 really resent the medical profession. These are people who are
271 supposed to be treating me, they should be listening to me and
272 they're just dismissing.

273 I: Hmmhmm.

when other become a
"they"

abstract: become one
don't really vast:
objectified too
"they" (them)

Head
what is the
implication:
Body/head?
of the area

beyond words
what you are
telling is
causing a right
because we
haven't had
anyone else
telling us
"top pain"
being demand

not being
believed.

dismissal:
grip poignant
massive feeling

Resentment
angry
↓
people should
be helpful
and happy
↓
enemy.
↓
help?

I know the proof is in my body

medical prof.

lack of trust

lack of care

not certain

ulterior motives

Reclaiming what's mine

Side-effects future

Uncertainty about future

prior experience of treatment and as such

→ cancer

harmful

274
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R: And I know for a fact, I know my own body, I know for a fact and the proofs in it that when I've stopped, I've come off it for four weeks I don't have that feeling.

I: Yeah.

R: Erm, so, so, I know, and then I just resent the medical profession. Then I think they really don't care. I'm just, you know, whether it's, it's a benefit to them to push the drug or they're, they're getting, erm, you know, money for it, I don't know.

I: Yeah.

R: But it's, it's not their body. And then there's all the long lasting side effects. They always say to me, "Oh it's a very safe drug." Fair enough Methotrexate's been around for, for years and years.

I: Hmm.

R: It's probably one of the oldest, but the Infliximab, oh, erm, it's fine the side effects. They don't know, 'cause it's a relatively new drug.

I: Hmmhmm.

R: How do they know how that affects me in ten years' time.

I: Hmmhmm.

R: I had a drug years and years ago, 20 years ago, the PUVA treatment and they said it was really safe. They gave me more than a lifetimes worth of treatment and now they recognise that skin cancer's very common in people who've had that treatment. And I know three people who've had skin cancer who had PUVA at the same time as me. So I, I'm very fearful.

what proof do you need? → I know whose body it is anyway?

→ don't care

I'm not at the centre of care. it's about something else let me. → enemy

what's going to happen? Unknown future

Uncertainty about future?

prior experience safe skin cancer

Fear of future implication of treatment experienced

uncertainty.

301 Erm, the, the other, erm, major health scares I've had the blood
302 clot on my lung, the, erm, problems with my liver, the problems
303 that I think I've got with my heart, how do I know it's not from
304 these drugs.

lots of other problems
may be related

side effect

Battle.
(I have no choice)
worry.

305 I: Yes.

306 R: But what's the alternative. I keep writing lists of pros and cons
307 every week. I worry all weekend about going for my
308 Methotrexate then I try and think shall I have, shan't I.

no choice.
constant
battle →
not settled
not adjustment
→ decision
and
exhausting

who is battling who?

309 I: Yes.

310 R: And I'm like, I've got this constant battle going on in my head. I
311 don't know whether to go ahead with it or not. But then when I
312 didn't have it, I was in a real mess and I couldn't cope anyway.

worse than
didn't have
it.

313 I: Yeah. Can you tell me about when you didn't have it, you said
314 you were bedridden...

315 R: Yeah

316 I: ____ [0:15:03]. without BT:

317 R: My psoriasis was that bad, it was really, really painful.

318 I: Hmmhmm.

319 R: Erm, I couldn't get through the night. I'd have a big tub of the
320 greasiest, greasiest emollient.

attacks sleep:
"basic necessity"
no sleep:

321 I: Yeah.

322 R: Every ten minutes I'd have to plaster it on and as soon as I'd
323 put it on it would be bone dry again.

constant

324 I: Yeah, yeah.

325 R: Erm, and I couldn't sleep and it was painful. Erm, and then
326 because I literally couldn't do anything and I couldn't wash my
327 hands and everything was painful. I'd dread getting washed or

→ demanding
blood-thirsty
ingratitude

basic things
unable to do

→ disability
profound.

328 having a bath, everything was painful and once it gets bad like
329 that it's really difficult to...

bath; supposed
to be
relaxing?
→ dread

330 I: Yeah.

331 R: ...to get it better. Erm, so I, I was just in a mess. I couldn't
332 sleep, I couldn't get dressed, I couldn't wash. The cream was
333 having no effect at all. Erm, I'd be crying all the time. I, I literally
334 wanted to die because I had no quality of life.

→ unable to
do simple
things

335 I: Yeah.

336 R: So then I knew then that I needed it, that it was keeping me well
337 and yet I still hate it. I don't understand, 'cause it's doing me
338 good but I hate it. And then I'm pretty sure that with all these
339 treatments and I think it does shorten my life, so that worries
340 me.

conflicted; doesn't
understand herself

death wish
suicidal
want to die
"no life"

keeping me
well but
hate it

hate (good)
well
→ unable to
animate
the two.

→ not me.

→ Kill me.

341 I speak to other people who are on it and, "Oh it's the best
342 thing." they say. Erm, "I'd rather have a shorter happier life
343 than...", and I'm not so sure I would, and I still - the very first
344 time I went on a biologic, I was sort of forced into it. I wasn't
345 given lots of information about it. This is a few years ago, and I

pros/cons
short happy / long
misadventure

346 was told it was a different hospital to what I'm at now, basically
347 well if you don't have this treatment, 'cause I said I'm a bit
348 worried about the side effects, well if you don't have this
349 treatment, if, if the treatment doesn't kill you, the disease will.

the decision
will
go.
→ no choice

350 So virtually you got no option but to go on it. Erm, fine, that was
351 for my arthritis, but the psoriasis I much prefer the old fashion
352 treatments of the creams. Yeah, nobody likes being in hospital,
353 but I'd rather spend a month in hospital having the old
354 fashioned treatments than having all this rubbish pumped into
355 me.

Contradiction.

Conflict:
wanted to
die but
still prefer that
to "poison"
toxicity.

356 I: There's the toxics that you ____ [0:17:16]?

357 R: Yeah, yeah.

358 I: Yeah. And yet you, you'd say that it's a constant battle that
359 you're having in your head?

360 R: Hmm.

361 I: Is this, erm, can you tell me a little bit about that, is this on a
362 weekly basis, is this all the time or in the weekend, you said
363 ____ [0:17:34] weekends?

364 R: The weekend, 'cause I have my Methotrexate on Mondays, so
365 the weekend, I spend all weekend worrying and my stomach's
366 churning...

Weekend:
no leisure

367 I: Yeah.

368 R: ...because I'm dreading going to the hospital on Monday. Erm,
369 it's not even so much the injection going in, although I can't look
370 and I don't like needles...

pain
syndrome
→ not
adjustment
very painful

① needle:
② aftermath
needs to cope
fear in present
very real,
in present,
anxiety

371 I: Yeah.

372 R: ...it's the way I know it's going to make me feel afterwards.

→ better

373 I: Yes.

374 R: So then my appointment's Monday morning right at the last
375 minute I'm thinking I won't go, I won't go and that's how I get
376 myself through the morning 'cause I think I'm not going. Erm,
then I always do go, very often I go.

avoidance
of fear
→ can only
put things
morning by
putting
she won't
cyclical
repeat so
never-ending

378 I: Hmm.

379 R: Erm, and I'm always, they know me now, I'm always late for my
380 appointment 'cause right up to the last minute I convince myself
381 I'm not going, and then I do go. Erm and I rush around trying to
382 get everything done before I go because I know for the rest of
383 Monday and Tuesday I'm, I'm out of it. I can't get much done.

Fear/avoidance
problem - so
put things
one and
done with

↓
incapacitated
as result
of treatment

384 I: Yes.

X
(not
normal)

385 R: So...

386 I: Yeah. So this, this, this fear that you have you said a little bit,
387 it's not just a needle phobia which you developed as a result...

388 R: Yeah.

389 I: ...of, of you said constantly...

390 R: Yeah.

391 I: ...being probed, and, erm, but, but it's, erm, just to make sure I
392 understand you correctly, but it's, it's knowing that it kind of in-
393 incapacitates you...

394 R: Yeah.

395 I: ...and therefore thinking this is a toxic...

396 R: Yeah.

397 I:and then not wanting it. So is that...

398 R: Yeah, yeah.

399 I: ...let's say, it's the two days that that come after it.

400 R: Yeah.

401 I: ...when you are...

402 R: Yeah, my taste goes, I can't enjoy – I mean I still eat and drink *o/r enjoy*
403 but coffee...

404 I: Yeah.

405 R: ...erm, the other thing's alcohol, I don't drink a lot of alcohol...

406 I: Yeah.

407 R: ...but sometimes I think, "Oh I'd like a glass of wine with, with
408 my meal," and I'm not supposed to drink...

*Coffee
Wine*

*symbol?
wine -
enjoyment
symbol?*

409 I: Yeah.

410 R: ...while I'm on it. Erm, and erm, and then I just start to feel
 411 better Thursday and Friday and then there's never a break, and
 412 then it's gosh, you know, it's the weekend..

413 I: Then you start over again.

414 R: ...time again. So it's, you know, if it was every month or two
 415 months, it wouldn't be so bad, but I just start to feel better and I
 416 feel better in my head...

417 I: Yeah.

418 R: ...and then wham, it's back again.

419 I: Does anyone know how you feel in the, are you being treated
 420 in, erm, Birmingham?

421 R: Yeah, yeah.

422 I: Are, are the people, the team treating you, I'm assuming there's
 423 a team, do they know how, how difficult it is for you to actually
 424 even can get into hospital?

425 R: I really don't think they do know, they tend to brush it off. The
 426 lady who actually gives me my injection...

427 I: Hmm.

428 R: ...erm, she knows that I've got a n-needle phobia. She knows
 429 that I don't like coming, 'cause she's very very good with the
 430 appointment. She'll give me time but she says come along
 431 whenever you can, any time...

432 I: Yeah.

433 R: ...on that specific day. so she's very good like that. But I, I don't
 434 think they really do understand the impact it has and how much

Never-
ending
cycle
breather/
break

recovery
→ wear
cycle

symbol? relentless

If spaced
further apart
cyclical
non-stop.

Being hit again

hit: punched

Being brushed
off!
I mean
inconceivable
how can

motivation
to get help.

found a
way:
individual
strategies
personalised

Medical
profession
↓
don't understand

they →

medical
profession
has become
the other.

objectification

435 I actually hate it. Nobody's got the time, they're there to do
 436 something. She's there to give the injection.

injection

get a job done
on someone

→ objectified

437 I: Yeah.

438 R: So they don't wanna hear when you start or if you say, "Well

don't want to know

439 I've got this, I think it's from the Methotrexate." They tend to poo
 440 poo the idea and say, "Oh it can't be from Methotrexate."

I dismiss her.

441 I: Yeah.

442 R: Erm, they have started really monitoring my bloods. I used to
 443 have a blood test every two months...

444 I: Yeah.

445 R: ...they're doing it every two weeks now.

446 I: Hmmhmm.

447 R: Erm, and then my liver's been, erm, reading's been creeping up
 448 and up and they, they keep an eye on that. But they're very
 449 cagy as well like I say. "Well what is it how..." "Oh it's nothing
 450 that we're too concerned, it's just it's rising." So I'm not getting
 451 the full true picture either.

minimised
'nothing'
secret / lack
of trust
(cagy)
outside looking
in →

452 I: Yeah, yeah, and how does that make you feel, this constant,
 453 you know the, something is rising but you're not, you feel as if
 454 it's not been completely...?

outward movement

totally being kept from her.

455 R: But they're not honest with me, if they showed me and
 456 explained everything... (caucasoid parent)

↓
explain / show

457 I: Yeah.

458 R: ...then, well I don't know what choice I have but I, I like to be
 459 kept in the picture.

experience of not being in the picture

show respect
→ quite telling

460 I: Yeah.

she is not in the picture
objectified

461 R: And, and then they, when I, when I, I don't know, I was perfectly
 462 healthy apart from this when the blood clot came I thought can
 463 it be from the Metho-?

example

464 I: Yeah.

→ find on my own.

465 R: No, definitely not. And then I do research and it could be from
 466 the treatments, other people have had it and they'll just...

*Own research
contradict
what she's
been told*

467 I: Yeah.

468 R: ...deny all responsibility, "Oh it's not from that."

469 I: Yeah.

470 R: And, and I'd like them to be more open 'cause if it is, you
 471 know...

*open / casing /
secret /
no trust*

472 I: Yeah.

*By being open - I could have
had a choice.*

473 R: ...obviously all things have side effects.

474 I: Yeah.

*experienced
as being forced
no choice
in her*

475 R: I can make, I could have made the choice in the beginning as to
 476 whether...

477 I: Hmm, yeah.

The illusion of choice

478 R: ...I wanted to have it.

479 I: Hmmhmm. Yeah, absolutely. So how do you, how do you cope
 480 with all this going on? What's your...

psych. implications

481 R: Erm, I, I'm finding it at the moment very, very difficult. I'm
 482 constantly in tears. I'm constantly stressed, erm, I'm not happy.
 483 I mean next week every day apart from Wednesday I have to
 484 go to the hospital, I'm exhausted. I'm exhausted with it all.

*psychological
impairment*

485 Every so often I think I've had enough, I've had enough of
 486 everything, there's no escape from it and I just think I've had
 487 enough. And I don't get understanding. If only people

*Saturation:
enough
endless /
cancer
no understanding.*

wish a thing.

lack of understanding
and oppos
social support

social support

488 understood and I mean people around me, erm, you know,
489 something simple like they'll phone me and say, erm, "Oh, I've
490 got an appointment in two weeks at the hospital and, and then
491 I'll phone you and let you know how I get on." And I think, "Well
492 you're never interested in how I get on," or you know, they
493 never ask, they never say, "Good luck at the hospital." And then
494 when I did mention it to a friend she goes, "It's 'cause you're
495 always there. We know you're used to it and it's nothing new,
496 Amanda's always at the hospital." But it's, it doesn't make it any
497 easier.

It's become easier for everyone
else but not for me.

It's become
normal and
routine for
A's friends
but not for
me.

↓
for her there
is a relentless
battle playing
it out
weekly.

498 I: Yeah. So you find that people in your, your surroundings,
499 they've kind of gotten used to it, but you're saying but you
500 haven't gotten used to it.

501 R: No, no.

502 I: This is just, just as new. The battle that you describe...

503 R: Hmm.

504 I: ...it's just as, you know, vivid as ever. There's no getting used
505 to this you said.

506 R: Yeah.

507 I: There's, it feels like there's no end.

Endless -

508 R: But it, it's the fact that there's no end to it and then the fact that
509 I'm on this and then my body gets used to it, so then I need
510 stronger and stronger stuff.

no end
friends get
used to it
body gets
used to
it
"more"
↓
kill?

511 I: Yeah.

doesn't stop

512 R: I mean the, the infusions I'm on now, they've tried me to, to get
513 me off that one...

Everyone gets
used to it
but not A's
mind/soul!

514 I: Yeah.

515 R: ...for about six months because they're saying it's not as
 516 effective, which I know it's not 'cause it used to keep me clear
 517 for the whole eight weeks, and then I flare up badly every five
 518 weeks.

less effective
now.

→ are looking at for
her: but... not perceived that
way.

519 I: Yeah.

520 R: Then they started giving me them every six weeks just as a, a
 521 one off, you know, a special that they'd got funding or they'd
 522 agreed it. But they say I can't have it every six weeks. That
 523 used to keep us at bay. So I have two or three weeks where I'm
 524 bad, not very bad but where I'm bad but I can cope with that
 525 'cause I know when I have my next infusion I'm gonna be clear
 526 again.

several degree
of bad.

cyclical
no end
pattern to
it. Ltr
weekly (or
six weekly

Denied
treatment.

→ she can
cope bcs
next
infusion

527 I: Okay.

528 R: So I can cope with, with that.

529 I: Okay.

530 R: But they keep saying, "We want you to go on to another one
 531 now because it's not as effective as it should be," but out of all
 532 of them I don't have any side effects from the infusions and I
 533 want to stay on that. And then after the next one they're saying
 534 to me, "Well there's nothing else in the pipeline." so I've been
 535 trying to hang on because when this does stop working what
 536 else is there? Erm, I just think I've gone through them all. It's
 537 like my body's getting used to it. I'm on stronger and stronger
 538 stuff, you know. It's frightening, I'm frightened.

→ end:
then what?

More and
more:
here body
is resilient

What do I
do if stop
working
Overdose
(more
more)

539 I: It's frightening, yes. So can you tell me a little bit about what
 540 you're frightened of?

Overdose
↓
kill?

541 R: Erm, what it's doing to my body.

542 I: Yeah.

543 R: What it's doing to my body, nobody knows the, the long term
 544 side effects because they're relatively new treatments, so what
 545 damage is it doing.

*Future
worry.*

546 I: Hmmhmm.

547 R: Clearly it's knocking, whether it's the disease or the drugs, you
 548 know, where I have my infusion there was actually a poster, not
 549 a poster, a big printout of a meeting one of the specialists there
 550 had attended, they'd done a talk. And I was reading it and it
 551 said something like people who've had very bad psoriasis since
 552 the age of 15, er, tend to have, erm, their life shortened by 10
 553 years. Then somebody who's had this and psoriatic arthritis and
 554 been on these treatments can shorten their life expectancy by
 555 15 to 20 years. This is what I'm reading when I'm having my
 556 infusion. So I actually said to the nurse, it was her who was
 557 doing it and she'd done this, attended this talk, I said, "I've just
 558 read that," I said, "That's not very helpful to me." I said, "I'm
 559 having an infusion which I dread and I'm reading my life
 560 expectancy's shortened." And she sort of made a joke of it, but
 561 then when I went again it had been taken down.

*bad name
life - shortened*

symbol

insensitivity

562 They'd just, I don't know the medical profession, they, I feel
 563 they really don't give a damn. It's not their bodies, it's me. They
 564 don't care, we're just a number and they'll just treat us, you
 565 know, they wanna get the, their numbers of patients out, and
 566 they don't care. I mean that was awful.

*Medical prof.
not a
caring profession,
but of course
prod + prom
→ number/
depersonalised
→ don't care.*

567 I: Yeah. Good on you for saying something, that's completely
 568 wrong.

569 R: Hmm.

570 I: Because, because it's almost like if you have a poster like
 571 that...

572 R: Hmm.

573 I: ...from, from a medical perspective, it's like right, you know,
574 these are the facts, blah, blah, which are by the way ~~don't know~~ ~
575 the research, you'll find anything that you want. ..

576 R: Yeah.

577 I: ____ [0:27:12] who, what did they conclude these numbers on,
578 you know, there's a lot to be, you know. asked -

579 R: Yeah.

580 I: It's not always, what's a fact, you know, what, just your
581 experience, I'm sorry to tell you this, just like you say, no that's
582 not side effect...

583 R: Hmm

584 I: ...of Methotrexate, does that lessen your experience of it?

585 R: Hmm.

586 I: So, so take it with a grain^{la} of salt as we say it, but how
587 unpleasant to be reading it. I mean it's almost like this is the,
588 erm, this is the medical ^{sign} where they always looking for the
589 juicy bits...

590 R: Yeah, yeah.

591 I: ...but not consider the impact that it has...

592 R: That it has.

593 I:upon a person, because there's a person behind...

594 R: Yeah.

595 I: ...the numbers and there's this person reading this, so...

596 R: Exactly, yes.

597 I: ...well done, for saying, "Hang on, what's his, here I am, you
598 know, getting treatment...

rambling.

↓

gone into
therapy or
make
wave
to validate
her exp.

599 R: Yeah.

600 I: ...and reading this unnecessary..." There's that, so yes, I
601 understand exactly what you, I think I understand what you're
602 saying. There's, could you say a little bit more about how this
603 has impacted you, this, you think ^{it} to, you said earlier the
604 medical profession is supposed to help me, you know that...

605 R: Hmm.

606 I: ...but somehow you don't feel, you don't feel it.

607 R: No.

608 I: No.

609 R: No, and erm, little things, like a couple of years ago, erm, I was

610 going on holiday, erm, to Wales in a cottage, self-catering. I

611 can't do the injections myself. When I first went on Methotrexate

612 I could do them myself and then I had I think a couple of blunt

613 needles because I did it the same as I always do it, and I was

614 trying to jab it in, it wouldn't go in and it just turned my stomach.

615 And I, I can't do it. I'd rather do it myself, because it would save

616 me traipsing up to the hospital every week. So it's in my own

617 interest...

618 I: Yeah.

619 R: ...to do it myself, but I can't do it.

620 I: Yeah.

621 R: And then I was wasting them 'cause they couldn't, so I, I've had

622 to go every week. So I was going on holiday and I tried to

623 arrange something, 'cause if I missed two I'd be bad, could the

624 local hospital, if I took them with me...

625 I: Yes.

Holiday
OK.

↓
Violation
trying to
have
herself

Needle phobia
unable
to self-inject.

can't self-inject

self-inject
rejection
turned on
herself.

tried to
be pro-active/
solve a problem

626 R: ...could they do it. And I, I asked where they give me my tablets
 627 at my hospital, "Oh no, they won't do that, that's not something
 628 we've heard of, oh no." I can phone, nobody would help me. So
 629 the medical profession are there to help me but then they're
 630 not, because I had to go two weeks without the injection, 'cause
 631 nothing could be arranged. There's a doctor I live five minutes
 632 away from my doctors surgery, I tried to find out, find out if they
 633 could give me my injection once a week instead of me having to
 634 traipse all the way to the hospital. "Oh no, we don't do those
 635 injections." "Why? I've got them, I'll bring them." "Oh no, it's
 636 classed as a highly, erm, dangerous, highly toxic substance."

chained to
scheme.

can't help
you
local gp
can't do it
either.

toxic:

637 So again I'm having that it's highly toxic, put, idea put in my
 638 brain which makes me dread it even more, but none of the
 639 doctors will do it 'cause they don't wanna take responsibility. So
 640 it's like they're not helping me. All these obstacles are being put
 641 in my way.

holiday
again: leisure
undermined
it's hard to
be proactive
→ experienced
as unhelpful

642 And then there's the thing, all the cut backs when I go for my
 643 infusion, it's not, even the surroundings aren't made
 644 comfortable. You're sitting in an uncomfortable chair, erm,
 645 there's absolutely no privacy. They come every time before they
 646 start your infusion to ask if you've had any infections. Someone
 647 could be there, there can be two men and myself and it's just
 648 not private. There's, there's a pull round curtain, but they can
 649 hear everything. There's no privacy.

surroundings
convey how little
care

no privacy
↓
objection
↓
put on
show
display.

650 I: Hmm.

651 R: And you're having your injection there, er, your infusion, there's
 652 no privacy. The, the whole what used to be the skin ward, has
 653 just been taken over. It's all managers' offices, and it's always
 654 dermatology and rheumatology are just shoved down in the
 655 corner and there's like three upright little chairs that you have to
 656 sit on to have your infusion. It's not comfortable, it's not
 657 pleasant surroundings.

symbol of
disregard!

designated

3 chairs
↳ infusions

658 I: And not private as you say.

659 R: Not private.

660 I: So is it quite, it's a very private moment...

661 R: It is.

662 I: ...isn't it, experience, you have to share something...

663 R: Yeah.

664 I: ...quite, you know, private with someone...

665 R: Yeah.

666 I: ...and the trust is not really there.

667 R: Yeah.

668 I: ... is that what I'm hearing, and then you, everyone can hear.

669 R: Everybody can hear, so if you have had any, any infection...

670 I: Yeah.

671 R: ...you know, and, and this is like a trained senior nurse, you

672 know, surely you can...

not even in a room.

673 I: Yeah.

674 R: ...but there are no rooms apart from her office, even then

675 there's a big gap, that it's not...

leaves not air-tight.

676 I: Yeah.

677 R: ...that it's not door to the ceiling, there's a gap, so they can still

678 hear.

679 I: Yeah.

680 R: But to be asked if you had any infections, if I have I don't want

681 to discuss it with a nurse in front of other patients.

*exposed
vulnerable
lack of privacy*

}

"On stage"
vulnerability
Exposure.
performing
in front
of strangers

wineable, exposed dependent
fearful, her grown up
on stage
vulnerability

682 I: Yeah.
683 R: And then because I'm such a coward and a baby with my
684 cannula I'm there like crying or making noises when it keeps
685 popping out and it's painful and I'm having to do that in front of
686 people. There's just no privacy, there's no, it's just...

687 I: How does that impact you having to do that, go through the
688 emotions like that in front of other people?

689 R: Well I get, I get really embarrassed. I get embarrassed if, the
690 one time there was somebody there having an infusion for the
691 first time, they shouldn't have to see and listen to me
692 performing when it's their first time and they're probably scared.

care for
other too
otherness?
thinking of
others & has
she affect
other.

693 I: Hmm.

694 R: But it doesn't take somebody intelligent to recognise that what's
695 going on with, with the health things. The other thing that gets
696 me when I go to rheumatology, erm, every week for my
697 injection there's all these posters all around the, the clinics and
698 the wards, you know, erm, rheumatoid arthritis, lupus,
699 osteoarthritis, it's all these leaflets for arthritis, there's never
700 anything for psoriatic arthritis. There's, there's nothing. There
701 must be other people with it.

Ignored -
no information
compared
with other
similar
diseases

reflected
stain
alone
isolation
invisible

"Am I the only person in the world?"

702 I: Hmmhmm. Yes. So, so you feel there hasn't been a lot of
703 support, am I right...

704 R: Hmm.

705 I: ...in the, have you been, have you, have you had any, erm,
706 have there been any offers to meet other people with psoriatic
707 arthritis, have you been offered, have you had any help apart
708 from just medical treatment?

no support

709 R: No.

710 I: No.

Nothing for psA patients

711 R: No, no. There's nothing. I mean there's even a poster on the
 712 wall or if you got rheumatoid arthritis or another type of arthritis,
 713 erm, you can come along to, to this swimming pool and that, but
 714 never psoriatic arthritis.

715 I: Have you mentioned this to anyone in your ward that have...?

716 R: Erm, I, I did say cause, erm, there was, there's somebody who
 717 comes in to do research there, and, erm, I did collar him and
 718 say, "Now how come there's never anything for psoriatic
 719 arthritis?" He said, erm, "I am working on it, very seen we hope
 720 we'll, we'll be able to start something up and maybe get a grant
 721 to look into it."

understand
 care given and
 ignored

722 I: Okay.

723 R: And the other thing was, erm, when I went to A&E last year I
 724 was getting terrible chest pains. Now I get a lot of arthritis in my
 725 chest and again it's the not being believed and being ridiculed
 726 by the medical profession. Erm, and I know I get very tender
 727 around there and I get pain but this was a different pain, and I
 728 did think it was my heart, it was a different pain. So I went to
 729 A&E, I'm explaining my symptoms, and, erm, and I said, "You
 730 know, I am very tender anyway, you know I get arthritis there,"
 731 "You don't get arthritis there." And this was a doctor, and the
 732 nurse laughed at me, "You don't get arthritis there," and I was
 733 saying, "Well actually I do, I get it in my rib cage, I get it here."
 734 And they just laugh at me, "You don't get arthritis there." Even
 735 the medical profession aren't aware of it.

laughed at
 ↓
 heart palpitations
 ↓
 ignorance

736 I: And how does that make you feel?

737 R: Erm, I can't even, I can't even put it into words. It, it, it just, I, I
 738 can't explain it. It affected me that badly I can't even find words
 739 to, you know, again it's not being believed.

impact of
 strength help
 ↓
 beyond
 expression

740 I: Yes, ho-how have you coped with not being believed, with not
 741 being heard, with ^{then} not being someone saying, "Okay
 742 Amanda... ² how would you, how do you manage that?

huge for
validation

743 R: Erm, I don't think I have coped because then it does, erm, start
 744 to affect my, my personal relationships because it could be
 745 something, over something absolutely minor, so between me
 746 and my partner, erm, and I've got this big thing at the moment
 747 that I'm not being believed. Now it's fine, normally, under
 748 normal circumstances, "Oh I don't agree with you," or, or joking,
 749 "Oh that didn't happen, "and it, and I just flare up, "You don't
 750 believe me," and it's like, for years not being believed. And it's
 751 so important to me to be believed and so it's become, erm, I
 752 can't think of the word, erm, in a way my behaviour's become
 753 irrational because it's like all blown up out of proportion that I'm
 754 not being believed.

impact on
personal
rel. ships

become an
issue

→ explosion

sensitive
impact of
not being
believed

755 I: Yeah. So not, not being believed has actually had an impact on,
 756 on your personality...

757 R: Yes.

758 I: ...and the way that you respond to minor...

759 R: Yes.

760 I: ...minor things...

761 R: Yeah.

762 I: ...which could be from what I'm picking up like a little joke or
 763 something...

764 R: Just a little joke but, yeah.

765 I: Yeah. Hmmhmm. Do you, do you remember, erm, an example
 766 of this taking place of how, how you recognise this ^{is} irrational
 767 but yet you feel, you feel it don't you, you feel this...?

768 R: Yeah, yeah, there was, erm, there was something, I can't even
 769 remember what it was about, but there was something at the
 770 weekend, I ended up having an argument with my partner
 771 because I said, "You don't believe me, you don't." He said, "It's
 772 not that I don't believe you." I said, "You don't believe me, do
 773 you." And then he said, "What's all this about," 'cause I'd gone
 774 over the top and then I just broke down and said, erm, "Nobody
 775 ever believes me." And, and I was in tears and, you know,
 776 nobody ever believes me.

*trigger was
obviously not
important*

*The impact
of not being
believed /
seen / heard*

*heard → exposed
to →*

777 I: Yeah. Yeah. Is there any, how would you, from what you're
 778 telling me, how do you think you can be helped and there are
 779 probably many others in your situation...

780 R: Hmm.

781 I: ...because psoriatic arthritis is very under researched..

782 R: Hmm.

783 I: ...and probably neglected...

784 R: Hmm.

785 I: ...as it's a neglected area of study.

786 R: Hmm.

787 I: I can barely understand why actually...

788 R: Yeah.

789 I: ...because psoriasis is very well researched.

790 R: Yeah.

791 I: That's now recognised...

792 R: Yeah.

793 I: ...as a very serious illness. Arthritis, especially rheumatoid
794 arthritis...

795 R: Yeah.

796 I: ...is recognised as a, as a very serious illness that can have
797 a...

798 R: Yeah.

799 I: ...big psychosocial impact...

therapy needs

800 R: Yeah.

801 I: ...on, on people's lives, and yet you have these two coexistent,
802 er, conditions...

803 R: Yeah.

804 I: ...and no one has really looked at it.

805 R: Exactly. Yeah and from my understanding, only what I've read
806 and found out myself, 'cause nobody tells me anything,
807 psoriatic arthritis is similar to rheumatoid arthritis.

*alone / each
of informative*

808 I: Yeah.

809 R: Now as you say that that's a serious disease, it can affect a
810 lot of things, and psoriatic arthritis is, is quite similar.

811 I: Hmmhmm.

812 R: So I've forgotten what you asked, what your question was.

813 I: Actually I just wanted to validate that you're right...

814 R: Yeah.

815 I: ...you're right in this.

816 R: Yeah.

*Lack
of information
no one
tells me
anything*

817 I: My question was what do you think would help you or others in
818 your situation?

819 R: Er, for, for the medical profession...

820 I: Hmm.

821 R: ...GPs, everyone to be far more aware, er, for the doctors and *ridicule*
822 nurses in hospitals *instead of laughing at a patient and saying, "We know better"*
823 "You don't get arthritis there," erm, and you say, psoriasis is *awareness*
824 very common so you'd think that everybody would be more
825 aware. And I remember when this probably started, I'm 48 and
826 it was when I was about 20, so it's 28 years ago, erm, I
827 remember going to my GP, feeling ill. And it would be, I'd get up
828 in the morning, I'd wake up and I'd feel like my body had gone *disoriented*
829 through a fast spin in the washing machine and it ached and it *up/down / full speed*
830 was, I was exhausted. And I kept going with these symptoms *misdiagnosis*
831 and, er, he said it was, erm, it was probably ME, a mild form of
832 ME. And I think now looking back that is when my arthritis first
833 started, because you know, and that was so 28 years, but it
834 was, it was the tiredness and just feeling generally under the *general fatigue: unwellness*
835 weather. No specific aches and pains but just generally and I
836 think now that that's when it first started.

837 I: Yeah.

Long time for diagnosis
838 R: So it, it took a long time for it to be diagnosed and then it started
839 getting worse and worse. Erm, and the other side of it as well,
840 doctors aren't aware of it, erm, I've always worked, all my life
841 until I, until I got quite ill with my psoriasis and arthritis. Erm,
842 and I've worked ever since I left school and I couldn't physically
843 do it, and just with my hospital appointments, so alone I couldn't
844 do it. Then I tried part time and I couldn't do it.

845 I: Hmmhmm.

846 R: And then I have someone say to me, erm, 'cause they've got, I
 847 think osteoarthritis and, "Well why don't you work just 'cause
 848 you got psoriasis or just 'cause you got arthritis." I'm not a lazy
 849 person, if I could I would. And then it's the whole benefits side
 850 of it. Erm, I'm not a scrounger and I applied for benefit 'cause
 851 when I'm bad I, I can't, and again it's not, it's not recognised.
 852 It's, oh it's just a skin disease, psoriasis is just a skin disease,
 853 oh a bit of arthritis, erm, you can do this to help yourself. But it's
 854 the feeling of tiredness, feeling unwell. You know, some days I
 855 can't do the simplest of things and, and I think it's not
 856 recognised within...

857 I: Hmmhmm.

858 R: ...the, the...

859 I: Yes.

860 R: ...benefit system as well.

861 I: There's a misconception that you meet from both friends,
 862 employers, and medical doctors.

863 R: Yeah, yeah.

864 I: So will it be fair to say that you find that this misconception of...

865 R: Yeah.

866 I: ...is, is all around?

867 R: Yeah, I'd just love to raise awareness of it all but it's, it's such a
 868 massive thing.

869 I: Well thank you because that's what you're doing now.

870 R: Hmm.

871 I: You're taking one step in, yes, that's exactly...

872 R: Hmm.

fear of
misunder-
standing,
being
labelled
'lazy'
and
scrounger

↓
worried
about being
seen as
such.

↓
"I'm not like this"

misconception

underesti-
mated
misunderstood

→ all-
encompassing

another system
that doesn't
know

Misconception
lack of knowledge

Awareness:
knowledge/
research

- 873 I: ...yeah, you're doing it right now. Thank you so much for
874 sharing this. We're not done yet, I just wanted to say...
- 875 R: Hmm.
- 876 I: ...this is so important...
- 877 R: Hmm.
- 878 I: ...that someone comes out and...
- 879 R: Hmm.
- 880 I: ...yes, that this is done. Yeah, so I was gonna ask a question
881 which I now forgot, something you just said, you were saying
882 that, erm, the awareness of it, hmm, right you were saying
883 when you were first, er, diagnosed, did you have psoriasis first?
- 884 R: Yeah, I've had psoriasis since I was about two, which started
885 just a tiny patch on my arm.
- 886 I: Hmmhmm.
- 887 R: As I got older it spread and spread and got worse. So I did
888 have psoriasis first...
- 889 I: Okay.
- 890 R: ...and then this happened with the, the tiredness and just not
891 feeling well...
- 892 I: Yeah.
- 893 R: ...when I was about 20.
- 894 I: Yeah.
- 895 R: Erm and it must have slowly progressed, erm, it went away for
896 a bit first and ...
- 897 I: Yeah.

898 R: ...it came back, went away, and then came back...

899 I: Yeah.

900 R: ...an then different things were happening. I'd get pains and,
901 erm, you know, I had an operation last year on my knee and,
902 erm, it, it's, it's just gradually got worse.

903 I: It's just gradually got worse. Okay, so could you tell me a little
904 bit about what it has been, you know, how psoriatic arthritis has,
905 has impacted your life, what you've been able to do? You
906 mentioned the tiredness, you mentioned the...

907 R: Hmm.

908 I: ...the pain, but could you give me some examples of, of...

909 R: Yeah, I mean, erm, people make light of it and say, "Oh well
910 you're getting older, it's your age." But I know it's not, 'cause I'm
911 48, I've had it for some time. Like I used to be able to clean the
912 whole house, erm, in a day, and then it was half the house in a
913 day. How I am now and I have been for the last two years, the
914 house, the housework, I, I'm really snowed under. I don't think, I
915 couldn't even let anyone in my house, it's so bad, because I
916 can't even do a room in a day now. I do part of a room. I just
917 can't, so, so I'm behind with everything.

918 It, you know, some, sometimes it just takes all my effort to
919 either cook a meal or to make a drink. So this is how I've got in
920 a mess. It takes all my energy, all my effort to get, I know it
921 sounds so stupid, to get a cup, to make a drink and then I just
922 put the mug there and leave it and then something else. I'm just
923 so exhausted all the time. Erm, and then it all mounts up, and
924 then I can't get on top of it, so the tiredness and that's...

925 I: What happens, you lie down, you have to lie down or you...?

0%
normalisation
misconception

Housework
symbol of
progression/
degradation

Unable to
do simple
tasks: clean,
cook, drink

↓
exhaustion
fatigue

natural
app

change from
symbol of
progression
to a sign
of a decline

House ~ sign
of a decline

embarrassment
→ what does
it mean to
be behind
with everything?

all energy
all-consuming

Fatigue
→ stops life
stupid: outside
looking in.

926 R: I don't lie down, I sit and rest, erm, and again I can't sit for long
927 periods because then I stiffen up and so I do a mixture of sitting
928 and pottering about.

no escape -
no lying down

929 I: Hmmhmm.

930 R: But I can't actually, and then even like tiredness, I'm tired in my
931 head, so even if I physically got the energy I'm just not getting
932 anywhere, not thinking. Erm, so I just get behind with it all and
933 I'm, I'm just tired.

mind/body
two voices

physical energy, mind's tired

934 I: Hmmhmm.

935 R: Erm.

936 I: Yes.

937 R: I've forgotten what you, what you asked, I was gonna lead on to
938 something and now I've forgotten.

939 I: I just said how it's impacted you, you could give examples of
940 how psoriatic arthritis has impacted you...

941 R: Yeah.

mind can't override body

942 I: ...and you said, yeah.

943 R: Yeah, and it also makes me, erm, very tearful and frustrated. I
944 get so annoyed with myself because I can't, sometimes my
945 mind's willing and I think, "Right I'm gonna do this today and
946 this today," and I can't, I end up not doing it. I try but I just don't
947 get anywhere. And then I get frustrated with myself and think I
948 should be able to do it. I'm 48 years old I should be able to do it,
949 and I always used to try and fight it in the beginning, instead of
950 giving in to it, I'd try and fight it. So then on good days I'd, I
951 couldn't pace myself, while I'd got a good day I'd try and get
952 everything done and then that would set me back even further.
953 So in the beginning it was difficult to pace myself, now I've just

outside looking in

separation
mind/body

self-beating
give up the fight

crash everything
in: make next
of it.

get excited
held back
full speed.

954 gone passed it, 'cause I'm just getting nowhere fast in
955 everything...

956 I: You got what, sorry?

957 R: I've just gone passed being able to pace myself, 'cause I'm just
958 in such a muddle now. Erm, so it makes me tearful and upset.

959 I'm frustrated, I get annoyed with myself. Erm, and before I got
960 this bad, when I was a teenager, I found I could never do two
961 things. Like if I was at school, I couldn't go out in the evening as
962 well and I think that was like tiredness. If I had to go out I
963 couldn't do anything that day and I'm very much like that now.

964 You might think like one hospital appointment going up, people
965 say to me, "Well you're only at the hospital for an hour," but...

966 I: Hmmhmm.

967 R: ...I'm exhausted and I have to gear myself up to it and then I'm
968 exhausted, so...

969 I: Yeah.

970 R: ...I find it hard doing two or three things on the same day.

971 I: Yeah. So you almost have to pick the thing that you're going to
972 be doing that day...

973 R: Yes.

974 I: ...and not put too much in.

975 R: And not put too much in, yeah.

976 I: Yeah, yes.

977 R: Yeah.

978 I: Yeah. So, erm, what you've just described now, this is while,
979 this is, erm, not being able to clean the house and having to sit
980 down.

stopped trying?

early signs

Impact of fatigue

exhaustion/fatigue
→ avoid looking

981 R: Hmm.

982 I: This is, erm, this is when you're on biologics right?

983 R: Yeah, when I'm on them, yeah.

984 I: Yes, so and you said you had that time two years ago where
985 you hadn't, how come you stopped, was it because you had
986 enough or...?

Rebellion: 987 R: I, I'd had enough so, erm, I just didn't go, erm, I didn't go, I don't
988 think I even phoned them, I didn't go for my injections, so I
989 missed four Methotrexate injections.

rebellion
→ didn't even phone

990 I: Right.

991 R: And then I was in a real mess.

992 I: Right.

993 R: So then I started going again.

994 I: Yeah.

Conflict - a scary friend
995 R: But without it, I'm in even, I am worse, so in a way the bio-
996 biolog-biologics are keeping me going.

: friend in a way:
but what kind of
friend.

no choice there.
997 I: Yeah.

998 R: So I would be worse without.

999 I: Yes. So you said you were worse, could you, could you
1000 describe that, how, how you were worse?

1001 R: Erm, physically, like I was virtually bedridden, with, with my skin
1002 and then my, my joints as well, swollen and I couldn't grip
1003 things.

before:
bedridden:
↓ ↓
skin joints

1004 I: Yeah.

1005 R: Erm, you know.

- 1006 I: Yeah. Yes. So you remember that as well?
- 1007 R: Yeah.
- 1008 I: That ____ [0:27:12] and I think from what you say that's a
1009 constant battle...
- 1010 R: Yeah.
- 1011 I: ...knowing that it actually does get better but...
- 1012 R: Yeah.
- 1013 I: ...having come to loath it at the same time.
- 1014 R: Yeah.
- 1015 I: And I think you said in your own words it's like you don't have a
1016 choice.
- 1017 R: I, I don't have a choice.
- 1018 I: Yeah, what does it feel like not to have a choice, how does this
1019 feel?
- 1020 R: Erm, well its 'like, I say to my partner, er, and I convince myself
1021 right up until the last minute that I'm not going and then he'll
1022 say, "Don't go then." He says, "You've got a choice, no one's
1023 forcing you." And I say, "But I haven't got a choice, I don't have
1024 a choice, what's my alternative. I'm, I'm in a mess again." And
1025 then he'll say, "So go and have it." And then I say, "I don't want
1026 it." And I'm very very short tempered all the way, on the way to
1027 the hospital 'cause I really don't want to have it.
- 1028 I: Hmm.
- 1029 R: And then it's like I, I don't feel - I strive to be normal to just, to
1030 be normal and I'm, I just want to have a normal life. I would go
1031 to work or to be able even to do nice things, go shopping, I

Battle for
choice

x

battle:

child:
yes/no
no choice:

→ angel:
what's
the PD
interpretation
of angel?

all I ask:
"normal"

not asking
the world

1032 don't even have time to do nice things or the energy to do nice
1033 things. I just want to have a few normal days.

1034 I: So do you think, you know the, the time that you have to spend
1035 as you said...

1036 R: The time, yeah.

1037 I: ...constantly going to hospital appointments...

1038 R: Yeah.

1039 I: ...and yes, I think you described that very well when you say.
1040 You mentioned quality of life before...

1041 R: Hmm.

1042 I: ...what does quality of life mean to you? What does it, when
1043 you say quality of life, what, what would that be literally?

1044 R: I'd like, I'd like to get up in the morning, feel well, feel refreshed,
1045 erm, get dressed, be able to go out shopping, walk from, all
1046 round the shops for hours, I'd like to be able to do that. And,
1047 erm, yeah on one hand the bio-, I can't say it all of a sudden,
1048 my biologics have helped me do that, erm, they help me walk a
1049 bit further, less pain in my joints.

u walk a
bit further -

1050 I: Hmm.

1051 R: But then I still can't, I still can't do, it doesn't cure it. It makes me
1052 better, but then I've got the side effects where I lose virtually
1053 two days a week and then every six to eight weeks I have my
1054 infusion and it's just...

cyclical
nature
endless

1055 I: Yes.

1056 R: ...I just get tired with it all.

1057 I: Yes. Yes.

1058 R: But then if I don't have it then I, I'm in even of a state. So you
 1059 think that, and, and this is where I get frustrated with myself,
 1060 you think it'll be clear cut, no, no decision to make, that I'll just
 1061 go ahead and, and accept all the, erm, treatments gladly, but I
 1062 don't. I can't. I-if there was an end to it, like if it's a broken leg,
 1063 you know you'll be in plaster for however many weeks or
 1064 months or whatever it is but there is no end to this.

at odds
loony

acute illnesses;
chronic
no end.

1065 I: Hmmhmm. Yeah, and how do you think that impacts you, this
 1066 feeling that there's no end?

1067 R: It, it, it does affect me. It's, I want to, I want it to stop, I want an
 1068 end to it all. And this, and this is why every so often I suddenly
 1069 stop having my treatment 'cause I have it right, I'm full of it and
 1070 I've had enough of it, so I'm...

1071 I: When, when you're full of it, when you've had enough of it, how
 1072 does, what does, what's that like, is it just...?

1073 R: It's, it's just I can't face going, I just can't face going. I was
 1074 supposed to have had my Methotrexate yesterday, didn't go,
 1075 couldn't face it. I knew I'd got a busy, it wasn't just that I'd got a
 1076 busy day today, if I'd had it yesterday and come 'cause I was
 1077 seeing...

1078 I: Yeah.

1079 R: ...the, the other lady, I can't think, I can't answer questions. I
 1080 can't think, I can't get up in the morning, my head's not right.

1081 I: Hmmhmm.

1082 R: And it just, the weeks come so quickly and then I get over it and
 1083 it's time to have it again.

1084 I: Hmmhmm. Yeah, yeah.

reclaim
right to
choice

can't face
it

skipped her
dose in order
to be 'normal'

endless
cyclical
Relentless.

1085

R: And I think partly because I've got all these hospital

1086

appointments next week it's just like, I just want a breather. I

1087

just want time out.

*that's looking
an B10L.**a breather
→ not possible
: end of cycle*

1088

I: Hmm. Hmmhmm and I know I think I might have asked this, you

1089

know, before but, but it just seems so, erm, no one's aware that

1090

you fee-, do, do they know how much you struggle just going to

1091

the appointments and you've never been, have you, have you

1092

been offered any kind of, you know, help, support, dealing with

1093

all this?

1094

R: No, and I'm, no, again, the medical profession, no. It's like no

*comes eyes/
ear*

1095

one wants to know. They, they ask me when I have my

→ superficial

1096

Methotrexate, "Oh how are you?" And I'd tell them, but it's all

1097

like service. They don't really take note, they make light of

*don't commit:
answer not heard
'being served in
& stop by a stranger*

1098

everything. I've been to my GP a couple of times, I went about

→ proactive:

1099

three weeks ago in tears and I said, "I'm, I'm fed up, I'm

1100

exhausted with all this, I'm sick of my hospital treatment." Erm,

1101

"Oh you're just going through er, a bit of a downer, everything's,

*normalise
it / feels like
disregard?*

1102

er, on top of you, and, erm, you have got lots on, but erm, you

1103

know, just stick with it, normally you can cope," and, and that's

1104

it. But...

1105

I: Hmmhmm.

1106

R: ...no, no advice, I don't know what they can do but nothing and

*→ no choice
→ nothing can do
- is that so?*

1107

I come away gotta deal with it on my own again.

Being alone.

1108

I: So dealing with on your own...

1109

R: Yeah.

1110

I: ...dealing with it on your own...

1111

R: Yeah.

1112

I: ...that seems to be...

1113

R: Yeah.

1114 I: ...yeah, quite representative...

1115 R: Hmm.

1116 I: ...from everything you've told me...

1117 R: Hmm.

1118 I: ...that - is it, is it, is it true that or is it right to assume you, you
1119 have felt very alone?

1120 R: Very, yeah, there, there's no one, I mean I wanted to get some
1121 sort of independent advice years ago...

1122 I: Hmmhmm.

1123 R: ...about all these bio-, all these drugs, whether to go on them or
1124 what. You can't get independent advice. The only people
1125 advising you are the people who are pushing the drug, who
1126 want you to have it or the GP who says, "Well yeah, the, the
1127 hospitals recommended it." But I want some sort of independent
1128 advice or somebody to say, "Well these are your options."

1129 I: Yeah.

1130 R: "This causes this side effect, this this," and, and give me the
1131 information and the time for you to go and read and...

1132 I: Hmmhmm.

1133 R: They, they kept a lot back from me on, on the side effects of
1134 these things. They, they don't tell you and then it's only after
1135 you've been on it for a while that...

1136 I: Yeah.

1137 R: ...things come to light, "Oh yes it does do that, oh yes," erm.

1138 I: Yeah.

grant: let's see if we can
get this for you.

what does
independent
advice mean.

in bed with
the enemy

people who
think you
are biased
reaction

Scary: what it
feels like
to be AH
- 1950's
exp. type

experiment
(scary)

in white
coats.

→ unethical

~ see what happens

scary!
don't tell
you

experiment

↓
dope cliff d.

↓
terrifying

1139 R: Suddenly now a classic example is one of the drugs, I don't
 1140 know whether it's the Infliximab or the, er, Methotrexate, every
 1141 time I went for my dermatology appointment, erm, they'd say,
 1142 "Have you got any on you, on your back?" And I said, "No, it's
 1143 only my legs and arms."

1144 I: Yeah.

1145 R: "Well let's have a look, take..." I said, "I haven't got any." "Let's
 1146 have a look,2 and they'd look and they'd say, "Oh you're clear."
 1147 And then one time it wasn't my normal consultant, it was a
 1148 student doctor and she said, "Let's have a look at your back." I
 1149 said, "I haven't got any psoriasis on my back." "Oh well we need
 1150 to look because, erm, you do understand the importance of
 1151 checking for skin lesions because you're prone to skin cancer
 1152 on the treatment you're on." This is what a student doctor said
 1153 to me, so that was the reason the consultant wanted to check
 1154 my back. They're not honest. She wasn't honest with me and I
 1155 had the shock of my life when the student doctor had said, "Oh
 1156 well you, you do understand the importance of checking for
 1157 lesions." No, I didn't know. No, I didn't know it caused skin
 1158 cancer.

1159 I: Hmm.

1160 R: So I come away, have all these shocks and I come away and
 1161 I'm left to deal with it on my own. So then I start looking on the
 1162 internet, ooh can it cause cancer and then I find all this
 1163 information on the internet. I've gotta deal with it all on my own.
 1164 They're not honest. I'm really starting to resent and detest the
 1165 medical profession.

1166 I: Hmm. Yeah. So you're saying you, you would rather have all
 1167 the information.

1168 R: Hmm.

truth from
evidence

Shock.

Keep information
front then

when info is
made adjustment
is not possible.

detective
a deal on my own -
shot at:
internet when
she finds for
info.

internet:
wild west:
→ what you
turn to
when lost.
→ makes
it worse.

isn't this
what is
actually
recommended:
pro-active
solution-focused
coping
(seems to be
denied her)

1169 I: I actually think that, you know, going to, with no one is static, we
 1170 go through different phases in life. Sometimes we're stronger
 1171 than others and we want all the information to deal.

my own
stuff:
↓
here

1172 R: Hmm.

1173 I: Sometimes we don't wanna know...

I wish I
hadn't known.

1174 R: Hmm.

1175 I: ...but it's very tricky I think probably as a doctor to negotiate
 1176 this. Er, you know, what do you say, what don't you say, but it's
 1177 finding out what the patient needs to hear and what can help...

1178 R: Hmm.

The right to
know

1179 I: ...you know, best and you seem to...

It's my body
I have
the right to
know

1180 R: Well to me the patient has the right to know, I have the right to
 1181 know.

Knowledge

1182 I: Yeah, it's your body as you ^sday.

1183 R: I'd rather, it's my body, it's not their body.

1184 I: No.

1185 R: I'd rather, I'd like to know everything...

1186 I: Yeah.

1187 R: ...and then and then weigh up the pros and cons...

informed
choice
my body:

1188 I: Yeah.

1189 R: ...and then it's my, I don't like to have a treatment and then,
 1190 erm, and be told it's fine and then have it over lifetimes worth of
 1191 treatment of it...

I don't
like being
lied to.

1192 I: Yeah.

↓
see the
medical
profession
as dishonest
liars

Kept in the dark

AH/15/12/2014

1193 R: ...and then to be told oh you'd probably get skin cancer, that
1194 isn't fair. I'd like to know.

1195 I: Yeah.

1196 R: And again it's the thing which I've said all along from years ago
1197 before all this psycho dermatology started...

1198 I: Yeah.

1199 R: ...you've got to treat the patient as a whole. It's not just treating
1200 the skin or just treating the arthritis. You gotta look at
1201 everything, how people can cope, how they can cope around
1202 the house, there's nothing, there's nothing.

1203 I: There's nothing. Erm, you were referred here, how did you find
1204 about...

1205 R: That was all down to me. I read an article in the Daily Mail
1206 about three years ago I said to, erm, dermatology where I go,
1207 "Look, you know, is there any sort of, erm, erm, help I can get
1208 like, erm, cognitive behavioural therapy for me to cope with,
1209 with my treatment, some and to try and help me accept my
1210 condition?" "Oh no, there's nothing like this. You, you could go
1211 somewhere privately, you could do this, do that."

1212 And then I read an article in the Daily Mail about the work Dr
1213 Musira had done. It was a case study, this man and it was so
1214 similar to me, and I thought that's what I want. So I went
1215 to the dermatology and I said, "Look, I really I've tried
1216 everything, I really have a good feeling about this, I'd like to try."
1217 "Go to your GP." Now to me they're, they're treating me, it
1218 would save them money, they're treating me, surely they could
1219 have referred me, go to your GP.

1220 So I go to my GP, thank goodness, I've got a good GP and he
1221 didn't hesitate. He read the article and he referred me. Now not
1222 many GPs would have referred me to, to London and he did

Kept in the dark

not being
seen;
not just
skin
gone
no holistic
treatment
'nothing'

pro-actve
asked for
CBT (not available)

no help from
dermatology

→ displaced

GP: good

1223 thankfully. Erm, so that's how I've, I've got this, but I'm having
 1224 to fight all the time. Why should I fight, why isn't stuff offered to,
 1225 for treatments for things. So again skin, rheumatology just wash
 1226 their hands.

1227 I: Hmm, okay. So there's nothing like that from where, where
 1228 you're based?

1229 R: There's nothing apparently in Birmingham or West Midlands.

1230 I: It's just medi-, okay, so it's, so it's, er, treatment just consists of
 1231 the medical profession...

1232 R: Yeah.

1233 I: ...it's a purely bio medical intervention...

1234 R: Yeah.

1235 I: ...with no, erm, you know, consideration...

1236 R: Yeah.

1237 I: ...for the person behind that....

1238 R: Yeah.

1239 I: ...would that be the correct...

1240 R: Yeah.

1241 I: ...way of putting it.

1242 R: And I've tried, you know, the other thing I find very, very helpful
 1243 for my arthritis is massage.

1244 I: Hmmhmm.

1245 R: Now I'm not working, I can't afford to, to go. Now it-it's beneficial
 1246 to my arthritis...

1247 I: Hmmhmm.

Fight:
collagen

not their problem
(only booked
goals)

my thyroid
experience

massage

extracurricular

✓ Despair: that it's like to be at the mercy
of people you don't trust..

15/12/2014

1248 R: ...massage, you can't get that, you can get it now the, the
1249 medical profession are accepting things like acupuncture now,
1250 they're more open to things like that.

1251 I: Hmmhmm.

massage: nothing
fancy about
that.

1252 R: But I still can't get massage which is beneficial for arthritis.

1253 Luckily, I'm getting hydrotherapy because of my knee operation

1254 I had, I'm still having hydrotherapy but that's beneficial for my

1255 psoriatic arthritis. That makes a world of difference.

"Hydrotherapy"

1256 I: Yeah.

hydrotherapy
around the
knee. int.

alternative
treatments

1257 R: Things like that should be, that should be treatments available
1258 to people.

1259 I: Hmmhmm. Yes. I couldn't agree more, I couldn't agree more.

1260 Erm, so just to, erm, kind of, so if you look back, if you take your

1261 consideration and your experience into consider-

1262 consideration...

1263 R: Hmm.

1264 I: ...everything you told me today...

1265 R: Hmm.

1266 I: ...and erm, what would you like to be made available? If you

1267 could wave a magic wand what would you like, what, what

1268 would help you and others in, in your situation, have, who have

1269 psoriatic arthritis?

1270 R: Erm, I definitely would like there to be more awareness for, for

1271 GPs and doctors and everything to, to be aware of the

1272 condition. I'd like something like, erm, a clinic, erm, in the

1273 rheumatology department, whether it be, erm, a group of people

1274 meeting together or, a, a clinic for psoriatic arthritis patients.

The importance
of social support
meet others
line herself.

social support

research
quite clear
in the benefits
of social support
(quite easy)

1275 I: Hmmhmm.

1276 R: Erm, I'd like, I'm asking the impossible because I know you
1277 don't get it for other things, but alternative treatments available
1278 for people.

help

1279 I: Hmmhmm.

Choice

1280 R: I'd like more information, erm, on the biologics and the
1281 treatment, erm, er, so that the person and it can weigh up
1282 whether they want to go on it.

 information
↓
patient to
enable
choice

1283 I: Hmmhmm.

little things
could help!

1284 R: I'd like things to be made easier, so instead of all these blocks
1285 put in your way, like save me going all the way to the hospital,
1286 why can't a doctor administer that treatment. They're even on
1287 about doing chemo for cancer patients in their own home. Why
1288 do, what, I feel like everything's been made twice as difficult for
1289 me when it's difficult enough anyway.

avoid hospital
more personal.

blocks.

1290 I: Hmmhmm.

1291 R: And why couldn't, if I'm away in this country, couldn't I take an
1292 injection to a hospital, because when I was on Warfarin I was
1293 able to go to a hospital in Wales and get my bloods checked out
1294 of my area. Why couldn't somebody have administered that
1295 injection?

 "Locked-in"
Can't go
anywhere
or miss
inf.

1296 I: Yeah.

1297 R: I'd like things to be made easier. It's, life is difficult enough as it
1298 is.

blocks.

1299 I: Yes. Absolutely.

1300 R: And maybe the other thing I'd like is when you have all these
1301 nasty horrible side effects, like for people with, erm, er, faradics,
1302 they, they can go along to certain centres and have, erm,
1303 aromatherapy massage or yoga or different things, there should
1304 be things for, for, available like that.

cancer

 what's
available to
others with
serious
disability
disorder

1305 I: Hmm.

Companion
again

→ relevant ~ that's how she sees herself, but not others: can't die from it like cancer

1306 R: You know, and for, for people receiving chemo or cancer they
1307 have like, erm, I've seen a, a notice up today if you're on
1308 chemo, erm, pamper days and things like that. There should be
1309 things like that.

1310 I: Yeah.

Not being
recognised as
serious
ad recognition

1311 R: It, it is a serious illness and it just gets you down, makes you
1312 feel run down. There should be things to help along the way.

1313 I: Yes. Yes. I hear you, yeah. So really to sum up, lack of
1314 information...

1315 R: Hmm.

1316 I: ... lack of, erm, awareness.

1317 R: Hmm.

1318 I: There's, er, literally no support...

1319 R: Hmm.

1320 I: ...whatsoever, er, apart from the, you know, purely medical
1321 intervention...

1322 R: Yeah.

1323 I: ...in your area.

1324 R: Yeah.

1325 I: Erm, and, and that's why you've had to come down here.

1326 R: I know. All the way to London, yeah.

1327 I: Yes, and how long have you been, erm, here, is it recent?

1328 R: Erm, just recently, I think this is my third one today, my third
1329 assessment...

- 1330 I: Yeah.
- 1331 R: ...and then, er, my treatment starts in February...
- 1332 I: Yeah.
- 1333 R: ...and I have to come up either every week for 12 sessions or
1334 every two weeks. Erm, the ironic thing is I can't...
- 1335 I: What kind of medical treatment?
- 1336 R: No, no, with, erm, psycho dermatology...
- 1337 I: Okay, yeah.
- 1338 R: ...with Dr Musira. Yeah, erm, so, erm, the ironic thing is I can't
1339 walk far, er, with my arthritis. I, I have trouble with crowds and
1340 travelling, so when I go into my local hospital I go by a taxi, er,
1341 or they provide transport. I'm having to come up to London, I
1342 mean at the moment my brother's able to bring me, er, but he
1343 starts a new job in January. He won't be available to bring me, I
1344 can't catch a train, so I'm gonna have to come by a taxi. I have,
1345 I have no alternative. I'm gonna have to catch a taxi.
- 1346 I: The train you said you have like a claustrophobia or?
- 1347 R: Erm, social phobia.
- 1348 I: Oh right.
- 1349 R: I can't go, I couldn't get on a crowded bus.
- 1350 I: Okay.
- 1351 R: I couldn't, even in, in Birmingham, erm, and especially on my
1352 own, it's easier with someone else, but it's still so traumatic.
- 1353 I: Yeah.
- 1354 R: Erm, I couldn't do that. I would have probably felt safe with my
1355 brother coming on the train, but I can't, I can't walk fa, erm.

2 far
(now)
Find the
help but
can't get to
it.

social phobia

- 1356 I: Okay.
- 1357 R: So, erm, and it's the crowd so...
- 1358 I: Is this something that you've always had or has this developed
1359 as...
- 1360 R: It's developed, it's...
- 1361 I: It's developed?
- 1362 R: Yeah, I haven't always had it, it, it's got worse but...
- 1363 I: Yeah.
- 1364 R: ...then because I just feel so low and run down with all this I
1365 think it's just made...
- 1366 I: Yeah.
- 1367 R: ...made worse.
- 1368 I: Yeah, okay. Okay, so this, erm, erm, there's the social phobia,
1369 you feel intensely uncomfortable in, in crowds?
- 1370 R: Yeah. I'm better than I was, I'm not as bad as I was, but again
1371 that's made worse with my psoriasis. when my psoriasis is bad
1372 on my hands and people treat you like a leper or they step back
1373 and they go, "Oh," or they stare or, you know, shops are an
1374 awful thing when they slam the change on the counter, they
1375 won't put it in my hand, 'cause I got psoriasis on my hand. I've
1376 come out with many - I, I build all my confidence, I pluck up the
1377 courage to go shopping and, and again it's this not being
1378 believed. Nobody would believe me when I said, "Oh, you
1379 know, that checkout assistant slammed the change on the
1380 counter," they put it in the person before and the person after's
1381 hand, and hand them the receipt. It was just me. Then I've got
1382 my friends and family saying, "oh don't be silly, it wasn't just you
1383 it's just your..."

fear, stigma,
contagion
stigma

psoriasis
fear of contagion
build up
corrosion

Hypersensitivity
to rejection

Not being
believed

awareness:

again - don't
believe you

Who notices
this? Only
when you
have been
receptive
attributed to this

1384 I was in a wheelchair when I first had my op, my partner had to
 1385 push me into the shop. Psoriasis was bad. He'd slammed the
 1386 change on the counter, wouldn't put it in my hand, threw my
 1387 receipts at me. We came out the shop, filled up with tears and I
 1388 said, "Was that me or..." to my partner, "Was that me?" He said,
 1389 "No, I'm going back in that shop, if you don't I'm going." So then
 1390 eventually he believed me. Erm, nobody believed me, it was
 1391 appalling the way I was treated. So erm...

reaction:
 as old:
 misinformed

saw with
 own eyes

treatment

→ when others see

A. not enough.

1392 I: Yeah.

1393 R: ...so that makes it worse.

1394 I: Yes.

1395 R: It takes a lot to get me to go and then when somebody stares or
 1396 somebody makes a comment it's, erm...

worried up
 carap
 : intrusion
 : judgement

1397 I: Yeah, so you think this feeling uncomfortable in crowds has
 1398 something to do with, with your psoriasis?

1399 R: Yeah.

1400 I: Yes, and now it's just become a way of, you know, that's how
 1401 you deal with it, you just like to stay away.

Defeated

1402 R: It's just easy. It's like with my arthritis, it's only if I have to walk a
 1403 long way, I need a stick with my knee, I need a stick. Now I
 1404 don't use a stick around the house.

1405 I: Hmm.

1406 R: If I take the dog in the park, 'cause it's a long way I use the
 1407 stick, it helps me.

Stren: what
 does it mean?
 → outward sign
 but doesn't
 feel it's
 legitimate

1408 I: Hmmhmm.

also feel judged

1409 R: But I feel people are looking and staring and judging, 'cause I
 1410 can walk normally with a stick, so I think they're looking and

When
 others
 see

Intrusion
 violation

Social
 phobia ~
 defeat?

stick-
 opp fighting?

Evaluation
 staring
 judgment
 &
 negative

1411 thinking, "Oh she doesn't, what she using a stick for, she
1412 doesn't need a stick."

?
what's this about?
→ judging
evaluate

1413 I: Right.

1414 R: And that's what the physio said, I came off my crutches too
1415 early because I could walk properly with my crutches and
1416 people would look and think, you know what she doing.

1417 I: Hmmhmm.

1418 R: But then when I didn't use my crutches I was struggling and it's
1419 like now, it's easier with a stick...

easier:
stick =
defeat?
feels guilty
using a stick?

1420 I: Yeah.

1421 R: ...but I don't like, I'm self-conscious I don't like to - 'cause I
1422 don't walk with a limp, you know, I don't have a limp and, and I
1423 think...

limp ~
writable
"excuse" -
legitimate
a stick?

1424 I: Yeah.

as the
beginning:

1425 R: ...so I don't bring it.

1426 I: Yeah, yeah. So what's it been like talking about this?

1427 R: Erm, I've, I've got, two, two ways, it's been I've got very worked
1428 up and it's brought it all to the surface and I feel quite upset,
1429 and I feel like I could have a good cry, but on the other hand it's
1430 a massive relief being able to tell someone everything I've
1431 bottled and stored for, for years, for years and actually have
1432 somebody sit and listen whether anything can be done about
1433 any of it, but it's a relief...

double-edged
sword.

talk = listen =
relief

1434 I: Hmm.

1435 R: ...that somebody's taken the time to listen.

1436 I: Yeah.

1437 R: And, and that I've made somebody aware and it's a massive,
 1438 I've released it all, it's a big relief to me. The same time me
 1439 getting upset at times, it's a relief.

⇒ have someone listen; relief.

1440 I: Yeah, yeah. It's almost like, erm, I hope you don't mind me
 1441 suggesting something, that it's almost, you're so eloquent and
 1442 you're able to express so well how, how this has impacted you,
 1443 and erm, it's almost like maybe that's, it's this, maybe you could
 1444 become the sort of, I don't know how exactly, but this, maybe
 1445 this is what you have to do. Your role right now is to make
 1446 people aware, this is what you're, you know, that could give you
 1447 some kind of, something to fight for.

gone into therapy made → want to make her feel better make her feel important that she has something v. important to do if she wants to.

1448 R: Hmm.

1449 I: Does that, maybe I put it wrong but...

1450 R: No.

1451 I: ...I think you, I'm so [1:08:46]

1452 R: Every so often I would, I would like to but I wouldn't know how
 1453 to go about it.

Needs support

1454 I: No, but you've started now, you've started now.

1455 R: Hmm.

1456 I: You really have. Thank you so much for, for sharing what I
 1457 know is quite, you know, has been difficult personal...

1458 R: Thanks for taking the time and taking the interest as well.

1459 I: Oh God, now, yeah, well I'm glad that you, that, you know, this
 1460 is the kind of, you telling me that, that...

1461 R: Hmm.

1462 I: ...that, er, your experience it actually just makes, makes me
 1463 thing that this research topic is right. This is...

- 1464 R: Oh definitely.
- 1465 I: ...I'm so glad I, because I've spoken to a few people, not
1466 everyone has...
- 1467 R: Yeah.
- 1468 I: ...of course they don't have the same experience. Some people
1469 have, you know, they go, "Great," you know, I sense it's not...
- 1470 R: That's everyone I've met who say, "It's great, brilliant," and I
1471 think it's just me then I think I'm like...
- 1472 I: No, no, no.
- 1473 R: ...it's only me.
- 1474 I: It isn't, Amanda, don't worry.
- 1475 R: There's more people that...
- 1476 I: I think we just need to speak to them because...
- 1477 R: Yeah.
- 1478 I: ...there are some big quantitative studies where you just
1479 have...
- 1480 R: Hmm.
- 1481 I: ...people fill out questionnaires and, erm, and, and, you know,
1482 from, erm, they've had 600, 700 people fill out questionnaires
1483 with psoriatic arthritis and...
- 1484 R: Yeah.
- 1485 I: ...how, erm...
- 1486 R: Yeah.
- 1487 I: ...how they feel after biologics and there's been this kind of
1488 weird disparity between...

1489 R: Oh.

1490 I: ...physiological improvement but not so much psychological
1491 improvement.

1492 R: Yeah.

1493 I: So you're not alone.

*want to make he
feel better and less
alone*

1494 R: Oh right.

1495 I: There are many others out there.

1496 R: Yeah.

1497 I: We just need to find, you know, others like you and speak to,
1498 and speak to them to find out...

1499 R: Yeah.

1500 I: ...what it is. And not everyone has the same response.

1501 R: Hmm.

1502 I: So you're not alone, you're not alone. I'm just so sorry that you
1503 feel so alone and I can understand why you feel so alone.

1504 R: Hmm.

1505 I: And, er, hopefully we can change that.

1506 R: Hmm.

1507 I: And I hope you'll have a good experience here.

1508 R: I hope so.

1509 I: It's a shame you don't live closer.

1510 R: I know.

1511 I: Because this is quite, a lot of the, erm, a lot of the, erm, people
1512 that I've spoken to have been referred here and because

1513 they've had the same experience as you, sort of saying, "Oh no
1514 you're alright," and complaining of pains...

*misdiagnosis /
under-estimate
cancer*

1515 R: Yeah.

1516 I: ...and they're like, "No, no there's nothing wrong..."

1517 R: Yeah.

1518 I: ...and so this, I think actually this, er, department's quite
1519 unique...

1520 R: I think so definitely.

1521 I: ...in that respect, and as you rightly said, unfortunately, er,
1522 compared to other illnesses it can be quite underfunded.

1523 R: Hmmhmm.

1524 I: But that's what we all, that's what we have to change...

1525 R: Hmm.

1526 I: ...because it is a serious, er, condition.

1527 R: Yeah.

1528

1529

1530

1531

1532

*My own stuff impeded
as well when she
talked about the
doctor not being
honest.*

Reflexive comment.

*Got pulled in:
her distress /
pain - difficult
not to be a
therapist:
suggesting "activity"
frilled by person
to give her life
meaning / purpose.
: difficult to
when he's
so alone.
→ felt "wrong"
→ lady on benefit
so desperate
that she'll
consider
taking a
taxi
from BH'*

END AUDIO

*different
treatment
diagnosis
phase*

Alice**Not being understood**

Legitimate disability
 Pain is invisible
 People don't understand
 It's not legitimate walking with a stick
 at my age
 No excuse not to work
 I'm not lazy
 I'm not a scrounger
 Not recognised or understood
 People don't understand what it takes
 Exhaustion

Misattributions of others

Troubles attributed to age
 People can't see and expect me to carry
 on as normal
 People think I'm lazy
 Normalisation "it's just your age"
 Make light of
 It's only one hour at the hospital

Perception of care

I detest my treatment

Never-ending

Relentless
 Stop working after 3 months
 Improvement followed by relapse
 Every week for 5 years

Conflicted self

Deep conflict between what I want and
 need
 You should be grateful
 Fed up/Can't stand it

I hate what is there to help me
 I was worse when I didn't have it
 I need what I loathe
 I don't understand as I know it's doing
 me good
 Unable to assimilate what I need as

being good for me

Violation of body

Intrusion
 Needle phobia
 Constantly prodded and poked

Objectification

I'm prodded and poked
 Constant intrusion
 I'm not a person, but an object

I am an experiment

Withhold information
 Let's see what happens
 Wool over my eyes
 Not being honest with me

**Comparison with other conditions/
disadvantaged self**

Comparison with cancer: at least
 treatment ends
 Pamper days
 No information pamphlets
 PsA ignored
 No help for people with PsA
 No leaflets
 Awareness in dep. that it's underfunded

Impact on self: Isolation.

Am I the only person in the world?

Neglected status of PsA

Side-effects/vulnerability/poison

Worry about side-effects
 Poison in my body
 Fear
 History of side-effects previously
 Scary reactions (anaphylactic shock/
 vomiting)
 Side-effects: mouth blister
 I'm putting highly toxic material that
 people won't touch in my mouth

Uncertainty about future

What's going to happen
 Worry about future side-effects
 Prior experience of treatment promoted
 as safe
 Fearful of future implications of
 treatment
 Experiment
 Current health problems because of
 biologics?
 What's it doing to my body?

Relationship to medical care team/
 Perception of medical profession
 Don't trust them
 No independent advice
 Can't get an honest answer

Resentment of medical profession
 They don't care about me
 Should listen but don't
 I know but they say I don't
 They don't care
 Ulterior motives
 Hidden agenda
 They're the enemy
 Not being listened to
 I am an inconvenience
 Not honest with me
 Lack of trust
 No explanation
 At least tell me
 Medical profession don't care/
 understand
 There to get a job done
 Don't want to know
 Dismissal
 Keep a lot from me
 Experiment nightmare
 Let's see what happens
 Only when you've been on it for a
 while
 Oh yes, that can happen
 Only admit when absolutely necessary

The less initiated are more honest
 (student doctor)

Profound lack of trust
 Keep information from me
 Not honest with me

**Contradicted by personalised
 strategy (nurse)**

Lack of trust
 In bed with enemy
 No independent advice

**I am an experiment (callous/cold-
 hearted medical profession)**

Only people advising you are the
 people pushing the drug
 Interesting use of word : push vs.
 grant
 I want options
 Information and options
 Self-efficacy

Experience of care

Dismissal
 Lack of trust leads to information
 search on internet
 Swept under the carpet
 I have to fight all the time
 Fear
 Insensitivity of medical (poster) facts
 I'm just a number
 They don't care
 Lack of info
 Nobody tells me anything
 No understanding from medical
 profession
 No one cares or wants to know
 When she tells them how she's feeling,
 it doesn't lead to anything
 Compared to "service" in shop
 (superficial)

Seeking information

The role of the Internet
 Lack of validation leads to internet as
 source of validation
 Negative cycle established

Turn to internet for information
 Makes it worse
 Don't know what is true
 Impact of unsolicited internet
 information
 Nasty cycle

Cumulative effect in both positive and negative direction

Vicious cycle of mistrust (internet)

Ownership

It's not their body it's mine
 I have a right to know
 Reclaiming what's mine
 I have the right to know
 It's my body
 Euthanasia analogy really
 Ownership
 I want to know in order to weigh up
 pros and cons

Benefits of biologics

Happy with biologics
 I was worse when I didn't have it

The body talks

Body rejects
 Body speaking/voicing what she feels
 (veins sunk)
 Couldn't swallow
 Hairs fell out, went brittle
 Symbol of poison
 Conditioner ineffective
 Harm herself - can't do it (needle
 phobia)

Emotional impact

Worry about reaction
 Weekend ruined due to worry
 Exhausted
 Negative emotion: angry, upset, tearful
 Helplessness

Social support

Lack of interest/support

Everyone else is used to it, but not me

Process over time

No adjustment
 Harder rather than easier

Opposites

Harder rather than easier
 Harm rather than help
 Body over mind

Time-consuming

Eats your time
 Never a day to myself
 Taken over life
 All-engulfing

Cyclical relentless regime

But endless cycle, no cure
 Never-ending (get tired of it all)
 Get over it and then time again
 So it's treatment needs to be recovered
 from
 Relentless cycle
 Need a breather
 Just a day to myself, when I don't feel
 bad
 Luxury of time on this particular
 biologics treatment (methotrexate)
 Eats you up/time

Not being believed/Not being heard/ seen

You're wrong
 This is not a side-effect
 Top-down communication
 That didn't believe me (doctors/nurses)
 Pathologised
 Objectified
 Non-personal care
 It took the two years before they
 believed me
 Sudden change - believe me with no
 logic to it

Appearance concerns

I looked a mess (hair)

Self-consciousness

Poison

Slow death

Poison effect

Tastebuds altered

Impact on self/mind

Affects my head/thoughts

Fuzzy head

Muddled head

Can't understand anything

Can't explain

Lack of choice

I don't have a choice

Treatment (biologics) forced on me

No option

I have no choice

There's no alternative

No solution

Helplessness

Not that anything can be done

Rebellion: Reclaiming choice

Stay away

Coping by pretending has the choice
not to go

Goes last minute

Fear/avoidance problem solving

Had enough/refused my injections

The illusion of choice

Reclaiming choice she knows she
doesn't have

I hate toxicity

Rather spend a month in hospital than
having all this rubbish put into me

I don't want it

Battle in my head

Constant worry

Constantly weighing up pros and cons

Not rational

Battle

Emotional impact

Ambivalence

I'm worse without it

In a way biologics keep me going

Biologics help me walk a bit further

PsA illness experience

Attack on self

Loss of basic self-care skills/abilities

No sleep

Psoriasis bad

Sucks you dry

Couldn't do anything (wash my hands)

Pain

Emotional impact

Wanted to die

Emotional impact of treatment/ reaction

Panic symptoms

I dread hospital

Fear

Impact of not being seen

Emotional impact

Exhaustion/stressed/tears

Fed up

No understanding

Impact of treatment

Incapacitated as result of methotrexate

Pattern to week

Relentless

Wham: like getting punched

Information and choice

Information leads to choice

Habituation

My body constantly needs stronger
stuff

Reduced effectiveness

Body is used to it

Always being at the hospital is normal
to everyone else, not for AH
Everyone else is used to it
Lack of support and understanding
from people

Dependency on biologics

I can cope with being bad for a few
weeks because I know it's going to go
away soon

Infringement on life/Chained to hospital

No freedom/flexibility
Too dangerous for local GP to
administer
Won't take responsibility
Obstacles put in my way
No flexibility

No leisure

Tried to be pro-active
Go on holiday
Ticking bomb

Exposure

Lack of regard/care reflected in
surroundings
No privacy
Put on display
Pull-around curtain
Shoved down in corner
3 upright, uncomfortable chairs
Violation in public
Not worthy of a room
Exposure in front of others
On show

Emotional impact

Embarrassed

Arrogance and misinformation

You are misinformed about your own
condition
Lack of awareness even among
medical profession

We know better

Tremendous impact of not being believed

What you're saying/experiencing
doesn't exist
Ridiculed by medical profession
Beyond words

(Hunger for validation)

Impact on life outside hospital / personal relationship

I've become irrational
Flare up at nothing
Loneliness
Worry
Anxiety

The hunt for diagnosis

Misdiagnoses
Started with unexplained symptoms
Long time for it to be diagnosed

Impact of treatment/illness

Impact on work life
Had to give up work
Hospital appointments alone were too
much

Impact of disease

Some days I can't do the simplest
things
Another system that doesn't recognise
psa
Ability to do housework symbol of
disease progression
Loss of skills/stamina
I'm behind with everything
I'm ashamed (house a mess)
Can't keep up
Some days it takes all my effort to
cook a meal, drink
It takes all my energy
Sounds stupid
Takes all my energy

Exhaustion

Fatigue

Takes over

Current state: Limbo (mixture of sitting/pottering about)

Fatigue that affects mind and body

All-encompassing

Frustration

Duality mind/body

When mind is willing, body is not

Body lets me down

Monster

Disease threatening to engulf you

Instead of giving in to it (monster), alien presence, threatening to engulf you

In the beginning I'd fight it

Tricky creature: when do too much, body would punish you

Difficult to pace myself

Losing the fight (self as weaker)

Losing battle against it all

Avoidance becomes a way of dealing with it

Defeat

It's just easy

Self-berating

I should be able...

Life without treatment

Bedridden

Skin and joints bad

My goal is to be normal / have a normal life

Work, shop, do nice things

Just a few normal days

Get up in morning refreshed, get dressed, walk around shops

Aversion

Can't face going

Can't be brought in contact with it

Skip dose in order to be normal

Paradox (treatment in order to be normal)

I'm alone/no support

Nothing was/is offered/available (psychoderma report - unacceptably scarce)

Sympathy (?) but no advice

No help

Going to go away and deal with it on my own again

Isolation

Frustration

Shocks but no follow-up to support

I'm left to deal with it on my own

Adjustment not possible because you simply don't know what you're dealing with

Note: pro-active information seeking is actually recommended for adjustment isn't it? Seems to be denied her

Growing resentment of medical profession

Been told later it's got a nasty side-effect

Wool pulled over my eyes

Lied to

Medical profession are dishonest and lie to you

It's not fair to be kept in the dark

Withhold information

I'm more than my condition

My condition is not just my skin or joints, it affects me

I'm more than my physical symptoms

Lack of person-centred treatment (holistic)

Experience of obstacles/being pro-

active

Self-referral
Proactive strategy
Asked for help dealing with situation
Again can't refer her
They are treating me (must be experts)
Yet can't refer med to specialised colleagues
Obstacles again

Good GP
Thank goodness - gratitude is afforded the GP
Not part of medical profession

I have to fight all the time
Wash their hands
It's not fair

Only biomedical goals (my own thyroid experience)

What I would like

More awareness from medical profession is necessary
Group meeting
Social support from group
Meeting others like myself
(Why this helps... Comparison not with others but with people who understand)
Alternative treatments to weigh up pros and cons
Things being made easier on a practical level
Comparison to cancer (even doing that in own homes, this is just an injection)
Little things would help (massage for arthritis, hydrotherapy)
Can't afford it now as on benefits
Little treatments aside from purely biomedical intervention

Obstacles all around/lack of freedom

Holiday made possible
I can't go anywhere

Chained to my treatment
Lack of freedom
Prison

I would like it to be recognised/ comparisons with other conditions

Included in centres
Possibilities (yoga, massage, aromatherapy) afforded others should be afforded to psa sufferers
Pamper days
Comparison with other conditions

It's a serious illness - not recognised

Now I have found help, it's ironic that I can't get here
Only alternative is to get a taxi because of crippling social anxiety
Traumatic

Psoriasis experience

Social outcast

People treat you like a leper
Stare at you
Social interaction in shops dreadful (slam down change)
Takes all confidence to go out - then devastating
Staring/comments
You become a public thing, because violating social norms
Hypersensitivity to rejection
Slam down change/ threw receipts at you
Intrusion

People don't believe you

Don't be silly - that didn't happen
Validated when saw with his own eyes (seems like it's never enough when it's just me saying it)

Negative expectation from others

Staring and judging when using a stick
Interpretation: limp (**not** legitimate vs.

others)

I've made somebody aware - it's a
relief

GP is person she goes to
Normalises it - just a bit of a downer

Appendix O

Clustering of Themes Across Transcripts

Super-Ordinate Themes	Sub-themes
The miracle of biologics	Turning back time/second chance/new lease of life I can be normal/freedom from shame/restrictions of disease Euphoria/intense appreciation of things most people take for granted
Living with uncertainty	The role of information as agency of choice The role social support Making sense of it/present-moment focus
Being seen/treated as a person	Seeing the person vs. being treated as a disease Everybody needs something different/variation

Cluster I: The miracle of Biologics: informed by a strong then/now and before/after dichotomy.

Past history crucial (backdrop to biologics)

Sneaky creature that evades diagnosis (no treatment, disease allowed to progress, deterioration)

Unpredictable, symptoms wax and wane

Keeps you on your toes/ tricky creature: when do too much, body would punish you

Unpredictability of disease
No telling what's next

Extraordinary (evil) combination (monster)

Two very different diseases
Such different conditions

Monster

Disease threatening to engulf you
Instead of giving in to it (monster), alien presence, threatening to engulf you
In the beginning I'd fight it

Difficult to pace myself
 Losing the fight (self as weaker)
 Losing battle against it all
 Avoidance becomes a way of
 dealing with it
 Defeat
 It's just easy

Mysterious/gradual onset of PsA

Body/disease wins

Progression of disease

*Monster eats your time as well,
 turns you into a recluse/social
 pariah and takes away your skills,
 mobility*

Battle/fight/defeat

I tried it fight it, but was defeated
 (monster/battle - gradually wears
 you down)

Battle image of disease

It never defeated me
 Enemy
 Battle

*Defeat: Feared future scenario
 (experience/images)*

ii) Lack of awareness of link between psoriasis and joint pain Not being believed/ dismissal

"Live one day in my shoes and then
 tell me I haven't got the pain"
 Not aware of link between skin and
 joint pains
 Didn't mention to dermatologist

iii) Emotional impact of not being believed is extreme

Effect on self: Doubting oneself/ am I the problem?

*You seek an explanation for pain.
 Driven towards seeking to
 understand what is causing this.
 Turns toward oneself if no one can
 offer explanation. Pathologising of
 people when disease has no name.*

Alone/no support

Frustration (stress)
 Physical impact: exacerbated
 psoriasis (95% covered)
 Nearly cry because of pain (yet not
 believed)
 Limp when it hurt, but soldier on

iv) Evaluation/Remembering what life was like before biologics

Still vivid (l. 739)
 Overwhelmed with emotion looking
 back
 Cried for a few years after in front
 of doctors
 Couldn't cope – too much/cruelty of
 disease

Being on the other side/coming out into the light again

Hell: I don't ever want to go back
 there
 A place he has now left
 'Beyond' discourse
 Making it through defies
 comprehension
 Multiple hospital admissions
 Don't know how I coped (l.257)
 Unbearable/beyond words
 Sighs, don't know how got through
 it, terrible, terrible time
Looking back
 You forget how you were
 You want to forget
 Don't want to remember
 You forget how bad you were
 Before PUVA was most miserable
 time

Fighting a losing battle

Battle/fight/defeat

I tried it fight it, but was defeated
 (monster/battle - gradually wears
 you down)
 Couldn't cope

v) Impact of the double whammy of PsA (Pain, reduced mobility and social exclusion)

Effect of disease

Reduced stamina
Restriction/freedom

Psoriasis experience of stigma

Specific experience: Friend let him know it wasn't acceptable for him to enter a busy pub at lunchtime (saw himself through eyes of others)

Become public property because you violate social norms

Become an object
Being pointed at (look!)
Violate social norms
(Unacceptable, people get out of your way,
Leper, gypsy example: screamed on train when saw him (by social outcast) On train: no where to go

Skin

Holiday marred by self-consciousness
Avoidance of exposure
Leisure limited
Physical aberrations (pockmarked, welts)

The other's response

Ignorance brings fear
Comparison with leprosy
Fear of contagion

Outcast: On the fringes

Staring, judging by others
Social pariah/ Outcast
Fear of contagion
Strangers ask if they can catch it

Emotional/psychological impact (skin)

In a terrible place (in a place with no light)

Dark place with no love
Love/hate discourse
Miserable existence
Psychological impact:
depression, Self-pity

Self-mutilation (itchiness) what is the PD understanding of itchiness

Despair leading to
Tear myself apart (lion)
Viciousness
Draw blood
Extensive pain
Itchy, broken skin
Skin pain, it's everywhere (not localised)

Eruption image (angry)

Skin cracks
Eruption (volcano, force cannot be kept back)
Welts

Self-image challenged (skin)

Impossible to maintain image of yourself as well-groomed
Dandruff
Unwelcome attention
Embarrassment
Shame and embarrassment
Feeling unacceptable
Can't show body
Felt dirty
Shedding

Constant self-awareness

No escape
No respite
Self-consciousness
Can't relax
Can't enjoy yourself on holiday
It's with you all the time
Constant checking if shed skin
I wouldn't want to sit in that chair
Leaving a trail
Hyperawareness
Psychologically on the back-foot all the time

Psychological place

Close to suicide, hate, isolation
 Hated people, isolation
 (Withdrawal: didn't want to see/talk to people)

Bad feeling in yourself
 Mentally hard to deal with
 Became very self-conscious, shame

Social outcast

People treat you like a leper
 Stare at you
 Social interaction in shops dreadful (slam down change)
 Takes all confidence to go out - then devastating
 Staring/comments
 You become a public thing, because violating social norms
 Hypersensitivity to rejection
 Slam down change/ threw receipts at you
 Intrusion
 Outcast
 Meaning of shedding of skin
 Socially unacceptable
 Stigma
 I am frowned upon/break rules

Psychological impact of psoriasis (you change)

(The psoriasis experience/ psychological effects of psoriasis on self-image)

Destruction of self-image
 I'm a deformation
 I am ugly
 I am unattractive
 Disgust
 Feeling dirty
 You're not looking after yourself

Dichotomy: now: love / before hate, isolation, shut down, constant anger, suicidal

Physiological situation

Pain unbearable

Beyond measure (20 on a scale from 1-10)

No sleep
 Constant pain

Concomitant health-problems

Blood pressure up
 Depression (refusal of anti-depressants)

Impact on life: Arthritis/joints**No life**

Able to do less and less
 Reduced to basic functioning
 Reduced to an illness: just going to hospital
 Overwhelming pain
 Sapped of strength
 Getting weaker
 Pain
 More frozen (visner/stivner)

Effect: Vicious cycle of avoidance and further deterioration**Double-whammy of psoriatic arthritis****Nothing worked**

Emotional impact: burst into tears in from of consultants
 What is the point?

Life with PsA

Life changes
 Little things like taking the bus become subject to careful planning
 Painful to walk
 Constant pain
 Describing pain is difficult
 Pain leads to breakdown of function and mobility
 Your body is not working anymore/ properly

Methotrexate treatment

Toxicity of previous treatments (methotrexate)
 Top ends in terms of safety
 Higher doses, but not improving

You're in hospital all the time

Before biologics

My life would have been dreadful
without biologics

Misery

Disruption

Treatment or disease takes over
your life

Inability to work

Impossible to maintain work

Intrusiveness

Time-consuming

Just maintenance, not cure, makes
it impossible to work

Minor ailment with major impact

PsA

Evil combination of opposites

Two such different manifestations
of same disease

Loss of skills

Simple things made difficult

Normal things difficult

Can't join in with other people

Some days I can't do the simplest
things

Couldn't do anything (wash my
hands)

Household chores/walking symbol

Able to do less and less

Degeneration (slow death)

Impact of treatment/illness

Impact on work life

Had to give up work

Hospital appointments alone were
too much

Impact of disease

Ability to do housework symbol of
disease progression

It takes all my energy

Loss of skills/stamina

I'm behind with everything

I'm ashamed (house a mess)

Can't keep up

Some days it takes all my effort to
cook a meal, drink

Exhaustion

Fatigue

Takes over

Judging with eyes of other/ defies normality

Sounds stupid

Just an hour at hospital

Attack on self

Loss of basic self-care skills/
abilities

No sleep

Sucks you dry

Pain

Emotional impact

Wanted to die

Feeling sorry for myself

My body is turning on itself/ breaking down

Comparison to leprosy

Comparison to cancer

Skin cells gone wild

What's wrong with my body?

Body is betraying me

Later life stage

Feeling old before time

Vulnerability

I'm too young for my body to be
breaking down

My body body breaking down is
supposed to happen later

Degeneration

It's all going to go downhill from
now

Beginning of the end

Degeneration/slow death

Psoriasis experience (skin)

Leave a trail

Snow inside

Baths and moisturizer
 Impact of psoriasis: Social embarrassment when shedding clothes
 Self-consciousness when trying on clothes
 Have to sit in bath for an hour
 Baths 3-4 times per day

Psoriasis experience

Embarrassed about visible manifestations on face
 Intrusive comments and questions
 Fear of contagion
 Ignorance
 Lack of awareness from others
 Stupid questions
 Outsider/stigma

What pushes over edge

Itchiness is the final straw
 Itchiness was unbearable
 Can't cope with itchiness
 Itchiness is constant [24/7](#)
 Relief: bath
 Relentless reminder
 You can never forget about the itchiness
 Relentless itching
 Constant intrusion

Self-mutilation

Scratch until you draw blood

Psychological impact

PsA experience: triple whammy

I ate when I couldn't do anything/
 boredom
 Joints were the worst
 Immense impact: Reduced to not being able to do anything (bath, peel...open a tin, can't lift, carry, walk up stairs, couldn't go to toilet, wipe myself)
 Helplessness and pain and itchiness
 Triple-whammy unbearable
 Couldn't walk
 Household cleaning symbol of disease progression (like AH)

*Seems like there is a symbol/
 comparison of regression for everyone*

Arthritis impact: couldn't move

Restricted mobility: Nothing, neck, jaw, teeth.
 I really wasn't good
 Couldn't get out of the bath

PsA experience

Unable to fulfill household chores
 "How can I go to the doctor when I've got nothing to tell him"?
 Don't understand what's happening
 Invisible
 One day I couldn't move
 Escalation: I didn't react, and it spread through my entire body

Sudden onset: paralysis
 Couldn't do anything – not move sit or get up
 Early signs, but didn't know what it was
 Feeling very tired all winter, joints swollen and tender
 Pain for 2 days from holding on to window
 Misattribution: I am lazy
 No reason for tiredness
 Couldn't do anything (change a nappy)

PsA experience (psoriasis on the inside and outside)

Emotional impact

Fright

Beginning of the end/

Degeneration PsA

Beginning of the end
 Allergic reaction?

Emotional impact of illness (varied)

It stopped my life.
 Frozen
 Crying all the time

Defeat
Never going to get better
Humour as coping

Later life-stage (degeneration)

Image

80-year old ladies with sticks were faster than me
This is me now

Loss

Big business had to close
Loss of job (source of validation and pride)
Source of self-esteem
Irreversible joint damage

Altered life-course

No longer fit/ability to work (medical evaluation)
Incapacitated/loss of job/source of validation
Have to accommodate losses associated with disease
Reinvention necessary: What do I do now?
Re-invent his career to something sedentary

Overall/combined impact

Couldn't smile
Couldn't sleep
Always sad

I was in prison (own home)

Reduced to basic functioning: work, sleep, eat, sleep
No leisure
No enjoyment
No seeing people

Life-stage matters

Late teenage years difficult
Detrimental impact on social life (no girlfriend for 10 years)

Coped by avoidance

Avoidance becomes coping mechanism (Cover up, avoidance

of exposure, social events, shy away from exposure)
Did not utilise social support (isolation/withdrawal)
I didn't want to explain/discuss situation
Kept to myself

Only partly effective

No hiding as skin would still shed
Visible in leaving a trail
You're snowing
Comments

Outside looking in: I used to be jealous of friends having a picnic/ my wife's skin

(Limp more acceptable)

Power of knowledge/ awareness/ information counters fear

Pub incident: defended by stranger
Awareness changes behaviour
Was ok with it himself because had grown up with friend who had it
I never took a second look

Have to talk back to yourself and instincts to hide (self-talk)

Why hide?
Build-up courage not to hide
It's not going to get better by hiding

v) Experience of previous treatments: Abuse of body Bruised and battered, time-consuming, no time for anything else

Losing hope/nothing works

You're the last one here/doesn't work

I was steadily going down-hill
Everything was deteriorating

Filling my body with toxins (medication overload)

Medication overload/fatigue but

nothing really helps

Excessive cream use
Desperation led to bad stress (BP 200)

(Also lost his business)

Serious side-effects of prior treatment (back-drop of biologics)

Chinese herbs treatment led to liver failure, covered in white spots
Swollen, couldn't breathe, skin burnt, like being in a fire, excessive steroid use

Experience of previous treatments

Sick on pills before PUVA (loathe vomiting)

Desperate search for cure/help

(alternative/private): Chinese, homeopathy, private, NHS

Treatment is time-consuming (the beast requires constant monitoring, tending to)

Moisturising 2-4 times per day
Maintenance requires you to stay at home

Treatment is taxing compared with relative ease of injection

Intrusiveness of treatments
Tedious and time-consuming vs. injections easy (compared to tedious previous treatments)
Quick and painless effect
Distinct difference

Self-care and discipline

Dread

Hospital appointments become a source of dread (helplessness, impersonal care)
Impact; Short-tempered
I was steadily going down-hill
Everything was deteriorating

The impact of pain: helplessness/something**particular nasty about this kind of helplessness that may lead to depression**

Disturbance of normal processes: sleep, getting out of bed, waking up, getting dressed marred by pain

Coping

You just have to manage

I didn't have a choice

The kids needed me

Responsibilities of home

Doesn't help to stay in bed

Didn't have time to look in the mirror

II) Miracle of biologics (skin)**Defies belief** (magic trick)/

vanishing act/ disappearance/ Soft skin - not used to it/Vanished after a few weeks/ Just a few spots now but calls it "nothing, gone"/ My skin is clear

Superlatives Amazing, Fantastic, Superb, Helped me a lot

Psychological/physical reaction:

Euphoria, elation

massive orgasm, goosebumps, physical reaction, still vivid, so happy, Singing in shower (l.25)
Skin clearing up was happiness

What is the meaning of singing in the shower? Archetypical image of happiness, joy in life, looking forward to what the day brings.

Biologics amazing (Before/after dichotomy)

Ineffective to helpful to unbelievable felt like a different person

I felt like a different person

immediately

Immobility to mobility

Rigid softened

Frozen to flexible

New lease of life

Better now than ever
 Biologics is worth every penny
 I was miserable then/lucky

Emotional gains
 I'm a nicer person
 Easier to live with

Benefits of biologics

Happy with biologics
 I was worse when I didn't have it
 Helped me walk a bit further
 In a way biologics keep me going
 Biologics help me walk a bit further

Biologic amazing

Biologics freed up time
 Biologics were amazing
 Easy
 Ever so good, really good
 I only had to inject myself and not
 take tablets all the time
 Amazing biologics I. 905.
 "They were like, the best thing" (I.
 1912)
 Attribution: Biologics healthier than
 tablets

Biologics compared to life on other treatments

Biologics were less time-
 consuming
 Sense of normality
 Freed up time: could get up, not
 have to sit in bath for an hour
 3-4 times per day

Impact of biologics

I felt normal
 I could do normal things like
 everyone else
 Normal routine
 I felt like everyone else
 Freed up mental space
 I didn't have to think about it all the
 time
 Paved way to normality – freed up
 time get up, not have to sit in bath
 for an hour

Baths 3-4 times per day
 Biologics made me normal as
 opposed to before
 I didn't feel normal before, do you
 know what I mean?
 Iron health: Didn't even have a cold

The success of biologics

Remission/cleared up/no mobility
 issues
 Going back in time/turning back the
 clock

Progression of disease halted Renewal

Reversal/going back in time
 Life-changing, altered life course
 Back till when I was 18
 Skin like a baby

Given a second chance/reversal of fortune

Regaining skills/ability to do things
 again:
 Able to shower without pain
 Go to gym
 Note: mundane tasks that many
 people take for granted become a
 source of happiness

All-encompassing (positive) effect (like its counterpart negative effect)

Affected all aspects positively
 Cumulative positive effect

New life (Re-entry into life)

Freedom from self-consciousness
 Go on holiday like my friends
 Opened the door
 Started life again (see people, went
 out, gym)

Freedom from shame/social things

I could do things without feeling
 self-conscious
 Sit in shorts/ Stopped covering up
 (wore shorts & t-shirt)

Freedom (go away, be
spontaneous
Going to public places

Emotional health after biologics

I can love again

Enjoy life now (embracing life with a fervor)

Wants to look forward

Doesn't want to get stuck in
negativity

Normal No longer the odd one out

Things can't do

Still can't go back to playing football

Still pain

Pain reduced but still there (9/10 to
7/10)

Cumulative (positive) effect

Made me able to bear pain of joints
because happy with appearance

Positive cycle: cumulative effect of both positive and negative

More stamina, more flexibility,
doing more, enjoying more (as
opposed to negative cycle)

Time is a great healer (life-events)
vs. leading to deterioration

injections easy (compared to
tedious previous treatments)
Quick and painless effect
Distinct difference

End/beginning of new? Biologics is the demarcation point.

It's over

It's behind me

Too busy to think about it
Self-managed until got fed up
Previous disgusting tar-treatments

Bothered me when on hands and
face

Couldn't cope with itchiness

The impact of itchiness: no sleep

Time-consuming self-care

I don't have time to sit in the bath
all day

Time-consuming aspect of treatment

I was in hospital all the time

Close monitoring

Treatment was very time-
consuming

Time/intrusiveness

Hated the one in which I needed an
injection every day

Biologics are judged for the
intrusive effects they have

The less time is involved the better
(hated the daily one)

Prior treatments-time

Busy running to hospital all the time

Treatment prior to biologics

consumes your life

Invades your life

Side-effects/taking medication

Went against the way I was raised
to take medication

I don't want to know about the side
effects of tablets

(methotrexate) because the I won't
take them

II. Cluster: Living with uncertainty

**It's a firewall, not a cure/
temporary aspect**

**Temporal aspect: Cyclical
relentless regime/ one is before/
after another is endless/cyclical.**

But endless cycle, no cure

Never-ending (get tired of it all)

Get over it and then time again

So it's treatment needs to be
recovered from

Relentless cycle

Need a breather

Just a day to myself, when I don't
feel bad
Luxury of time on this
particular biologics treatment
(methotrexate)
Eats you up/time

Temporary barrier
It has to continue forever
There is no cure
There is no end

**Not knowing why it works/the
uncertainty/all that is unknown**

No one knows why it works
Suspended in time/Limbo/neither
here nor there
Stronger and stronger stuff

**Worry about side-effects /What
is going to happen?**

Uncertainty about what would
happen

Comparison with HIV

Suppression of immune-system
Leaving yourself open to
infection

Leaving yourself open

Exposure

Vulnerability

Importing info from other diseases

So much is unknown

Nobody really knows
Lack of knowledge and
understanding
Why does it work?
Accidental discovery
There is a lot we don't know
We still don't know why it's effective
Using something that has an effect
but don't know why
Is anyone any wiser than 20 years
ago?

Psoriasis is underresearched
medically

Medicine is a broad brush stroke
where you just hope you get
something right.

Some things we can know, but a lot
of it is just down to luck and chance

**Worry about impact of treatment
(experiment)**

I need stronger and stronger stuff
I am an experiment
Leap of faith
Uncertainty
Gamble/experiment
Giving yourself up to
experimentation

Psoriasis is under researched
medically

Feeling safe

**Role of social support from
medics or others important**

*Self-referred (best decision ever
made apart from marrying my wife)*

**They care about me (perception
of care)**

Out of this world, superb, makes
me feel so much better, proactive
treatment, fill out forms to monitor,
it's all for me

**Being treated as a person not
just a patient (I.594)**

Effects of being seen

Positive spin on everything
Gives me strength to fight it
Feeling better in yourself can only
help whatever condition you've got
Normalisation: not worried about
side-effects (every med has side-
effects)

Positive about future

It's just going to get better and
better

Came out stronger (can deal with
anything life throws at me)

**Feeling unsafe/ Side-effects/
vulnerability/poison**

Worry about side-effects, poison in
my body
fear, I'm putting highly toxic
material that people won't touch in
my mouth

Note: All share past history of bad side-effects, but the others are able to not let this impinge on biologics, why?

History of side-effects previously, scary reactions (anaphylactic shock/vomiting) and mouth blister

No support/lack of regard/ Exposure

Lack of regard/care reflected in surroundings

No privacy

Put on display

Pull-around curtain

Shoved down in corner

3 upright, uncomfortable chairs

Violation in public

Not worthy of a room

Exposure in front of others

On show

Emotional impact

Embarrassed

Arrogance and misinformation

You are misinformed about your own condition

Lack of awareness even among medical profession

We know better

Tremendous impact of not being believed

What you're saying/experiencing doesn't exist

Ridiculed by medical profession

Beyond words

It's temporary / habituation

My body constantly needs stronger stuff

Reduced effectiveness

Body is used to it

Always being at the hospital is normal to everyone else, not for AH

Everyone else is used to it

Lack of support and understanding from people

Positive experience of medical profession

Evidence of personal care

Hug and kiss when see each other

She knows me very well

Testimony of relationship

Cried in front of them

Sole confidantes through years of suffering (wasn't talking to anyone else)

Doctors are generally good guys/allies

Uncertainty about future

What's going to happen

Worry about future side-effects

Prior experience of treatment promoted as safe

Fearful of future implications of treatment

Experiment

Current health problems because of biologics?

What's it doing to my body?

Accepting what's against one's ethos: Medication overload not the real me (so ambiguity)

The real me - I wouldn't even touch a panadol

I went from nothing to loads/ filling my body with everything

Petrified of side-effects/how cope (experiment)

Chose not to read

Fear would prevent her from taking

Chose not to know

Reading about it doesn't make you wiser

Safeguard themselves

If you read it, you'd never take anything

Information overload

Coping strategy: read after when it's started to work to counterbalance fear

Relationship to medical care

team

Enemy/ Not on my side/ In bed with enemy

Experiment nightmare (callous/ cold-hearted medical profession)

Only people advising you are the people pushing the drug
Interesting use of word : push vs. grant
Let's see what happens

Hidden agenda

Ulterior motives
Keep a lot from me
No explanation
At least tell me
Swept under the carpet

Information withheld

Only when you've been on it for a while
Oh yes, that can happen
Only admit when absolutely necessary
The less initiated are more honest (student doctor)

Lack of trust

Don't trust them
Lack of trust
Profound lack of trust
Lack of trust leads to information search on internet

Contradicted by personalised strategy (nurse)

Psychological impact of not being acknowledged

I have to fight all the time
Fear

Not honest

No independent advice
Can't get an honest answer
Not honest with me
Keep information from me
Not honest with me

Lack of info

Nobody tells me anything

Don't care about me

They don't care
There to get a job done
Don't want to know
Medical profession don't care/ understand
Compared to "service" in shop (superficial)
Insensitivity of medical (poster) facts
I'm just a number

I am not seen/heard/dismissal

No understanding from medical profession
No one cares or wants to know
When she tells them how she's feeling, it doesn't lead to anything
I know, but they say I don't
They don't listen
Should listen but don't
Not being listened to (talking to blind/deaf ears)

I am an inconvenience

Lack of trust leads to internet for information

The role of the Internet
Lack of validation leads to internet as source of validation
Negative cycle established
Turn to internet for information
Makes it worse
Don't know what is true
Impact of unsolicited internet information
Nasty cycle

Cumulative effect in both positive and negative direction
Vicious cycle of mistrust (internet)

Ownership

It's not their body it's mine
I have a right to know

Reclaiming what's mine
It's my body
Euthanasia analogy really

Information

I want to know in order to weigh up
pros and cons
I want options
Information and options
Self-efficacy

The role of information (linked to self-efficacy, taking charge when feels unsafe)

*Pro-active information-search
(internet)*

Done my own research
Internet is the Wild West (not
reliable source)
Can draw you in

The role of social support (medical staff here subsume)

Comfort of knowing there are
others who are going through and
coping with it
More information

Misattributions of others

Troubles attributed to age
People can't see and expect me to
carry on as normal
People think I'm lazy
Normalisation "it's just your age"
Make light of
It's only one hour at the hospital

Not being believed/Not being heard/seen

You're wrong
This is not a side-effect
Top-down communication
That didn't believe me (doctors/
nurses)
Pathologised
Objectified
Non-personal care
It took the two years before they
believed me

Sudden change - believe me with
no logic to it

Perception of care

I detest my treatment

Negative emotion: angry, upset
tearful
Helplessness

Perception of care

Hospital is amazing (perception of
care)
Everyone has been really nice
They really care. I can't get over it.
Building of relationship
I see the same people all the time
They are so nice all of them, like
really, really nice

I hate toxicity

Rather spend a month in hospital
than having all this rubbish put into
me

I don't want it

Emotional impact of treatment/ reaction

Panic symptoms
I dread hospital
Fear

Growing resentment of medical profession

Been told later it's got a nasty side-
effect
Wool pulled over my eyes
Lied to
Medical profession are dishonest
and lie to you
It's not fair to be kept in the dark
Withhold information

Perception of treatment

Harm/poison

Incapacitated as result of
methotrexate
Wham: like getting punched

Pattern to week

Relentless

Information and choice (be treated like a person)

Information leads to choice

What I want

Sensitivity to context

Information and support

Validation

Understanding

The role of doctors is surely to be on top of this?

Never-ending

Relentless

Stop working after 3 months

Improvement followed by relapse

Every week for 5 years

Time-consuming

Eats your time

Never a day to myself

Taken over life

All-engulfing

Infringement on life/Chained to hospital

No freedom/flexibility

Dependency on biologics/ chained to treatment

I can cope with being bad for a few weeks because I know it's going to go away soon

No leisure

Tried to be pro-active

Go on holiday

Ticking bomb

Too dangerous for local GP to administer

Won't take responsibility

Obstacles put in my way

No flexibility

Uncertainty: Seeking explanation/knowledge/wanting to understand

Where does my PsA come from?

Low down on genetic research

Low priority

Why does it happen?

Link to processing of stressful events?

Result of mental inability to process?

What is the connection of body and mind?

Can you make yourself ill because of stress?

Why is it irreversible? Stress goes down

Perception of care/medical treatment

NHS is wonderful

Self-referred (best decision ever made apart from marrying my wife)

Out of this world

Superb

Makes me feel so much better

Amazing treatment here

Been on other side

Coping must be here: focusing on now I think, either spirals AH into future-thinking, feeling more unsafe, out of control or the now.

Choice of coping strategy

Humans characterised by ability to adapt

Choice: You either overcome or overcompensate

You manage

Coping

No choice but to get on – I had children

Coping

Many people have it: Normalisation (as opposed to AH: am I the only person in the world?)

Everybody's got something

People always want more/ something else

People aren't happy with what they've got

People want to make their breasts bigger or change their noses

She happened to find out that what life gave her was good, but you don't always get the opportunity to find out

Social support/ Neglected status of PsA

Not being understood (can be subsumed under social support?)
 Legitimate disability
 Pain is invisible
 People don't understand
 It's not legitimate walking with a stick at my age
 No excuse not to work
 I'm not lazy
 I'm not a scrounger
 Not recognised or understood
 People don't understand what it takes
 Exhaustion

Support

Gift of (good) counselling
 Sympathy is overrated
 Meaning of sympathy (when nothing can be done)?
 Classic doctor's manner: Sympathy and acceptance (written off? Now deal with it)

I'm alone/no support

Nothing was/is offered/available (psychoderma report - unacceptably scarce)
 Sympathy (?) but no advice
 No help
 Going to go away and deal with it on my own again
 I have to fight all the time
 Wash their hands
 It's not fair
 Shocks but no follow-up to support
 I'm left to deal with it on my own

Social support

Lack of interest/support
 Everyone else is used to it, but not me

Impact on self: Isolation.

Am I the only person in the world?
 Isolation
 Frustration

Secret club

Psoriasis is initiation marks/
 membership to club in Dead Sea
 Social support: meeting others like yourself
 Information sharing

Coping with uncertainty (current life-perspective)

Present-moment focus
 Don't want to think about past or future
 I think about now (l.798)

What tomorrow brings no one knows

Pointlessness of worry
 No one knows anything anyway
 No guarantees in life (even for the well) TV-analogy
 I'll cross that bridge when I come to it
 Futility of worrying about future and trying to safe-proof yourself
 Ruins the moment, which is all there is

Philosophy in life

Living in the moment
 People spend too much time worrying
 /planning for future (like AK's mortgage example)
 You are not in control
 Illness brings about a perspective that you are not in control?
 Perspective brought about with age
 One day at the time

NB! Interesting that can draw parallels between disease and being at war which supports battle image and that disease becomes

an existential thing/dilemma, which forces you to think about life.

Life-lesson in troubled place

Learning from life

We forget we are not in control

Israel/England

Attempts to minimise impact (others or self?)

Pull yourself together

Dismissal of impact

Man up

Worse things could happen (which you know on a rational level)

Different coping mechanisms for different times

Denial

Rebellion

Self-care and discipline

Note: What is coping: it's deciding on a strategy in a difficult/challenging situation.

Fine line: Managing

uncertainty (both in regard to progression of disease and effects of treatment).

Uncertainty/what to expect

The role of information

I am an experiment

Withhold information

Let's see what happens

Wool over my eyes

Not being honest with me

Drugs : Gamble/experiment

More information sharing

The whys of treatment

Leap of faith

What's going to happen

The role of information

No warning that psoriasis might lead to arthritis

Balance between information/causing worry

Fine line

You don't want to start a fire

Note enough information

Familiarity with disease

Informed of treatment possibilities

Proactive information sharing/support

The importance of an empathic and proactive approach

It has to be handled sensitively because you don't want to start a fire

Proactive information sharing

Information and choice

Information is important for choice

It's my body

Ownership

Empowerment

Information as road to

empowerment via choice - regain sense of control in an uncontrollable situation

Scared to hope

Not too high hopes/ Scared to expect/hope

Note: Times have changed. An abundance of information is now available at the click of fingertip/no longer the privilege of the physician. Lack of trust and uncertainty leads to internet with more uncertainty to follow. Trust is paramount that got your best interests at heart.

How I coped

Withdrawal (I always kept it to myself) and burden discourse

Not impinge on surroundings

(implication being that don't won't be a burden) with build-up of pressure (links back to volcanic eruption)

Role of faith

Everything that happens is for your good
 Trust in life
 Analogy of parent giving injection to child for their benefit (God) but the child doesn't understand
 What happens is good keeps us going
 Everything is from God
 There is a plan, sometimes we don't understand it but you have to trust in life and God
 God doesn't send you anything you can't cope with
 There are no coincidences, everything is pre-ordained, meant to happen
 I would say I would have had to have had it (PsA) and the good lord has made it as easy as possible
 You can't demand from God
 You make sense of it but also must believe the things you can't make sense of are good
 Sometimes you see/understand and sometimes you don't

I'm not alone/coping

Everyone has got something to battle (comparison with other diseases IBS, migraine)
 So many people in the world are ill

Rebellion: Reclaiming choice

Stay away
 Coping by pretending has the choice not to go
 Goes last minute
 Fear/avoidance problem solving
 Had enough/refused my injections

The illusion of choice

Reclaiming choice she knows she doesn't have

forever: Obstacles all around/ lack of freedom

Holiday made possible
 I can't go anywhere
 Chained to my treatment
 Lack of freedom
 Prison

**Chained to treatment – results in
lack of freedom: go in circles**

III. Cluster: Being seen as a person and not just a disease (does not work in LT conditions)

Seeing the person in the disease Not being seen/a bunch of cells

Never looked me in the eyes
Paperwork and skin
Might as well been looking at a
Petri dish

Impact of not being seen

Emotional impact
Exhaustion/stressed/tears
Fed up
No understanding

Overwhelming joy of diagnosis

Happiness
Brilliant/Fantastic)
Self-belief restored (To be
validated/ Vindication/Wasn't
deluded after all) Shift of locus of
problem from inside persons to
disease

Explanation/ It's got a name!
**Knowing what you are dealing
with**

*Note: Weight off my
shoulders (what does this mean?)
Not alone anymore, burden/
suspicion on him lifted. Wandering
through desert for 20 years!*

Self-efficacy and agency (note: role of PMP is that it counters helplessness)

Activates the self
(Meditation)
I can cope through the
subconscious

I can cope now

Finding my way

Personal coping strategies:
Downward social comparison

Evaluation (I'm lucky to have
treatment available compared to
granddad)

Comparison with others and other diseases

There's always someone worse -
coping mantra
Young cousins died of cancer
Thinking there's always someone
worse than you might get you up in
the morning (inspiration looking at
others in similar situations Look,
they get up)

*Note: Is feeling fortunate healing?
Is it feeling lucky or not being alone
in suffering or inspiration?*

Being treated as a person not just a patient

Spill over effect of being seen

Person subsumed under system

Separate treatment/Disconnect in
patient care
Opposing ideas of treatment
Ridiculous loop
They didn't speak to each other
Result was frustration and negative
emotion
Patient caught in the middle

Negative experience (this person is interesting as has tried both)

Like Alice Jack experiences doctors
not sympathetic

Physical status under prior treatments (methotrexate)

Condition continually worsening/
progression of disease/nothing
worked
Incapacitated: walk with a stick

Side-effects of methotrexate: Body begins to alter/warning signs/
Rebellion/Fed up (like AH stopped medication)

Prior negative experience of care

Disregard
 Discounting impact of pain
 Not being seen or heard
 De-sensitisation to pain impact
 Worn out by pain/depleted
 Asking for help but being dismissed
 Only way to manage pain was through painkillers
 There was nothing else

Shift in perspective

Not bothered about little things
 Gratitude towards NHS/department
 Cumulative positive effect (want to give back)
 More tolerant
 Don't let little things wind me up

Scale/perspective shifted

Just a few patches
 Note: when been 'out there' scale has shifted. A new normal has been created

Development of new perspective

Current situation/Benefit/focus on positive

Still in pain but it's ok (p.25) (like Hanif's sleep example)
 Not getting worse/in pain, but still get about
 Still quite impaired, but relative compared to his experience
 Can't put socks/t-shirt on/walk around supermarket

Scale/perspective shifted/ Been to hell and back (backdrop of everything he is experiencing now)
Note: when been 'out there' scale has shifted. A new normal has been created

Evaluation: I'm lucky (just a few patches)

I'm lucky

I'm lucky to be born now

Life stage (autumn) time to reap benefits

Can't do that if haven't got health
 Importance of health

Coping and self-efficacy: I can deal with it now

Acceptance of condition

New confidence

I can deal with anything life throws at me

Self-belief in abilities

Learning new ways of being/ living/coping (counterintuitive):

Finding a way that works (I have a plan, walking can reduce your pain, socialising helps, medication can't help, painkillers can't help)

Effects of being seen

Positive spin on everything
 Gives me strength to fight it
 Feeling better in yourself can only help whatever condition you've got

Personal

Proactive treatment, fill out forms to monitor, it's all for me

Biologics is reassuring (something battling elements together)

Objectification: you become your disease

Nodding, stripping, looked at

Being studied

You feel like the elephant man

Medical voyeurism

Being prodded and poked

The amount of blood taken out of me

Invasion

Interrelatedness of physical and

psychological

One affects the other (headache makes you want to retreat)
False dichotomy
Not either/or

Both have their limitations (psychology and medicine)

Psychology can't help when physical condition is really bad
Good psychologist worth a lot
Has to be the right one as experience of it not helping
Get to know the problem (his solution)

Same situation, different perspective, new behaviours (habituation/adjustment)

Still pain but don't care about it
Nothing has changed, but the way I think about it has changed
Learning new behaviours: Not just go straight to medicine-cabinet
Relax & stay calm
Deep breathing

Transformation/altering your experience/new perspective on pain (related to it differently: the pain that was disabling before)

I befriend it, it's a part of me that I can't get rid of
I understand my pain
I can see my pain
Look pain in the eye
Get to know your pain (advice)

Enlightenment/ Education and information about pain can help

Learning to understand the nature of pain (l. 359)
New behaviours/another way; Pill-taking pacified and teaches you that you must get rid of it
Most people think only way to deal with pain is to get rid of it by taking a pill

Getting to know your pain transforms it

More to know about pain
Pain has many faces
Many different types of pain (headache vs. arthritis) snow (Greenland)

You have power, There is a way/ You can do something/self-efficacy/ power of mind over pain/countering passivity/ Finding what works for you

Your brain is magnificent
Utilising power within you
Small exercises can help you manage the pain
Countering helplessness
Control over pain
Example: pain with each breath
Managed it through breathing
I found a way and now I can cope
Hypnotism

Agency, employing the self/ Countering helplessness / Pain-management programme transformative

Wish it was offered earlier
Other strategies to manage pain

What I learnt about suffering

There's a psychological component to suffering that can be managed
Note: ACT on pain
Situation with sleep now and then (Same but response different)

There is learning and growth in suffering

Walking in rain example - this is life

Everyone is different (no hard and fast rules)

Medicine works differently on different people, but if each

individual person learns to utilise their mental power, this can help
 Amitriptyline no effect on me but great for my friend
 If you can manage yourself mentally - helps

Variation of impact

We're all different
 Variation in response
 Everyone is different
 Element of choice (you can't predict..)
 Personality factors to do with coping
Benefit finding
 I've always seen the positives
 Always been able to focus on positives rather than negatives

The psychological impact of physical conditions (variation)

Personality is a variable
 Became short-tempered

Inter-linked

Not easy to separate components (because not separate)
 What leads to what?
 Vicious cycle of life
 Interconnectedness
 Bi-directionality

Duality mind/body but interconnectedness as can't do one without the other

When mind is willing, body is not
 Body lets me down

Conflicted self

Deep conflict between what I want and need
 You should be grateful
 Fed up/Can't stand it

I hate what is there to help me
 I was worse when I didn't have it
 I need what I loathe
 I don't understand as I know it's

doing me good
 Unable to assimilate what I need as being good for me

Violation of body

Intrusion
 Needle phobia
 Constantly prodded and poked

It's killing me as evidenced by hair, mind etc.

Appearance concerns

I looked a mess (hair)
 Self-consciousness

Poison

Slow death
 Poison effect
 Tastebuds altered

Impact on self/mind

Affects my head/thoughts
 Fuzzy head
 Muddled head
 Can't understand anything
 Can't explain

I'm more than my condition

My condition is not just my skin or joints, it affects me
 I'm more than my physical symptoms
 Lack of person-centred treatment (holistic)

Objectification

I'm prodded and poked
 Constant intrusion
 I'm not a person, but an object

At the heart of AH's conflict is the lack of choice, forcing her to undertake a treatment which she perceives as dangerous and unsafe. In order to cope, driven towards a need for self-

protection, she occasionally rebels, whereby she is reminded that she does not have a choice or copes by pretending to herself that she is going to rebel and not go.

Helplessness/ I don't have a choice. As a result she is in a persistent battle mode with high anxiety, which her body voices.

Treatment (biologics) forced on me
No option

I have no choice

There's no alternative/ Not that anything can be done

No solution

Battle in my head

Constant worry

Constantly weighing up pros and cons

Not rational

Battle

Emotional impact

Ambivalence

I'm worse without it

In a way biologics keep me going

Biologics help me walk a bit further

The body talks

Body rejects

Body speaking/voicing what she feels (veins sunk)

Couldn't swallow

Hairs fell out, went brittle

Symbol of poison

Conditioner ineffective

Harm herself - can't do it (needle phobia)

Emotional impact

Worry about reaction

Weekend ruined due to worry

Exhausted

Comparison with other conditions/disadvantaged self

Comparison with cancer: at least

treatment ends

Pamper days

No information pamphlets

PsA ignored

No help for people with PsA

No leaflets

Awareness in dep. that it's underfunded

Note: She persistently wishes herself to be in a different position than she is, with a different condition, even terminal, as she sees this as being understood/ support being offered.

Impact on life outside hospital / personal relationship

I've become irrational

Flare up at nothing

Loneliness

Worry

Anxiety

Process over time

No adjustment

Harder rather than easier

Harder rather than easier

Harm rather than help

Body over mind

Get together

This is dumb (disjointed care)

This is classic silo working

It's not rocket science

Come on guys, get together

We wouldn't be too much of a bother

You could probably get through us all in a morning

Internal dialogue decisive (what the self feels that matters)

Your internal psychological dialogue is deciding factor when comes to self-image

What other people say doesn't matter

They don't really mean it

You know you're damaged goods

Where is the cut-off point?

When is it classified as more than a superficial complaint?

Note: This is what biomedical thinking is about – which doesn't really work as everyone is different. Yet, has to be incorporated into a system and not be arbitrary/random/at the doctor's fancy.

Heart of battle is a paradox (skips treatment in order to be normal)

Aversion

Can't face going

Can't be brought in contact with it

My goal is to be normal / have a normal life

Work, shop, do nice things

Just a few normal days

Get up in morning refreshed, get dressed, walk around shops

Experience of obstacles/being pro-active

Self-referral

Proactive strategy

Asked for help dealing with situation

Again can't refer her

They are treating me (must be experts)

Yet can't refer med to specialised colleagues

Obstacles again

The system: person is embedded in a system (ethics and cost-effectiveness in medicine)

What justifies being on a dangerous medication for years that isn't working

The ethics of medicine and cost-effectiveness is brutal

Do you experiment first?

Who makes this decision?

Brutal selection process

Brutality in medicine

What justification do you have for withholding a medicine that cures, even if it's expensive?

Note: Different people need different things, but all need to be seen/heard; help them! Find different things difficult depending on their life stage, situation but it seems that everyone needs to feel safe in regard to their treatment.

Variability in coping/The psychological component of illness

Why do some people deal with things wonderfully and other people fall apart?

Meaning making

Responses vary from depression, bitterness, anger to calmness

What is it?

You don't know how you are going to cope

Unpredictable

Social/illness comparison/ Positioning psoriasis on a scale/ Psoriasis is a well illness

Comparison and evaluation:

could be a lot worse

A paralysed lady who is so happy is awe inspiring

I could never cope with that

I could never have coped (lupus)

I felt lucky after I saw what people deal with

Some people have an ill child

Reframing: I don't have it so bad

I'm lucky compared with what everyone else has got

Evaluation: I'm lucky

I'm quite happy with my psoriasis

Lucky that it didn't strike before

(when children were little, washing, cooking

"Thank goodness I got this"

I'm lucky that this is my life and not something else

Lucky that I'm having it now when all my kids are gone and I don't have much work to do

I was lucky that tablets had side-effects (methotrexate)

Reminder that I'm lucky just to have psoriasis

Thank God, I only have this

**Variation in impact of disease/
can't use biomedical marker**

You can't predict how something is going to affect you or affects different people

No objective cut-off-point

Can't use a biomedical marker

Everyone reacts differently

Why do people cope so differently?

Variation in response: same situation, three coped, one didn't (bereavement)

The way you are born

Set in stone

Why did one of us get terrible teeth when we were brought up the same

Same conditions, different response

**Impact depends on life-stage/
culture**

The importance of appearance varies according to different life-stages

There can be no hard and fast rules for when counselling is offered, as everyone is affected differently

It's probably worse for some (young women/men)

I can't imagine how that must feel
Enormously devastating for self-image

Protected by her culture/life stage/ lucky that I'm Jewish

Limited exposure of body

Maybe because we're Jewish, we don't go around in bikinis.

My life-stage "I was already married"

If you are in a bikini and not married...it's probably much harder, right?

My culture has made it easier for me

It would bother me a lot more if I had to wander around in a bikini

We don't have that kind of pressure (change noses/breasts bigger)

It's harder for non-Jewish

Protected by our culture's norms for covering up

We don't have to look good

We don't have to wander around in bikinis

Appearance is less important

It's not like I have to go around in a bikini

Less pressure on appearance

No choice (related to life-stage as well: for NH it was easier when she was busy with children)

I have no choice

I can't go to weddings covered in psoriasis

Fed up – defeat seeking help/ medical help

New life stage now

Now a representative (wedding)

Mind and body (stress)

Everyone reacts to stress in certain ways

Stress has an effect on body

Everybody has a different reaction

There is a connection between mind and body

Body/soul split

Society immature about mental health as opposed to physical health

Many people's problems are psychological in origin

As a society we're afraid of mental as opposed to physical health problems

Fearful of what can't be seen

Not a holistic approach to health, which is physical as well as mental.

Good example: GP provided holistic care (counselling for depression)

Care is not holistic

The true cost of mental health issue to society is never measured

Helping people with psychological issues is complex

Helped, but the cost..

Different people need different things

Need the equivalent of a hospital for mental issues

It's complicated/no simple fix

It's not like putting on a band aid or cast on broken limb?

What would have liked

Would have liked warning about potential psychological effects

Normalization of potential psychological response? (feels shame?)

Empowerment through proactive information

Having the ability to act before it's too late

Creeping up on you (snatches you) Comparison with cancer where counselling is offered

You might go through a rough ride up there in the head

Psychological impact of disease

Helplessness (no agency) can lead to depression/so important to

activate the self

There was no help

Isn't it their job to know something about managing pain?

Emotional impact of pain (anger and depression)

Depression as divide between how things are and how you would like them to be

Not having a helpful strategy to deal with divide

Inability to cope

Helplessness/despair

Jack interesting as tried two very opposing types of care: Current perception of care is positive

Joint patient disease care/looked at disease together/joining of forces

Perception of care

Positive feelings towards hospital

Gratitude to hospital

Your pain is what matters

Different things are important to different people

You can only understand once you've been through it

No matter what people tell you, it's how you feel that matters

Things can only be understood retrospectively (Kierkegaard)

Benefit finding/gratitude

At least I lost weight

Worth having the illness to get thin (1523)

Excuse to stay in bed and enjoy luxury of DVD

I was lucky that tablets had side-effects (methotrexate)

I'm still walking, I can still use my functions

My old friend has kidney failure

Existential Life Wisdom/trust/

gratitude/faith

Sometimes you think you are
unlucky, but you are not
Grass is always greener tendency
You can't always expect to
understand why something is
handed to you
Trust in God
Blaming doesn't help

Gratitude to the NHS

Could never have afforded this
myself

Appendix P**Master Theme Table With Quotes**

Master theme : New Lease of Life		
<i>Sub-theme 1: Miracle of biologics</i>		
Participant	Page & line-number	Quote
Hanif	691	Happiness
Matthew	1034 -1040	Yes, physical, totally. It was from the pit of my stomach and it went upwards and up. I know, this is how I got it, the feeling went from the pit of my stomach up, and then I got a tingling on my hair like goosebumps, and then I could feel it – look, I’m getting it again now a bit.. Because I know, I remember it so vividly. What a feeling
Matthew	419-426	It was... Oh, you see I wouldn’t want to be, I don’t want to sound crude, but it was probably, when it went, it wasn’t gradual. A few bits went, and then after about a week, my wife turned around and said to me, “It’s gone.” Because my back was always the hardest part to go, and I could see it going everywhere else, but when the back went, yes. It was – I don’t want to sound crude but it was like a massive orgasm. The elation, it was like from the pit of my stomach up, and I got goosebumps. I could feel it on the top - it was so...
Hanif	671-678	I do remember the time when my skin was clear, one day when I brought myself under the shower, I was singing for the first time, and I was so happy because I couldn’t take a shower easily, because when water brought to my skin, the pain was terrible and my skin came, became like a baby, very soft. It took four or five weeks
Rebecca	905-911	but for me, like, biologics are amazing. I really have been, like, so much happier and nor- more, you know. Like I said, I just felt normal (..)I didn't feel normal before, do you know what I mean? Like, why, like why have you got it and no-one else has it, you know
Samuel	447-451	But what I couldn’t believe was how quickly, relatively speaking because I was told that it might take two, three, four months before it kicks in. I think it kicked in within four or five weeks, and I was beginning to really feel a distinct difference
Samuel	141-144	The Methotrexate was a bit more helpful but the Enbrel was unbelievable. Almost immediately, within four or five weeks I felt a different person. That’s the case up until today
Jack	172-174	So it’s, so going on to biologics has been a huge success story. Erm, for me, it’s enabled to go back to before I ever had any manifestations of the, of the, er, symptoms

Jack	155-163	I mean, from having a situation where I had, I had large areas of plaque all over my back, erm, all the joints, hands, erm, er, er, scalp, some small ones on the face, it completely cleared up within a very short amount of time. And as far as I'm concerned, while I have Humira, erm, I, I don't have, I don't have any of the manifestations. I get some small areas of plaque (...) but virtually on the level of dry skin. Erm, and I have no mobility issues at all
Hanif	610	It helped me a lot, and it was life-changing, for me
Jack	150-154	that you have to self-inject every two weeks. And, erm, that immediately set to work on condition, on the condition very quickly. Not only did it put the, erm, psoriasis into remission but I gained mobility as well. So it was an enormously successfully, successful thing
Hanif	116-117	fortunately, the biologic medicine helped me a lot. It was like magic after a few weeks – gone
Matthew	291-296	I mean, as with the skin, it has been a miracle. To me, it's been such fantastic results. It's amazing
Matthew	1052-1057	How you feel to how – you know, and to me, getting that first time when I was clear, I didn't have a single plaque on my body for the first time in so many years. It was, hold on, this is not right, you know? It's so good, and I know, you know, it can only be good for me. It can only – if you're feeling better in yourself, surely it's going to help whatever condition you've got “
Matthew	512-515	You don't imagine you'll ever get that. You know, I mean I'd touch my wife's skin, and she's got very, very soft skin and I'd touch her and I'd be jealous, you know? I'd be so jealous, and then I could feel – and it's great. It's great
Matthew	445-447	Yes, it was. I'm back to how I was when I was 18. You know? That was a part of my life,,which was hard, but it was behind me now. It was, oh, it was so good. It was so good
Samuel	444	I started giving myself the injections which I found very easy
Rebecca	172-197	But the truth is, having said that about biologics, the tablets, I had to go the whole time to hospital. I had to go for a blood test the whole time, and I had to be monitored, and I had to... I was like much busier with the tablets than with the biologics (...) The biologics, you don't need to go the whole time, you just have to go for your injection, and that's it, So for me, it was amazing (..) amazing, amazing, It was brilliant, 'cause all I had to do was inject myself. I didn't have to take four tablets a day..It was like so easy..It was ever so good, It was really, really good

<i>Treatments before biologics</i>		
Matthew	304-309	They were trying different cures, they gave light treatment and I actually burnt. I was in underneath the lamp, and I could see the smoke coming off my skin. It actually burnt me (...) So they won't let me have that again, but it was quite severe to look at. So many people likened it to I'd been in a fire, you know?
Matthew	487-490	He goes, "You've got a bit of an infection in your skin." I said, "Right." So he gave me penicillin and I'd never been allergic before but I just had an allergic reaction and all my legs went black and I was in hospital for quite a few weeks with it
Hanif	720-724	I tried to stay at home and moisturise myself two or three times a day, and just imagine if you moisturise yourself three or four times a day and each time takes ages, because all over your body'
Matthew	476-480	She was there through the real bad time when I the allergic reaction to the penicillin. She was through that. I couldn't be touched, physically touched. I couldn't, the pain was so extreme. Oh, it was – I was near enough one big blister
Matthew	620-625	I'd like to change the fact that I had to keep on trying so many different creams that were all steroid-based because I mean, my legs are scarred to hell now because of it
Hanif	216-219	I was admitted in hospital for my psoriasis four times, five times, plus in one occasion for the liver failure and even that one was related to psoriasis anyway
Samuel	365-377	You know, one of the things with psoriasis is you've got to be quite a disciplined person, putting on the creams and the potions and lotions (...) making sure you applied the creams sufficiently so that you're not in discomfort became tedious. Also in those days, less so today although I think they're still the better drugs, the tar-based ones were the ones that stained your clothing, the very strong ones, and the smell was quite –
Matthew	435-443	Because all the years through the treatment, all I kept on getting told by the nurses and everything, "It'll go after 10 years. It'll go, it'll go." Then it never went, never went, and they used to say to me, a receptionist up at the Willington Hospital, she used to say to me, "You're the longest one here." You know, because everyone else is getting treated and it's cleared and gone, and you're still coming after like 13, 14 years. You know, I said, "Well I don't know
Jack	169-76	Erm, and the, the, the thing is, erm, er, you know, constantly taking a medication which really has no effect is very depressing (..)And, and your, and the, and the local use of creams and, and things is, is messy and horrible
Jack	624-627	I, I'd, I'd got to the point where I was at, at, you know, Methotrexate, you know, is variable and milligrams on the dosage and I got pretty well up to the top in, in quotes, 'safe dosage'. Erm, and it wasn't having any effect

Jack	108-118	It was getting worse. And it got to the point about eight years ago when I, I had to buy myself a walking stick. I mean, my, my, the, the rheumatoid part of the condition had got very bad. Erm, and I could only walk with a stick..Erm, and at that point, I got really fed up with it all. I stopped taking any medication and I went to the doctor, the doctor and explained the situation and I was lucky that that doctor knew, erm, had several contacts here at, erm, the Royal Free and suggested that I transfer to the Royal Free
Hanif	145-162	Even at one point, at one stage I was tired of all these medications because I was under lots of them. But you can't believe it, I tried Chinese herb. I saw someone in Harley Street, who specialised in Chinese herbs. You know what happened when I used it? After three days, my liver failed. Yes, my liver failed and my knees size was this much. I couldn't wear trousers, and I was admitted hospital again under, I was given lots of steroids and it took about two weeks time for me to go back to normal. Yes. All of my body was white spots, liver failed, I couldn't breathe. Every day in the hospital, every day, they took one to one and a half litre of water from each knee
Jack	696-719	But again, the thing is, I was trying to do a, to work for a living... Then you've got the point that, that – you're gonna have to start taking a lot of time off work to come to a hospital repeatedly to do – I mean, it, it becomes something which, er, you know, as you said earlier, might be regarded as a, erm, minor ailment, starts to have major, major, like even more major, life impacts (...).I can't remember what the frequency was..(..)But I remember thinking, "Well, I, the condition I've got is very severe and what's the photo-, you know, what, what's that treatment going to be?" And I was thinking, well, you know, "Can't they, can't give you the option of, of getting the right, erm, type of lamp that you could have at home?" for instance...But then I understand it's got to be monitored and it's got to be done. So, I mean, it, it, again, that's an example of where, erm, the cure or maybe the, just the maintenance of it becomes something which, , you can't work anymore
<i>Sub-theme 2: Being able to do things again</i>		
Samuel	177-184	You feel as if you've got a new lease of life. I'm probably fitter now, with all the pills that I take and all the drugs that I inject and so on, at 67 than I was when I was in my mid-40s because in my mid-40s I was carrying around 20 stone and I was probably eating incorrectly and so on, and working hard and being on the treadmill of life. So I'm probably better off now than I was then

Rebecca	186-199	I felt normal. You know? I, like, I told you my kids say, erm, that our house is the only house in the world were it snows inside instead of outside (..) I used to leave trails of, you know, like scales the whole time...And always had to have baths, always had to put moisturiser on, Even when I went shopping and I tried on a skirt, I was so embarrassed, you know, 'cause like all the scales used to come off on the skirt, if I didn't buy it. And you know, like, it wasn't..It was, you know, it wasn't, it wasn't nice to live with it, but I did, so this biologics is brilliant
Samuel	209-214	You can enjoy your life. If you reach good years and you've got grandchildren and you've got positive things in your life, this is probably the only time in your life when you can actually sit back and enjoy them. If you haven't got your health at whatever level, that impacts on it. It must impact on it
Rebecca	241 – 257	It felt normal. I could get up in the morning, I didn't have to start having a bath with oil, sit in it for an hour, then put on cream, and then... I, I used to have a bath, like sometimes three, four times a day, 'cause I couldn't cope with my skin. And everything used to be oily, you know? (..) And here, I just felt like a normal person. I could get up in the morning, and get dressed, and go out, and you know, like-I just, yeah, I felt normal (..)I felt like everyone else does, you know. It was really, really – I really felt good, I really, really did...Like my whole mood was good, you know, 'cause like I didn't have to think about it the whole time
Matthew	827-833	It just is – I mean, I never had a holiday for, as I say the best part of, well it would have been about 13, 14 years. I never had a holiday. Not a break, you know? But now, I went for a week away with my wife down to the coast this year. I went in May. I'm going again in September. It's just these are the little things now that I can say, "That's what I want to do." You know, if I want to go away, I can go away.
Hanif	693-94	And I started again to see people, and tried to go out and going to the gym at the time
Samuel	162-173	My ability to use my body in whichever way I want to is pretty good, and much, much better than it was three or four years ago where I was walking almost rigid and stiff, and so on. I'm much more flexible and so on
Samuel	473-479	Now if you ask me to put myself back into that frame of mind of how I was, I was miserable, and I'm not miserable now. So that's the major change. Did the arthritis stop me from doing anything? Well yes, it restricted certain things and it restricted therefore as a result stamina to do things for a longer period of time. So therefore I've got more stamina and I've got more flexibility, and therefore I'm doing more things, and therefore I'm enjoying things more
<i>Life with pain, stiffness and immobility</i>		

Jack	1241 - 1244	But, yes, it was really, er, when I think about it, it was, I was, it was really painful. Getting to sleep was really difficult. Waking up and then you were incredibly stiff. And try, and getting out of bed in the morning and standing up and getting dressed were painful processes
Samuel	106-112	I started getting aches and pains and lacking strength in my upper torso and not being able to create any strength. Even if the muscular strength was there, the pain level sort of iAvivaibited it, and the two things became a vicious circle. The more painful it is to do something, the less you do it. Therefore the less you do it, the more painful it becomes
Alice	317-334	My psoriasis was that bad, it was really, really painful..Erm, I couldn't get through the night. I'd have a big tub of the greasiest, greasiest emollient...Every ten minutes I'd have to plaster it on and as soon as I'd put it on it would be bone dry again...Erm, and I couldn't sleep and it was painful. Erm, and then because I literally couldn't do anything and I couldn't wash my hands and everything was painful. I'd dread getting washed or having a bath, everything was painful and once it gets bad like that it's really difficult to.....to get it better. Erm, so I, I was just in a mess. I couldn't sleep, I couldn't get dressed, I couldn't wash. The cream was having no effect at all. Erm, I'd be crying all the time. I, I literally wanted to die because I had no quality of life"
Jack	309 -333	I had the arthritic condition (..)So that was really reducing my mobility (..) Where it, er, where it was painful to walk (..) Erm, and certain amounts of joint pain in other, other joints as well (..) er, again, for, for, er, for me, it was suddenly being confronted with, er, I, I guess it would be, erm, I imagine (...) And suddenly, erm, it's something that you think, "Well, I'm old now." (...) Because this is something which, generally speaking in, erm, in, the, the body breaking down. It's something which I associate with a, a, with a -- a later stage (...) A, a later or even a sort of proto-final phase of life (..) You, you think, "Well, it's going to go, it's all going to be degenerative from now on.
Rebecca	1543	I said, I couldn't get out of the bath. I couldn't peel. I couldn't – I can't open tins, even now my husband has to open one tin that I haven't, doesn't [thing 0:54:40]. I can't, I can't carry, I can't – you know, I, it's been impacting me loads (..)I mean, I couldn't even walk to the Royal Free. I was like laughing, there was like 80-year-old ladies walking past me, and they had a stick, and they were walking faster than me
Rebecca	151-155	I was itching, It, I was like, I couldn't cope any more. I was like, I couldn't sleep at night, I couldn't do anything. I had to sit in the bath the whole day, practically. I didn't have time for that

Rebecca	269-278	My mood, but my mood was only low because of the psoriasis, do you now what I mean. I wasn't even low, I just, I couldn't be bothered any more. Maybe I'm lazy, I don't know. But you know, like the whole time, to have that, and also I was itching and that. That I couldn't cope with (..) I can cope with anything else, but the itching I couldn't cope with (..)The whole time, the whole 24/7, the whole time. Itching, itching, itching. I couldn't cope with it
Rebecca	1414-1416	I came home and phoned my kids and told them right, this is me, you know, this is the old ladies walking faster than me, you know
Rebecca	1422-1440	It had stopped my life, literally. My life stopped for months (..)I wasn't able to do anything, I couldn't hardly go up and down the stairs, Every time I went to the toilet it was like, nightmare. Because I couldn't walk to the toilet, I couldn't, I, I'm so embarrassed to say this, but I couldn't even wipe myself after I'd been, do you know what I mean? It was, everything was hurting me..."And I couldn't itch myself, like that was the worst. That was again the worst, the itching. So my psoriasis went really bad, and the itching. So if I would have felt okay, if I would have been able to itch myself, I would have been okay, but I couldn't even itch myself. I couldn't do anything. So it was like, you know-
Samuel	845-852	I think my body would have started – it does close down on you, your body a little bit quicker doesn't it, because there's this vicious downward cycle of you used to walk two miles a day and now you only walk a mile a day, now you only walk half a mile a day and so on and everything starts coming in. Well you haven't got any of those restrictions. You do what you want to do, as you want to do it, not because you're being restricted. So you've got a freedom"
Samuel	106-112	I started getting aches and pains and lacking strength in my upper torso and not being able to create any strength. Even if the muscular strength was there, the pain level sort of inhibited it, and the two things became a vicious circle. The more painful it is to do something, the less you do it. Therefore the less you do it, the more painful it becomes"
Samuel	475-479	Did the arthritis stop me from doing anything? Well yes, it restricted certain things and it restricted therefore as a result stamina to do things for a longer period of time. So therefore I've got more stamina and I've got more flexibility, and therefore I'm doing more things, and therefore I'm enjoying things more
Rebecca	1393-1395	I mean, I couldn't even walk to the Royal Free. I was like laughing, there was like 80-year-old ladies walking past me, and they had a stick, and they were walking faster than me.

Sub-theme 3: Freedom from stigma and shame

Matthew	450-461	I mean, straight away I could wear shorts, and t-shirts or a vest, you know? I could do that, but I'd have to walk around and all my friends might be in shorts and I'm in jeans and I'm sweating. Oh, just that. I mean, I still have the joint pain so it's not like I can go back to playing football again or that sort of thing, but as regards, I can go out and not feel – I'd be jealous. Friends of mine would say, "Oh, we went down to the boating lake. We sat there, we had a picnic." Things like that. I could actually go and do that without being self-conscious. It was superb. I could sit in shorts, without looking out of place because I'd normally have to wear a long-sleeved top and jeans, and everyone else is in t-shirts and shorts. You feel very, very different then, so that only adds to the self-consciousness
Hanif	693-94	And I started again to see people, and tried to go out and going to the gym at the time
Matthew	463-468	But it was just little things like that. I could go to a beach. I went abroad for the first time, because I didn't see the point of going abroad. All my friends were going to Spain and to Portugal and the likes, and why would I go when I've got to walk around with them? I could go abroad, so I did. It was, you know, it opened the door a bit. It was great. It was just a fantastic feeling
Rebecca	199-213	I felt normal. You know? I, like, I told you my kids say, erm, that our house is the only house in the world were it snows inside instead of outside (..) I used to leave trails of, you know, like scales the whole time....And always had to have baths, always had to put moisturiser on, Even when I went shopping and I tried on a skirt, I was so embarrassed, you know, 'cause like all the scales used to come off on the skirt, if I didn't buy it. And you know, like, it wasn't..It was, you know, it wasn't, it wasn't nice to live with it, but I did, so this biologics is brilliant
Hanif	251	Yes, I'm very well now and I can love, and I couldn't love at all. No
<i>Life with stigma and shame</i>		
Hanif	715-718	Actually, one of the reasons, yes, because when I was out everyone was just showing me to each other, you know?... Actually when you feel this way, you don't feel good when – on the other hand, I had pain as well. Then I didn't go out, because of the people first, and the pain as well

Matthew	327-342	Well, I just used to cover myself up all the time and try and avoid situations. I didn't have a girlfriend for 10 years because I was too ashamed of how I looked. Yes, it was hard, because getting it at a certain time, I'm not sure if I'm right but it probably would have been easier to deal with if I was 9 rather than 19, or 29. But latter teenage years, yes, it was difficult. In my early 20s it was very difficult, because even if I covered up, sometimes I'd move and some skin would fall out and land on the floor around me, you know? People, they used to comment on it. "You're snowing." (...) You know? But strangers would comment on it, and say, "What's that? Can I catch it?" Can they catch it off me, you know? It wasn't easy so I tried avoiding a lot of social – the social side of anything, I tried to avoid it, you know?
Rebecca	391-395	I was like more embarrassed, more, you know, like, but – you know, people say stupid things, as well. You know what I mean? Oh, yes. People like, when I went swimming, I remember I used to go swimming. People used to come up to me and say, "Is it catching?" You know. People don't know, you know
Samuel	314-320	Well, I didn't take part in much sport during that period of time. Not anywhere where you sort of undress. I mean you know psoriasis, I had lumps, an area that big there, an area that big there. Both my buttocks would be completely covered. My back would be pockmarked. I'd have enormous welts over the arms and so on, so you just wouldn't undress
Samuel	221-233	At the time that I had the physical side of the psoriasis with the encrustation and so on, I was very embarrassed by it, and the form of embarrassment is the sort of thing that you wouldn't go swimming. If you went on holiday, you would be covered up. Not because you didn't want to uncover yourself, but you just felt self-conscious. So that's one side of it. The other side of it is the physicality of the arthritis where you can't participate in simple things the way other people are. So if you're going swimming for example, I couldn't do the crawl. I might be able to do the breast stroke because it was easier swimming stroke for me, but crawl which is what I used to do, I couldn't do it
Samuel	326-332	One is the ignorance of other people, because when they see that, I'm not saying it's leprosy because it's not leprosy, it's nothing like leprosy but people who don't know what it is and don't know psoriasis at all and most people, and why should they, think it might be infectious so there was that element of it. So there's the ignorance element of the third party
Rebecca	399	What's on your face," or, "Ew, your hands," you know, like-
Samuel	333-334	I never felt clean. I never felt clean, and I was always very conscious of the flaking skin and so on
Jack	186-189	Plus the fact that you're, you know, you're shedding skin at a, at a kind of mega-dandruff level (Laughter) all over your body, it makes, it, you know, it, it absolutely destroys your self-image

Jack	222-229	It rather goes back to that thing that, you know, that, that the very simplest thing that, erm, that dandruff is a, erm, you know, a kind of a socially frowned-upon thing. And you can't wear any dark clothes, And it, and, erm, and it, it generally, erm, it seems to be, to me, er, one of, an example of one of those things, and it may just be me, but it's one of those things where it kind of shows that somebody isn't looking after themselves well
Jack	231-236	Because it's, erm, and, and that may be, that may be very harsh..But the fact is it's an unattractive condition. Erm, and I think that, erm, that when you get on to the plaques that form from, erm, from psoriasis, erm, it, it just does make you, it, it made me feel, you know, ugly and, er, and, er, it's like having a deformation
Jack	284-295	It's the fact that you're shedding skin...and you, you, you, you get into habits like, you know, surreptitiously checking a chair where you've been sitting...Because it, you think, "Well, I wouldn't want to go and sit in a chair that was covered with... You know, with, er, with skin particles, so, you know, you, you, you're just feeling psychologically, I think, on the back foot all the time
Jack	467-479	Because psychologically you're kind of feeling like a, er, I mean I wholly inappropriate comparison. But you're, erm, you know, you're, you're feeling like the Elephant Man. (Laughter)
Matthew	540-565	I mean I remember once, alright it worked in my favour but I was on a tube on the London Underground and a gypsy came over begging with her daughter. She was going through the train begging, and she got to me and she was like, she physically screamed. She got down and she was grabbing her daughter, "Get off, get off. You'll catch it. Don't go near him." In front of the whole train, so in one sense she didn't beg off of me, but she made me – and there was nowhere to go. Once you're on a tube train and you're going through the tunnel, there's nowhere to go. So for the rest of the time to the next stop, everyone was just looking at me. It was, you know, people's perceptions...(.) But you know, some people, I can remember I went to a pub with some friends and it was a very, very busy pub and this couple, I didn't know them, and they came in and there was only space to get to the bar between me and the next person. The girl walked in like that, she's gone, "Do you mind?" I said, "No, no." She's gone to the bar and her boyfriend pulled her back and said, "No. Look, don't go near him. Look at the state of him." (..) Yes, but I was so happy when she turned around and she gave him a little smack on the face. She goes, "That's psoriasis." She knew it. She didn't know me, but she said, "That's psoriasis. There's nothing wrong with it. Idiot." She swore at him and I was like, "Thank you." You know? It was brilliant. She was with her boyfriend but she took my side on that. You know, that was good

Alice	1370-95	When my psoriasis is bad on my hands and people treat you like a leper or they step back and they go, "Oh," or they stare or, you know, shops are an awful thing when they slam the change on the counter, they won't put it in my hand, 'cause I got psoriasis on my hand. I've come out with many - I, I build all my confidence, I pluck up the courage to go shopping and, and again it's this not being believed. Nobody would believe me when I said, "Oh, you know, that checkout assistant slammed the change on the counter," they put it in the person before and the person after's hand, and hand them the receipt. It was just me. Then I've got my friends and family saying, "oh don't be silly, it wasn't just you it's just your..." "I was in a wheelchair when I first had my op, my partner had to push me into the shop. Psoriasis was bad. He'd slammed the change on the counter, wouldn't put it in my hand, threw my receipts at me. We came out the shop, filled up with tears and I said, "Was that me or..." to my partner, "Was that me?" He said, "No, I'm going back in that shop, if you don't I'm going." So then eventually he believed me. Erm, nobody believed me, it was appalling the way I was treated. So erm, so that makes it worse (..)It takes a lot to get me to go and then when somebody stares or somebody makes a comment it's, erm..."
Hanif	417	I was like a person who is in a prison. My office is in my home, just upstairs, actually
Hanif	428-437	Before this course, I was in a prison in my home, 24 hours a day, just I visited my client, doing the web design, and searching the internet and that's it, and go to sleep, shower, work, eat (...) And out? No. Visiting people? No. Going on holiday? No"
Hanif,	128-133	In one word, I can describe in one word. I coming close to suicide. I was suicidal, and it was terrible. It was terrible, and I couldn't sleep. I had pain all the time. I hated people. I didn't want to talk to someone. I didn't want to see someone. Just a terrible situation
Hanif	235-238	At the time, I didn't know what is love. I hated everyone, as I mentioned. I didn't want to see anyone at all. Just I came to the hospital and see the doctor. That's it

Master-theme: Living with the fear of the unknown

Participant	Page & line-number	Quote
<i>Sub-theme: It's a firewall not a cure</i>		
Jack	730-744	But going through that self-injecting process is very much a reminder, erm, that, you know, I'm, it, I've, I've got a, I've a firewall against something which if I stopped doing that would probably return with a vengeance very quickly. So (...) well, I'm saying an effective treatment that, one, you have to continue for ever, because it's not a cure - is no more than an firewall, is it? I mean, you've put, you've created an effective barrier to the manifestation of the condition

Alice	19-26	I shouldn't detest them so much because it's there to help me but I hate it, because it's every single week. It has been for the last five years. I've had other biologics previous to that..Erm and very often they work for the first sort of three months on me then they stop working.
Alice	508-510	But it, it's the fact that there's no end to it and then the fact that I'm on this and then my body gets used to it, so then I need stronger and stronger stuff
Alice	1048-1056	My biologics have helped me do that, erm, they help me walk a bit further, less pain in my joints...but then I still can't, I still can't do, it doesn't cure it. It makes me better, but then I've got the side effects where I lose virtually two days a week and then every six to eight weeks I have my infusion and it's just.....I just get tired with it all
Rebecca	557-559	Because I think your body gets used to it, maybe, or, I don't know..They always gave me another one
Alice	410- 418	Erm, and erm, and then I just start to feel better Thursday and Friday and then there's never a break, and then it's gosh, you know, it's the weekend (pause) time again. So it's, you know, if it was every month or two months, it wouldn't be so bad, but I just start to feel better and I feel better in my head.....and then wham, it's back again
Alice	1082-1087	"And it just, the weeks come so quickly and then I get over it and it's time to have it again....and I think partly because I've got all these hospital appointments next week it's just like, I just want a breather. I just want time out"
Alice	1062-1070	I-if there was an end to it, like if it's a broken leg, you know you'll be in plaster for however many weeks or months or whatever it is but there is no end to this...It, it, it does affect me. It's, I want to, I want it to stop, I want an end to it all. And this, and this is why every so often I suddenly stop having my treatment 'cause I have it right, I'm full of it and I've had enough of it, so I'm...
Alice	144-148	It's exhausting and I don't, I feel I never have one day at home to myself. Erm, I have my Methotrexate Monday, Tuesday I feel ill all day, so I can't do anything. I'm tired and I feel ill, so I can't really do much.
Alice	200-204	Erm, I feel terribly sick after the tablets...and I'd come back after I'd taken them, I'd lie on the settee, blanket over me, and the rest of that day or the next day I'd feel sick
Alice	37-45	I was supposed to have had it yesterday, but I didn't have it 'cause I've had it absolutely up to here with it all and every so often I just can't stand it. And yet I know I need it because about two years ago, erm, I'd had enough of it, the side effects and, erm, I didn't, I missed four injections and I was bedridden with my psoriasis and my arthritis. I was that bad. So I know I need it. So, and people say to me, erm, "Well you know you need it. It's for your benefit so you should." And I still can't accept it. It's, there's no end to it

<i>Sub-theme: Embodying an experiment</i>		
Jack	377-389	you, you, there was a medication, er, prescribed that was, that had dangerous side effects anyway and the fact that, erm, the fact that they are, erm, that they are anti-immunes, means potentially, because no-, because nobody could say exactly. But that meant that, well, if you, if you're reducing your, of the, erm, efficacy of your immune system, what are the other ailments are you leaving yourself open to? And that was never really explained (...) But if you depress the immune system, or, you know, suppress it, it must have, you know, immunosuppressant things must have other things. As we – I mean, you know, it, it, it's all those things that you start to worry
Alice	123-126	I just feel like I'm being prodded and poked. And that can be like Monday I have my Methotrexate injection, erm, then Friday I have my infusion, then I have to have my bloods done every two weeks, and, and I'm just, I hate it
Jack	747-764	“it's unknown it's quite extraordinary that you've got these twin things about psoria-, about in psoriatic arthropathy, with two very different manifestations of what allegedly is the same condition. But in was, you can't imagine anything more difficult, more different – than a rheumatoid condition and then a skin – one. It's an extraordinary, erm, an evil combination of opposites...Erm, with a treatment that's not quite known how it works with a condition that's ____ [0:41:32] what it is Erm, (Laughter) –So, it, it feels quite a strange position
Samuel	645-654	Also, there wasn't a great deal of opportunity to discuss anything more than the basics, so even something like the Tigason which was at experimental stages when I started to take it, there wasn't a long discussion about – yes, “Look, I've got this drug. It's new, it's experimental in the sense that only X number of people are on it in the United Kingdom but it's having great results and so on. Would you like to take it?” Well, you're going to be stupid if you're going to say “No.” You're going to say “Yes” and that's about as much discussion as there was with it
Jack	414-417	Erm, none of them were evolved as a treatment for psoriasis ..And they happened to work on psoriasis

Alice	1147-1165	<p>And then one time it wasn't my normal consultant, it was a student doctor and she said, "Let's have a look at your back." I said, "I haven't got any psoriasis on my back." "Oh well we need to look because, erm, you do understand the importance of checking for skin lesions because you're prone to skin cancer on the treatment you're on." This is what a student doctor said to me, so that was the reason the consultant wanted to check my back. They're not honest. She wasn't honest with me and I had the shock of my life when the student doctor had said, "Oh well you, you do understand the importance of checking for lesions." No, I didn't know. No, I didn't know it caused skin cancer.. So I come away, have all these shocks and I come away and I'm left to deal with it on my own. So then I start looking on the internet, ooh can it cause cancer and then I find all this information on the internet. I've gotta deal with it all on my own. They're not honest. I'm really starting to resent and detest the medical profession</p>
Jack	423-434	<p>But it's also worrying that you're taking something that – I mean, to me it's a, there's a parallel with the over prescription of antibiotics.. You find something that's effective..Erm, you, you can end up, erm, you're, you're not prescribing a targeted, erm, cure. You're using something which has an effect but you don't understand (Laughter) why it has an effect..It's just it is effective. Well, that's is, is not best medicine, in my view</p>
Alice	295-304	<p>I had a drug years and years ago, 20 years ago, the PUVA treatment and they said it was really safe. They gave me more than a lifetimes worth of treatment and now they recognise that skin cancer's very common in people who've had that treatment. And I know three people who've had skin cancer who had PUVA at the same time as me. So I, I'm very fearful. Erm, the, the other, erm, major health scares I've had the blood clot on my lung, the, erm, problems with my liver, the problems that I think I've got with my heart, how do I know it's not from these drugs</p>
Jack	391-406	<p>I mean, it's rather like somebody who, erm, erm, who becomes HIV..And, you know, a, a, terrible part of that disease, of that virus – is that is the depression of the immune system and leaving individuals open to other sorts of, of, er, of, er, viruses which they, which might not affect [the strong 0:21:12]. But anything else, erm, can become a serious condition in its own right. So you're thinking, "Well, they're giving me a medication, there's a medication..." The state of the thing is not only have you got, erm, a condition which is not really, it doesn't really, it's not going into remission, but you're doing, you're, you're, there are quite serious side effects..Erm, and also it's medication which the medical profession doesn't know why it works</p>
Alice	543-545	<p>What it's doing to my body, nobody knows the, the long term side effects because they're relatively new treatments, so what damage is it doing</p>

Matthew	812-819	I don't have any worries, you know? I don't. As with any medicine, there's always some sort of side effect, or chance of a side effect with anything. A cold remedy, you can get a side effect, so I don't worry about that. You know, there's just no stress whatsoever from – you know?
Alice	289-293	But it's, it's not their body. And then there's all the long lasting side effects.. They don't know, 'cause it's a relatively new drug....how do they know how that affects me in ten years' time?
Alice	58-62	so you can't get any independent information. So I look on the internet and hear all this worrying, er, all this worrying information, you know, this treatment can cause this, this, this. And then I suggest it to the hospital, "Oh don't take any notice of that, don't look on there, oh you're alright.
Samuel	667-677	Maybe not. Maybe not, because you don't want to be told when you're going to die. You know you're going to die but you don't really want to know when you're going to die because you'll spend your whole life focused on the wrong thing. But it was never mentioned at any stage, "By the way, you should be aware that 10%, 20%, 30% of people who have psoriasis will also have other problems that are psoriatic arthritis." It was never mentioned, so when I first got my pains and so on, we didn't know what it was so obviously it was diagnosed. So there's not enough information out there
Samuel	559-570	I don't think enough of that is done in what I call long-term conditions. So, okay, you wake up one day and somebody tells you you've got arthritis, but they don't really tell you what your life's going to be like with it, or what expectations you've got for life, or even to say to you, "Look, don't worry about it. There are six million other people in the country that have got these problems, or however many, and everyone's coping with it relatively well." Of course there are some that are better than others but there's no picture painted unless you do the research yourself, of what you've got to expect going forward. I think that...
Samuel	577-589	So there's very little intercommunication between the medical practitioner who knows what they're doing, and the ability to transmit the thought processes that they're going through that would clarify what they're doing. So in other words, "I think you should be on Sulfasalazine. We'll put you on Sulfasalazine. You'll have X number of these at 2.5 mg" or whatever it is, or two tablets a day or whatever it is, and we'll start off with one tablet and so on, but none of that is really explained well. They usually give you a leaflet, and I find that the leaflets are over-simplistic in some respects, and they don't do anything about conveying emotion. They only just talk about hard facts
Alice	54-57	you can't get any independent advice from anyone as to the side effects 'cause the people who give it you if, like I was treated for a blood clot on my lung, now I'm having heart problems

Alice	62-69	I mean for the last, I don't know how many months, my liver count's been rising and rising which I think is to do with the Methotrexate. So they keep their eye on it...but they don't do anything. Finally now I'm going for a liver scan but they don't, they, they don't willingly do anything. It's just swept under the carpet and they just..
Alice	69-75	It's not their body, it's my body and I resent it every week. If I have a headache I don't even like taking a Paracetamol...and I resent having a highly toxic drug.....into my body. I hate it
Alice	101-107	And there's always the scare before I go for my Infliximab. I've seen one person having it and they, er, had some problem with their heart and they were rushed, they went into cardiac arrest, they were rushed over to, you know, the, the A&E. And I always have a, a fear before I go (...) so I spend all weekend worrying about it
<i>Sub-theme 3: The role of information</i>		
Samuel	662-665	Nobody ever mentioned to me that one of the things that you might have to face in future years, X percentage of people who have psoriasis will also have psoriatic arthritis. It never was discussed
Alice	58-62	so you can't get any independent information. So I look on the internet and hear all this worrying, er, all this worrying information, you know, this treatment can cause this, this, this. And then I suggest it to the hospital, "Oh don't take any notice of that, don't look on there, oh you're alright."
Hanif	568-582	just one leaflet, one booklet can help to realise about the pain, because most people don't know about the pain. They believe if they have headaches, they have to take Paracetamol and the headache gone... As I mentioned, you have to know what is the pain, and you have to take, even if you want to take one painkiller, you need to know each painkiller works for different things. You can't take Gabapentin for headache, or you can't take Paracetamol for your slipped disc. You have to know your pain, and you have to know these. You have to educate
Rebecca	621-629	But you have to do it. I mean, even when you take a panadol, they give you a hundred things...And half the time when I was taking now, erm, leflunomide, even, yeAlice. The very fact I'm taking it was for my skin, and my inflammation. And that's one of the side effects that they causes, so I don't understand the whole thing. It causes rashes, it causes inflammation, I don't understand, you know. So they're just writing everything
Rebecca	640-649	Exactly. So, but I suppose they have to write everything, I don't know (..) They have to safeguard themselves (..)Yes, you never, you'd never take anything, You'll never take anything"
Rebecca	656-659	I would take the information home..And I would read it after, when it like, when it worked and everything
Rebecca	168-170	So even when they gave me things, leaflets to read and everything, I said, "I'm not reading it, because then I'm not gonna take the tablets

Alice	470-478	And, and I'd like them to be more open 'cause if it is, you know.....obviously all things have side effects, I can make, I could have made the choice in the beginning as to whether...I wanted to have it
Alice	1124-1137	You can't get independent advice. The only people advising you are the people who are pushing the drug, who want you to have it or the GP who says, "Well yeAlice, the, the hospitals recommended it." But I want some sort of independent advice or somebody to say, "Well these are your options..This causes this side effect, this this," and, and give me the information and the time for you to go and read and...They, they kept a lot back from me on, on the side effects of these things. They, they don't tell you and then it's only after you've been on it for a while that..... things come to light, "Oh yes it does do that, oh yes,"
Samuel	796-800	But when you've got to live with something for a long period of time, I think the communication of what to expect, how to treat, and how things develop, how things may not develop and so on, I think that's still relatively under-served, that area"
Samuel	806-811	I mean, if I'm going to spend shall we say 30 or so years of my life with problems related to psoriatic arthritis, I shouldn't become an expert at it but I should know what my path might be, what the options are in what you do for yourself and what your options are if your body goes in a particular direction
Alice	1180-1194	Well to me the patient has the right to know, I have the right to know...I'd rather, it's my body, it's not their body...I'd rather, I'd like to know everything.....and then and then weigh up the pros and cons.....and then it's my, I don't like to have a treatment and then, erm, and be told it's fine and then have it over lifetimes worth of treatment of it.....and then to be told oh you'd probably get skin cancer, that isn't fair. I'd like to know
Jack	1260-1306	So I think offering that right package of saying, erm, "We do need to, to tell you that," er, from a, in a proactive way – "We do need to tell you about this, that we do not, we are not, erm, oblivious to the fact that something like this, that might take a while to cure, erm, it might remain in a very mild manifestation that happily will clear up and a few months visiting a clinic and medication will work and you won't have it providing you take certain things. It might not be troublesome.."But also –"– it is going to, it is something that you're going to find upsetting. And we are not –"– we're not oblivious to that side of it."So I think that that positive thing. And it has to handled sensitively because you don't' want to start a fire where (..) – there isn't one"
Jack	1310 – 1312	But personally, I feel like it should probably be proactive..Erm, in the information that's given out

Alice	343-350	The very first time I went on a biologic, I was sort of forced into it. I wasn't given lots of information about it. This is a few years ago, and I was told it was a different hospital to what I'm at now, basically well if you don't have this treatment, 'cause I said I'm a bit worried about the side effects, well if you don't have this treatment, if, if the treatment doesn't kill you, the disease will. So virtually you got no option but to go on it
Jack	391-406	I mean, it's rather like somebody who, erm, erm, who becomes HIV..And, you know, a, a, terrible part of that disease, of that virus – is that is the depression of the immune system and leaving individuals open to other sorts of, of, er, of, er, viruses which they, which might not affect [the strong 0:21:12]. But anything else, erm, can become a serious condition in its own right. So you're thinking, "Well, they're giving me a medication, there's a medication..." The state of the thing is not only have you got, erm, a condition which is not really, it doesn't really, it's not going into remission, but you're doing, you're, you're, there are quite serious side effects..Erm, and also it's medication which the medical profession doesn't know why it works
Alice	455-459	But they're not honest with me, if they showed me and explained everything.....then, well I don't know what choice I have but I, I like to be kept in the picture
<i>Sub-theme 4: Coping with the fear of what tomorrow brings</i>		
Matthew	397-405	I really don't know. I just – my mum is a very strong-willed woman and I think I do take after her and she'd say, "You've just got to get on." Her dad had it (...) She used to say to me, "He just had to get on with it. Get up, go to work." She said, "Back then when he was a young man, there was nothing." There was nothing. You might get a load of coal tar and that was it. Smother yourself in that or put petroleum jelly. That was it. That was the basics back when he had it. So she said, "You've just got to get on with it. You still have to go to work. You can't not work." I just took it on board and said, "Well, yes." Obviously she's seen my grandfather doing it, so just get on with it. That was it, I just dealt with it

Rebecca	792-811	You see so much in the world now, like so many afflictions, and you read so many stories about this person who's not well, and that person, or this person has an ill child, or you know. Like for me, I was like – 'cause I, I remember once, 'cause Jewish people organise things, and one lady brought somebody over, have you heard of like healing, like heat, heat healing, or..I don't know, you have all those people, dowsing and all that type of thing. Have you heard about these things? Yeah, like alternative medicines. I went once, to this like man, he was like – I mean, he didn't touch us or anything, 'cause we're not allowed anyway. So I thought, you know, you can't lose, you can only lose money. So I went to him, and there were loads of people in the waiting room. And if I promise you, I came out thinking, "Thank God I have my psoriasis." Because other people had so much worse. Like phys- you know, some people had like no, the oxygen in their legs, or something. I can't even remember any more. All I can remember is coming out thinking, "It was worth going just to know that I'm happy with my psoriasis."
Matthew	647-651	"No, you're lucky you've got some treatment." You know, she said, "And there's always someone worse off than you." You know, so you can keep on thinking that every day of the week, every day of the week. It's what might get you up. You know, it probably got me up out of bed a few times, you know?"
Matthew	747-753	It's totally helped me, so – but some days all I want to do is go and lie down, curl in a ball and cry. I don't. I haven't done it, but I've wanted to on quite a number of occasions. But just there, saying you know, I know people. I know a few people that have got terminal cancer. I know three or four people, it's not great but I do know them, and I think to myself, "Well, look at them. They're getting up and going." You know?
Rebecca	1111	I read stories, like I read now something, erm, about this lady, what was it? I don't know, I think she's practically paralysed or something. And, erm, and she's like so positive. Because we have like Jewish magazines, and people write in their stories... She's so positive, and so, erm, like smiles, and, and, and you know, I think to myself, again, "Thank goodness I got this." I could never cope with that, you know (..) Like, it just, there are so much worse things around..But I don't know"
Rebecca	168-170	So even when they gave me things, leaflets to read and everything, I said, "I'm not reading it, because then I'm not gonna take the tablets"
Matthew	409-415	There's always someone worse. I've always focused on that. There's always someone worse, you know?" (...)I've had a couple of very young cousins die of cancer, when I was younger. It was like, there's always someone worse (...) Yes, stop moaning about it and just... So that was basically it

Rebecca	114	And you know what? When you see what everyone else has got, I was quite happy with, you know, my psoriasis (..) It's a well illness, and it, you know, erm (..) Yeah. that's what it's called, It's called a well illness, Thank God, you know, like
Rebecca	1464-1474	But you'll laugh at me now, 'cause I'm saying that my sister has lupus. Do you know what lupus is? So she had it since she's been married. That means she had it with having been pregnant, having kids. Having to change their nappies, having to lift them And I thought, "Thank God it happened to me now. I could never have coped like she did, with the kids. Never.
Rebecca	1338-1375	You should have seen me six – that was one good thing that came out of this illness, I tell everybody, I was like – I lost weight because I didn't eat..And I was tired, and I didn't – and I think the tablets also made me like a bit nauseous, you know...And, and it was – so now I'm keeping it up. I tell you, it was the best thing. I was like, I was, I was very overweight before..Really, really overweight..Yeah, I'm really happy. So it was worth having the illness
Rebecca	1506-1515	When I got better, I enjoyed the excuse for staying in bed..I enjoyed the excuse for staying..I got myself a DVD machine.. And I, and I watched DVDs.
Matthew	812-819	It's been fantastic so to me, even if I'm on the same dose of Humira for the next however long, five months, five years, whatever it may be, I know my condition will only get better. I'm positive about that so I mean, as regards that, I don't have any worries, you know? I don't. As with any medicine, there's always some sort of side effect, or chance of a side effect with anything. A cold remedy, you can get a side effect, so I don't worry about that. You know, there's just no stress whatsoever from – you know?
Samuel	710-712	I don't concern myself about the future. I've learnt to live for today and not in excess, but to take each day as it comes
Samuel	715-722	No, I think it's my general philosophy on life. I've always had this feeling that people spend too much time projecting too far forward because there are many things that happen in life that are outside of your control, and you need to be resilient enough to adapt accordingly. But okay, maybe when you're in your 20s you don't see that quite so clearly, but I think as you get older you realise that there's nothing forever

Samuel	736-748	But I would have been like that if I hadn't had the illness. I learnt very early on when we went to live in Israel, Israel is a troubled place at the moment (..)But one of the things we learnt because of that stressful type of society that Israel is, because of what goes on there, was that you need to live for today because you don't know what tomorrow will bring and I think that most of us in England don't have that attitude, purely and simply because our lives are, well, we don't expect to be living in a warzone
Hanif	762-789	I try to stop myself to think about these things. It may come back, but I don't want to think about it..If it happens, I'll think about it later. Now, it's gone. (Laughter) Do you see my point?... Yes, I do remember there was a programme in the TV and someone had an interview with one guy who suffered from, he try and be positive and he was doing something and he said, "You know you are suffering from this disease and you don't live more than three years, five years", I don't know. I don't remember how many years, and he said, "Is there any guarantee that you live more than me?" To the interviewer (...) It may happen. In my case, my psoriasis may come back in a few years' time, but if it comes back I want to think about this, in a few years but not now
Hanif	801-807	A few days ago we had one conversation about the interest rate of the mortgage. Oh, it's going to be blah, blah, blah, in this country, the most part of your earning goes for the mortgage and I said to myself, "How about now? If it's going to be in a few years time, in six months time, I will think about it then, not now.
Rebecca	1333	And she realised that, you know, like, you've got to make the best out of your life..And not always think you could have done better, you could have had this, do you know what I mean? It was such a good story, it was like, you know...So she happened to find out that what, what life gave her was good, really
Rebecca	1654-1717	It does help, but like let's say, like, 'cause we believe that God doesn't send you anything that you can't cope with. But we do, we don't believe that anything is coincidence. Everything is pre-ordained, you know. Everything is Pre-ordained. (so) I'd say that I would have to have, I had to have it. And the good Lord made it as easy as possible, in a way. Because whatever you're sent, it's how you deal with it. Whatever you're sent-The thing is how you're gonna deal with it.Yeah. That's how you stop yourself going down, no? Making sense of it. But there's a lot of things that don't make sense with it. Because you make sense of some things, you have to believe that the things you can't make sense of are also good. Yeah, because you don't know it. "So sometimes you do see why this is good, and why this had to happen to you, but loads of times you don't see it..You can't always say, "Oh, thank you God for giving me this," and, "Thank you God for giving me that," when he doesn't give you something..You say, "Oh, why haven't you given me this?" You can't thank somebody, and then get annoyed when he doesn't. You have to believe that everything he gives you is

Matthew	856-85	If I'm out walking, if I have to stop I have to stop, simple. If I have to sit down, I sit down or if I have to get up, I get up. I can deal with that. I can deal with that because it's such an improvement on what it was, such an improvement
Matthew	894-896	How I've dealt with things in the past, I can deal with stuff, and I don't let it get on top of me. So to me that's a massive positive coming through my own experiences with the –“
Rebecca	848	I know my cousin, that she has, erm, migraines. She literally has to stay in bed, and has migraines. It's also stress, you know what I mean. Everything's really stressed. I don't know, some people can cope, you know (...) IBS, you know, like, everybody's got something
Rebecca	1606-1616	It, it is part of Jewish – a very big part of Jewish culture, that everything what happens is for your good (..) You know, it doesn't always have to – it's like a, it's like, er, when you give injections to a child, you really, the kid's screaming and doesn't want you to give it, and really you're cruel, but you're not, because you know the bigger picture sort of thing. So that is our culture, but it's not rammed down our throats, it's just that we, we, we try and like learn it through life, that this happens, it's for the good, you know. That's what keeps us going, I suppose

Master-theme: The importance of seeing the person and the disease

Participant	Page & line-number	Quote
<i>Sub-theme: I am a person not a petri-dish</i>		
Matthew	350- 365	“it was very – that was, I mean I saw one doctor there. I won't mention his name but it was terrible because not once, I saw him for about four or five years and not once did he look me in the eyes in all those times. He was always staring at his paperwork. He'd look at my skin, but not once in my eyes, and then say, “Right, those tablets and that cream aren't working. Here's another set” and that's all I ever got for four or five years from the one doctor (..) No, nothing. He never looked me in the eyes once (...) And that is, you know, you'd think there's got to be some sort of (..) Between patient and doctor, there's got to be some sort of (...) how do you put it
Matthew	374-377	“Yes. He might as well have been looking in a petri dish..Yes, he might as well have just been looking in that, because that's all he saw the skin as. He never... You know?”
Alice	626-631	And I, I asked where they give me my tablets at my hospital, “Oh no, they won't do that, that's not something we've heard of, oh no.” I can phone, nobody would help me. So the medical profession are there to help me but then they're not, because I had to go two weeks without the injection, 'cause nothing could be arranged

Jack	68-80	And it ended up being – I’d have a – so I’d be going regularly for blood monitoring and monitoring things for the psoriasis and a separate se-, a completely separate series of appointments for rheumatology. And it seemed to be they, it was just stuck in a ridiculous loop where each department had an idea about what Methotrexate dosage there, there should be, Which varied, But they didn’t seem to speak to each other, Erm, it, meanwhile, both conditions were worsening
Jack	127-130	Erm, which I did...Erm, and what was good about it, and, and, and I – did I go back on to the Metho- I, I think I went back on to Methotrexate. I don’t recall. Erm, but, erm, (Pause) er, basically I then went on, on to this – it was a joint clinic, so they were looking at both aspects
Alice	1094-1098	No, and I’m, no, again, the medical profession, no. It’s like no one wants to know. They, they ask me when I have my Methotrexate, “Oh how are you?” And I’d tell them, but it’s all like service. They don’t really take note, they make light of everything
Alice	433-440	But I, I don’t think they really do understand the impact it has and how much I actually hate it. Nobody’s got the time, they’re there to do something. She’s there to give the injection...so they don’t wanna hear when you start or if you say, “Well I’ve got this, I think it’s from the Methotrexate.” They tend to poo poo the idea and say, “Oh it can’t be from Methotrexate”
Matthew	973-979	You know, when I noticed the two different sides to the treatment, it was like, “Wow. All I’ve been doing at the Whittington Hospital was as it I was just going through the motions.” Turn up, take them, go away. Turn up, take them, go away, and I did that for so many years. But here, everything is proactive because I never filled out a form like that, nothing like this at the other hospital, nothing. There was none of this
Samuel	577-589	So there’s very little intercommunication between the medical practitioner who knows what they’re doing, and the ability to transmit the thought processes that they’re going through that would clarify what they’re doing. So in other words, “I think you should be on Sulfasalazine. We’ll put you on Sulfasalazine. You’ll have X number of these at 2.5 mg” or whatever it is, or two tablets a day or whatever it is, and we’ll start off with one tablet and so on, but none of that is really explained well. They usually give you a leaflet, and I find that the leaflets are over-simplistic in some respects, and they don’t do anything about conveying emotion. They only just talk about hard facts
Jack	1042-1045	So I think overall we deal with it very badly on every level...Erm, and, erm, I, I guess may- maybe because it’s at the heart of it it’s something we’re very fearful of. More than physical conditions

Jack	986-990	Well, I think it's one of the big – I think it's one of the things enormously to our demerit as a society that, erm, er, anything from, er, form severe mental illness to personality disorders to psychological conditions, erm, are – we're very, I believe, we're very immature about it as a society
Jack	853-862	There may be a trigger point. Because it's gonna vary with people..Also, people deal with conditions, people. I mean, you know, we've all seen or experienced cases of different people with a similar ailment. Some people deal with it wonderfully. Other people can have a much milder form of it and it, they fall apart (...) Well, that obviously there's a psycho-, there's a psychological component to all conditions"
Jack	865-872	And, you know, we, we all know that, you know, the response to it can vary from depression to bitterness and anger, erm, to a, a great calmness and, er, and people who are, are suffering from bad conditions who, it humbles you to see their response to it (...) And, and it's unpredictable. Whoever you are as an individual, I don't think you can predict, erm, extremis or things that effect you, er, physical and psychologically. It's very difficult to, er, to predict
<i>Sub-theme: Not being seen or heard</i>		
Alice	644-649	You're sitting in an uncomfortable chair, erm, there's absolutely no privacy. They come every time before they start your infusion to ask if you've had any infections. Someone could be there, there can be two men and myself and it's just not private. There's, there's a pull round curtain, but they can hear everything. There's no privacy
Alice	652-657	The, the whole what used to be the skin ward, has just been taken over. It's all managers' offices, and it's always dermatology and rheumatology are just shoved down in the corner and there's like three upright little chairs that you have to sit on to have your infusion. It's not comfortable, it's not pleasant surroundings
Alice	695-701	The other thing that gets me when I go to rheumatology, erm, every week for my injection there's all these posters all around the, the clinics and the wards, you know, erm, rheumatoid arthritis, lupus, osteoarthritis, it's all these leaflets for arthritis, there's never anything for psoriatic arthritis. There's, there's nothing. There must be other people with it
Matthew	21-26	It was frustrating because I mean, by the end of it I saw three or four different rheumatologists, and in the end they were very curt with me. It was like, "Look, they're not inflamed. We've taken x-rays. They're not inflamed. You haven't got it. You have to get over it." I was like, well, this is strange because I know the pain I was feeling

Alice	724-735	Now I get a lot of arthritis in my chest and again it's the not being believed and being ridiculed by the medical profession. "You know, I am very tender anyway, you know I get arthritis there," "You don't get arthritis there." And this was a doctor, and the nurse laughed at me, "You don't get arthritis there," and I was saying, "Well actually I do, I get it in my rib cage, I get it here." And they just laugh at me, "You don't get arthritis there." Even the medical profession aren't aware of it
Matthew	31-37	Before I came here, there was no link. Even though I was in pain and it all coincided at the same time, there was no actual link. They said, "You haven't got rheumatoid arthritis." I said, "Right, fine, but I've got pains." No, that's it, you haven't got rheumatoid. They didn't link it with the psoriasis, you know? So obviously that was just an oversight but it was very frustrating for quite a few years
Samuel	345-350	You see, the trouble is, it's not life-threatening, and because it's not life-threatening, people turn around to you and say, "Pull yourself together. There are much worse things in life than psoriasis" and they're absolutely correct, but when a person has got a condition, you focus on your own problems and you become self-pitying and so on
Matthew	48-53	I thought I was maybe losing it, you know? (Laughter) But then the relief, the weight off my shoulders when I actually got told, "Yes, there is a link" and they put a name on it as psoriatic arthritis (...) I was happy. (Laughter) I was happy, even in the pain, I was happy, you know?
Alice	737-739	Erm, I can't even, I can't even put it into words. It, it, it just, I, I can't explain it. It affected me that badly I can't even find words to, you know, again it's not being believed
Alice	744-754	It could be something, over something absolutely minor. so between me and my partner, erm, and I've got this big thing at the moment that I'm not being believed. Now it's fine, normally, under normal circumstances, "Oh I don't agree with you," or, or joking, "Oh that didn't happen, "and it, and I just flare up, "You don't believe me," and it's like, for years not being believed. And it's so important to me to be believed and so it's become, erm, I can't think of the word, erm, in a way my behaviour's become irrational because it's like all blown up out of proportion that I'm not being believed
Alice	768-776	There was something, I can't even remember what it was about, but there was something at the weekend, I ended up having an argument with my partner because I said, "You don't believe me, you don't." He said, "It's not that I don't believe you." I said, "You don't believe me, do you." And then he said, "What's all this about," 'cause I'd gone over the top and then I just broke down and said, erm, "Nobody ever believes me." And, and I was in tears and, you know, nobody ever believes me"

Matthew	101-112	I mean it was always there, thinking, “Am I imagining this because I’ve got one condition, am I imagining another condition?” I was self-doubting. You know, was I feeling it (...) It was. It was strange. It’s very hard to explain (...) Well, the feelings I was having, because to keep getting told, “You haven’t got it.” It’s not easy (...) Not easy, and you know, I even said to one of the nurses there, I said, “I’d just like the doctor to live one day in my shoes, and then tell me I haven’t got the pain.” You know?
Mathew	155-164	Oh, it’s okay. It’s all different now, I mean the relief, the joy you feel when someone just says, “Well this is it.” That’s like, I knew it all along, you know? It’s like, “Yes.” (Laughter) You know (...) Yes, I mean it seems strange to be happy that you’ve got something, but just because you’ve been told that it is something (...) Yes, and that’s all I got for nearly 20 years. So the frustration is... (Laughter)
Alice	1222-1226	I’ve got this, but I’m having to fight all the time. Why should I fight, why isn’t stuff offered to, for treatments for things. So again skin rheumatology just wash their hands
Alice	1306-1312	You know, and for, for people receiving chemo or cancer they have like, erm, I’ve seen a, a notice up today if you’re on chemo, erm, pamper days and things like that. There should be things like that...it, it is a serious illness and it just gets you down, makes you feel run down. There should be things to help along the way
Alice	824-839	So you’d think that everybody would be more aware. And I remember when this probably started, I’m 48 and it was when I was about 20, so it’s 28 years ago, erm, I remember going to my GP, feeling ill. And it would be, I’d get up in the morning, I’d wake up and I’d feel like my body had gone through a fast spin in the washing machine and it ached and it was, I was exhausted. And I kept going with these symptoms and, er, he said it was, erm, it was probably ME, a mild form of ME. And I think now looking back that is when my arthritis first started, because you know, and that was so 28 years, but it was, it was the tiredness and just feeling generally under the weather. No specific aches and pains but just generally and I think now that that’s when it first started. So it, it took a long time for it to be diagnosed and then it started getting worse and worse.
Jack	1207-1231	Well, also, no you’ve even go, that practical thing about the fact that you’re in a hospital all the time..Because you’ve got two parallel sets of thinking. . You’re thinking, “This is dumb...This is dumb. This is, this is, this is silo, classically silo working. Get – “Come on guys, get together (Laughter) Is it really that hard to work out? And because, again, you know, I think we mentioned it before. I forget the percentage, but I mean, it’s comparatively small percentage of people who have, erm, psoriasis ____, psoriachical arthropathy. So actually, it’s not like you’ve got to majorly disrupt running a joint clinic... You’d probably get through your psoriatic arthropathy patients in a morning

Hanif	175-180	It started with my knees pain, back pain, shoulder pain, my hand was terrible and gradually, because I didn't discuss this with my Dermatologist (...) Because I didn't know it's related to each other
<i>Sub-theme: Mobilising the self to help the body</i>		
Alice		.
Hanif	329-334	Yes, I think at the time, I suffered a lot. I'm not sure if you believe it or not. I think partly I suffered psychologically, not just physically. I believe at the time, if I could manage myself psychologically, maybe I suffered less, but I'm not sure
Hanif	815-846	They are related..But in my case, at the time, I couldn't or I didn't think about it psychologically. I just physically, it helped me physically, a lot physically, and but obviously, when you suffer a lot, and this medication can help you physically, obviously it improves your condition psychologically as well (...) Yes, for instance, at the time when psoriasis patches were all over my body, I didn't go out, and partly because of the pain I had, but partly because of people. I didn't want to contact with people in my condition but when my psoriasis gone with the help of biologic treatment, firstly I didn't have pain anymore on my skin. I'm not talking about the joint pain. I didn't have any pain on my skin and I was happier and even with the small headache, when you have a headache – I'm sure you have headache in your life. Even with the headache, you don't want to – when you are on headache, you don't want to go to your friends (...) Or if your friends, even if your friend called, you see his or her name, you don't answer your phone. It's your friend, but you don't want to talk to her.
Hanif	345-346	And I wish I was in this [pain management] programme in first stage. I learned a lot
Hanif	356-363	Yes, actually I have pain, and I need to take painkiller. When I take it, it doesn't work. In this programme, first of all, I understood what is the pain, how pain affects to your brain, to your system and I realised even through the meditation, through the subconscious I can cope with the pain
Hanif	974-979	It's very difficult, I don't know. Just try to convince the patient to know the problem, to know the pain, and how to cope with the pain. Not just the medication because I believe the effect of mental part to – it's very strong, it's very powerful

Hanif	1024-1052	I don't know how to explain, it's nothing changed, but the way I think about the pain is totally different (...) If I have pain now, I don't go to my cupboard and take the medication straight away. I try to think about the pain first, try to be relaxed, try to be calm and breathing helped me a lot, deep breathing. Breathing in and exhaling, and going out, even for five or ten minutes of walking. Yesterday it was raining. I have a programme in my life now. I have a time schedule for myself, waking up, having breakfast, having fruit and walking, and going to bed. Yesterday, it was raining but I wanted to go out (...) I don't care about the rain. I went out, I was wet but I enjoyed it (...) It was so good. Much better than a sunny day (..) I really enjoyed it, and it was a sunny day with the rain. I was totally wet but I really, really enjoyed it(..)This is life
Hanif	989-993	Actually, on the other hand, I just went back to 15, 16 years ago, at a time when psoriasis was all over my body, even if a good Psychologist advised me something, did I listen to him or her, or not?
Matthew	291-296	I mean, as with the skin, it has been a miracle. To me, it's been such fantastic results. It's amazing, and that makes it, I think psychologically the way I've looked at it, it's made me be able to bear the pain from the joints that much more, because I'm happier with my appearance, you know?
Matthew	1013-1022	Oh, much more now. Oh, totally, totally. I know everything that gets done here is totally proactive and it's for my own good, you know? I know it's all for me. You know, that's how I get made to feel here. It's proactive for me. Not to go in a textbook about the disease. It's all for me and to feel like that, it does, I'm sure it must have something to do with the fact that your skin is so good anyway, now it has to have, you know? Because if you get – the feeling that it's all for you, it puts a positive spin on everything because you're thinking, "Oh yes, it's because they're focused on me. I'm going to focus on me. I'm going to beat this.
Matthew	1051-1057	I'm no doctor but I do believe they go hand in hand together, how you feel to how – you know, and to me, getting that first time when I was clear, I didn't have a single plaque on my body for the first time in so many years. It was, hold on, this is not right, you know? It's so good, and I know, you know, it can only be good for me. It can only – if you're feeling better in yourself, surely it's going to help whatever condition you've got
Rebecca	1736-1746	"Brilliant. I don't know, amazing. I, I wanted to phone somebody to thank them, because – thank them, because the truth is, I could never have afforded it without the NHS (..)Do you know what I mean? And they were, I don't know, they were like the best thing. Like, if I ever complain about the NHS, I don't complain any more. (Laughs)

Hanif	396-403	Just the best way is knowing the pain. I didn't know what is the pain, this is the most important thing. I had a friend a long time ago in Germany, and he, what do you call it? He was Psychologist with the hypnotism, and I do remember one day he put one cigarette on my hand, and it didn't burn at all, but he put his finger on my hand, and it burnt" (Hanif,)
Matthew	591-599	It took a long time but it's there now. I mean, I get it all the time now. I have to say, this clinic, everything, even the rheumat- Everyone I see, all of it, is based on you as a person, not just you as a patient (...) I've noticed a massive – it's fantastic. The facilities here in the Royal Free are fantastic for it, absolutely superb for it. The difference, because I got treated for so many years in a different hospital, the difference is amazing
Matthew	920-922	Yes, I self-referred, and since I've done that, which was the best decision, other than marrying my wife, it's probably the best decision I've ever made in my life (...) Honestly
Rebecca	646-653	so I just started here, and I've really been happy, and everyone's been really nice, and you know (..)They're really, really nice (..)Really, really nice. They really care. They really, really care. I can't get over it (..) And also, I see the same people the whole time. They're so nice, all of them, like really, really nice
Matthew	657-673	But now, psychologically it's fantastic. I mean, I come here, I hear people moaning because they're waiting an hour for an appointment. It doesn't bother me if my appointment's at 9 o'clock and I don't get seen until 3 o'clock. I don't care, because I'm just so happy with everything, the way the treatment is. I don't know if that answers your question (..) It's massively improved now. You know, no-one likes going to the hospital, no-one likes that obviously. But I used to dread going to appointments before because I knew there would be no outcome. It would just be change this, change that, go out and get on with it. I dreaded it. I thought, "Why am I wasting my time coming here?" But here, I mean I don't care, as I was saying. My appointment could be 9 o'clock. 3 o'clock, if I get seen, I get seen. It's fine. I've done it before. I've walked away from here. They said, "Sorry, no-one's going to get seen." "No problem, I'll come back next week." People are moaning and shouting. "Yes, no problem."
Matthew	678 – 697	Yes, I'm probably more tolerant of things than I ever used to be before (...) But I mean, I'm in pain now a lot of the time. I don't let things wind me up. I don't. It's a massive difference on my psyche that way (...) I think I'm just feeling better in myself (..) The skin has cleared up, the joint – I mean, the joints were getting worse steadily anyway, but now it's like it's levelled off. They're not getting worse. They're not great, but they're not getting as bad as they were. If I hadn't had the biologics, I know I'd probably have been walking the way I was before. I'd be struggling to walk around at the moment, whereas alright it hurts, but I still get about

Matthew	946-956	You know, I can only say how happy I am in myself and I'm not saying it just because we're here in this hospital. I'm not, but the treatment I get here is out of this world. After a lot of years of frustration, the treatment I get here, and I mean that, I'm not saying it just because we're here (...) It's superb (...) It's superb..It just makes me feel so much better
Jack	853-862	There may be a trigger point. Because it's gonna vary with people..Also, people deal with conditions, people. I mean, you know, we've all seen or experienced cases of different people with a similar ailment. Some people deal with it wonderfully. Other people can have a much milder form of it and it, they fall apart (...) Well, that obviously there's a psycho-, there's a psychological component to all conditions
Jack	865-872	And, you know, we, we all know that, you know, the response to it can vary from depression to bitterness and anger, erm, to a, a great calmness and, er, and people who are, are suffering from bad conditions who, it humbles you to see their response to it (..) And, and it's unpredictable. Whoever you are as an individual, I don't think you can predict, erm, extremis or things that effect you, er, physical and psychologically. It's very difficult to, er, to predict
Jack	986-990	Well, I think it's one of the big – I think it's one of the things enormously to our demerit as a society that, erm, er, anything from, er, form severe mental illness to personality disorders to psychological conditions, erm, are – we're very, I believe, we're very immature about it as a society....
Rebecca	591-598	The funny thing was, that I didn't get ill so often before. I used to get colds, or, or, you know, ear- I don't know, you know, I used to get things (...) And since I was on the biologics, I was supposed to get even iller because my immune system was so low. And thank God, I don't think I was ill once, really, I don't think I had a cough or cold or anything. Maybe because my mood was like good, or, you know
Matthew	90-96	It was totally frustrating, and I'm positive because, I'm not saying it was mistreatment or anything because my skin, it looks great now but for years it's been very, very bad. I mean, the amount of time I've gone, I've probably gone maybe a whole year at one stage where I had about 95% of my skin covered and everything. But I'm positive that had something to do with it. The fact that they wouldn't recognise the pain I was in. I'm sure that made the skin flare up

Matthew	155-164	Oh, it's okay. It's all different now, I mean the relief, the joy you feel when someone just says, "Well this is it." That's like, I knew it all along, you know? It's like, "Yes." (Laughter) You know (..) Yes, I mean it seems strange to be happy that you've got something, but just because you've been told that it is something (..) Yes, and that's all I got for nearly 20 years. So the frustration is... (Laughter)
Hanif	531-536	It's for instance, last night, I had pain. I had pain on my ribcage. The pain was under the rib and I had this pain with each breath in and out, one deep pain in and one deep pain out, in time, and I could see it, and with breathing, I could manage to stop the pain
Hanif	543-545	Yes, I've found a way, because you know, sometimes you tried everything and it doesn't work. I found a way and now I can cope with it
Hanif	480-483	Yes, it may help to some people, but if you could manage yourself mentally, definitely it works, but you can't say medication 100% works
Alice	268-272	Erm, at first I'd get annoyed, I'd get angry and I'd get annoyed with them, and, erm, then it has a longer lasting effect that I really resent the medical profession. These are people who are supposed to be treating me, they should be listening to me and they're just dismissing
Alice	150-158	Oh this isn't, erm, this isn't a side effect, it's probably not from your Methotrexate. Have a word with your doctor." And I knew it was because I'd get it every, erm, a few hours after my Methotrexate and it would last all day Tuesday and then other times for any reason I haven't had my Methotrexate I don't get those feelings..And I've been telling them for years this is what I get. Suddenly now they recognise it
Alice	30-32	Now I've developed, which I've never had before, a needle phobia and it's from all the injections and having my bloods taken all the time
Alice	110-114	I've never had a problem with, with having my blood taken or cannulas, but I think it's my, my veins have, have, when they're overused, if they sunk or something or they, they're scarred so the cannula pops out and I dread having that done, 'cause it's three or four attempts now having that in. Erm, and I hate it
Alice	179-186	Erm, and then I'd put it in my mouth and if I couldn't swallow it straightaway where the tablet had been I'd get blisters in my mouth. I could feel it stick all the way down
Hanif	568-582	Just one leaflet, one booklet can help to realise about the pain, because most people don't know about the pain. They believe if they have headaches, they have to take Paracetamol and the headache gone... As I mentioned, you have to know what is the pain, and you have to take, even if you want to take one painkiller, you need to know each painkiller works for different things. You can't take Gabapentin for headache, or you can't take Paracetamol for your slipped disc. You have to know your pain, and you have to know these. You have to educate

Jack	1221-1259	<p>Well, again, it reminds me, which I, I, which, erm, I, erm, which I'd forgotten completely actually, was that the rheumatic pain was so bad that one of the things that really pissed me off, to use a technical term, at the Whittington was that the doctors in there, in the rheumatology department seemed to utterly discount the fact that rheumatoid, that rheumatoid conditions are very, arthritic conditions – are very painful. And at times, I, I was absolutely exhausted and worn out by pain. I was on quite strong pain killers and there seemed to be, I don't know, maybe a, maybe a (Pause) complete insensitivity that it was because I – maybe if you're in that kind of department, all your patients are going to suffer from pain (..)But I remember saying, you know, "I really need some help for managing pain."And getting really nothing (...)But, yes, it was really, er, when I think about it, it was, I was, it was really painful. Getting to sleep was really difficult. Waking up and then you were incredibly stiff. And try, and getting out of bed in the morning and standing up and getting dressed were painful processes..And there was no help for it... And I was thinking, well, I was aware of the concept of pain management yet it wasn't offered...And you think, "Well, this is dumb, this is dumb." Because whatever else that, that the doctors are doing – the practical thing of being able to suggest something. That surely there must be some things about pain management..And, and it was, it was quite acute</p>
Jack	1252-1278	<p>Well, it makes you angry (..) And then ultimately, I think it does make you depressed, Because, because, you know – if you could, if you could maybe, or for me, if, if, if one could pinpoint the origin of depression, it's rightly or – well, that's, it's not a right or wrong thing. It, it originates out of an area of, erm, frustration of not being able to be in synch with, er, how maybe you would like things to be. Erm, and not having a successful mental stratagem for dealing with how they are..And that divergence spirals into depression...Because it's, it, it's like an inability to cope</p>
Alice	1207-1211	<p>Look, you know, is there any sort of, erm, erm, help I can get like, erm,, cognitive behavioural therapy for me to cope with, with my treatment, some and to try and help me accept my condition?" "Oh no, there's nothing like this. You, you could go somewhere privately, you could do this, do that."</p>

